Bio-Psycho-Social Obstetrics and Gynecology

A Competency-Oriented Approach

K. Marieke Paarlberg
Harry B.M. van de Wiel
Editors

Springer

Bio-Psycho-Social Obstetrics and Gynecology

K. Marieke Paarlberg
Harry B.M. van de Wiel
Editors

Bio-Psycho-Social Obstetrics and Gynecology

A Competency-Oriented Approach

Springer

Editors
K. Marieke Paarlberg, MD PhD
Department of Obstetrics and Gynecology
Gelre Hospitals
Apeldoorn Location
Apeldoorn
The Netherlands

Harry B.M. van de Wiel, PhD
Wenckebach Institute
University of Groningen
University Medical Center Groningen
Groningen
The Netherlands

ISBN 978-3-319-40402-8 ISBN 978-3-319-40404-2 (eBook)
DOI 10.1007/978-3-319-40404-2

Library of Congress Control Number: 2017930130

Printed on acid-free paper

This Springer imprint is published by Springer Nature
The registered company is Springer International Publishing AG
The registered company address is: Gewerbestrasse 11, 6330 Cham, Switzerland

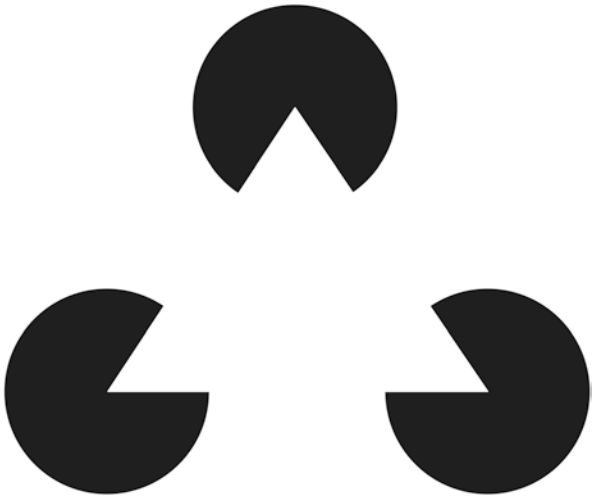
This book is dedicated to the members of the International Society of Psychosomatic Obstetrics and Gynecology (ISPOG).

Preface

Dear Reader,
This book is not a usual book about a usual medical topic. As you will immediately find out when looking at the table of contents, it is a practical guide written and edited by pairs: pairs of scientists and clinicians, physicians and social scientists, gynecologists and midwives, professionals from East and West and North and South, and men and women. This dual approach is no coincidence but reflects the multidimensional approach of the topic involved: psychosomatic obstetrics and gynecology.

Psychosomatic obstetrics and gynecology (POG) is a complex but also *unique* topic. Its uniqueness certainly lies in the ability to solve problems that are seen as *crux medicorum* in the biomedical routine. But, maybe even more, its uniqueness lies in its ability to combine different ways of looking at women's health (care). Of course, POG makes use of the great scientific and technological breakthroughs that the natural sciences have brought and are still bringing us today. It teaches us to lay a rational and empirical foundation under our daily medical practice. At the same time, POG shows us how to put these problems, including the underlying (pathological) mechanisms, in a broader psychosocial and societal context. This enables us to give meaning to the experiences of our patients and to understand them. POG thereby not only makes us observe better, but it also shows how and why we look the way we look. This empathetic mirror image is the bridge that connects healthcare professionals with their patients and enables us to cure, care, and prevent, but also to help them to help themselves.

Building on Popper's three-world theory and, as illustrated in the image below, by combining the bio, the psycho, and the social perspectives, a unique new meta-perspective arises: unique, because it has new features that cannot be reduced to the three constituting domains, like the emerging equilateral triangle. In fact, these unique characteristics, like safety, synergy, and flow, but also their counterparts, are what enable us to practice what we call POG.



Form follows function, so in order to use the best of both worlds (sharp scientific observations and empathy-based signification), the structure of this book is also unusual. Where normally the focus is on different specialized subthemes, here the normal routine of everyday practice is followed. A woman enters our office with one or more healthcare-related problems, questions, or worries such as premenstrual syndrome, post-traumatic stress disorder, provoked vulvodynia, etc. In Part I of this book, 20 of these POG topics have been worked out in a clear and uniform structure. Every chapter or theme is illustrated by a case description that connects theory with practice and vice versa. Every chapter ends with a summary of tips and tricks or dos and don'ts, which should belong in the toolkit of every practitioner.

Because knowledge and skills can only be combined into useful competency with the background of clear roles, Part II addresses a more fundamental introduction to the concept of clinical roles in general and to the so-called meta-competences such as communication, collaboration, etc. Based on the input of all the chapter authors of Part I, a specific POG-competency profile was developed. This profile makes clear which elements form the heart of what we called the psychosomatic approach.

In Part III, the seven CanMEDS competences are discussed in different topics such as the bio-psycho-social model, communicative strategies, and the nature of traumatic experiences. This part, which combines in-depth information with practical suggestions, is written with the purpose of adding an extra layer above the chapters in Part I and to provide some background knowledge on the clinical roles that constitute the psychosomatic profile as described in Part II.

Last but not least, this book was also not a usual expedition for us as editors. Thanks to our chapter authors and the assistance of Springer, we were able to take one of the most interesting journeys in our professional lives.

Apeldoorn, The Netherlands — K. Marieke Paarlberg, MD, PhD
Groningen, The Netherlands — Harry B.M. van de Wiel, PhD

Contents

Contributors

Lobke Bastings, PhD, MD Department of Obstetrics and Gynecology, Radboud University Medical Center, Nijmegen, The Netherlands

Catharina Beerendonk, PhD, MD Department of Obstetrics and Gynecology, Radboud University Medical Center, Nijmegen, The Netherlands

Linda Cardozo, OBE, MD, FRCOG Department of Urogynecology, King's College Hospital, London, UK

Denise Defey Department of Obstetrics, University of Uruguay, Maternity Hospital Uruguay, Montevideo, Uruguay

Mijke Lambregtse-van den Berg, MD, PhD Department of Psychiatry/Child and Adolescent Psychiatry, Erasmus Medical Center, Rotterdam, The Netherlands

Sylvia M. Dermout, MD, PhD Gynaecological Centre Dermout and Albicher, Alkmaar, The Netherlands

Jane Fisher, BSc (Hons), PhD, MAPS Jean Hailes Research Unit, School of Public Health and Preventive Medicine, Monash University, Melbourne, Australia

Katja N. Gaarenstroom, MD, PhD Department of Gynecology, Leiden University Medical Centre, Leiden, The Netherlands

Agnieszka Grabowski, MA, LCSW Wildflower Center for Emotional Health LLC, Chicago, IL, USA

Karin Hammarberg, RN, BSc, PhD Jean Hailes Research Unit, School of Public Health and Preventive Medicine, Monash University, Melbourne, Australia

Heribert Kentenich, Prof MD Fertility Center Berlin, Berlin, Germany

Ellen T.M. Laan, PhD Department of Sexology and Psychosomatic Obstetrics and Gynecology, Division of Obstetrics and Gynecology, Academic Medical Center University of Amsterdam, Amsterdam, The Netherlands

Frits C. Meijering, MEd Department of Social Work, NHL University of Applied Science, Groningen, The Netherlands

Devinalini Misir, MD Department of Psychiatry, University of Buffalo, Erie County Medical Center, Buffalo, NY, USA

Zahra Naleie, MA Federation of Somali Associations in The Netherlands (FSAN), Amsterdam, The Netherlands

Shaughn O'Brien, DSc, MB, BCh, MD, FRCOG Department of Obstetrics and Gynecology, University Hospital North Staffordshire, Maternity Hospital UHNS, Stoke on Trent, UK

K. Marieke Paarlberg, MD, PhD Department of Obstetrics and Gynecology, Gelre Hospitals, Apeldoorn Location, Apeldoorn, The Netherlands

Teri Pearlstein, MD Alpert Medical School of Brown University, Providence, RI, USA

Vesna Pirec, MD, PhD Department of Psychiatry, Insight Behavioral Health Centers, University of Illinois at Chicago, Chicago, IL, USA

Department of Psychiatry, Rush University Medical School, Chicago, IL, USA

Heather Rowe, BSc (Hons), PhD Jean Hailes Research Unit, School of Public Health and Preventive Medicine, Monash University, Melbourne, Australia

Pauline Slade, BSc, MSc, PhD Institute of Psychology Health and Society, University of Liverpool, Liverpool, UK

Symon K. Spoelstra, MD Department of Obstetrics and Gynecology, University Medical Center Groningen, Groningen, The Netherlands

Sushma Srikrishna, FRCOG Department of Urogynecology, King's College Hospital, London, UK

Claire Stramrood, MD, PhD Department of Obstetrics and Gynecology, University Medical Center Utrecht, Utrecht, The Netherlands

Moniek M. ter Kuile, PhD Department of Gynecology, Leiden University Medical Centre, Leiden, The Netherlands

Eva Thurner, MD Department of Obstetrics and Gynecology/Psychosomatic Outpatient-Clinic for Women, State Hospital Korneuburg/Teaching Hospital of Medical University of Vienna (MUW), Korneuburg, Austria

Sibil Tschudin, MD Department of Obstetrics and Gynecology, University Hospital Basel, Basel, Switzerland

Inge L. van Kamp, MD, PhD Department of Obstetrics, Leiden University Medical Center, Leiden, The Netherlands

Rik H.W. van Lunsen, MD, PhD Department of Sexology and Psychosomatic Obstetrics and Gynecology, Division of Obstetrics and Gynecology, Academic Medical Center University of Amsterdam, Amsterdam, The Netherlands

Harry B.M. van de Wiel, PhD Wenckebach Institute, University of Groningen, University Medical Center Groningen, Groningen, The Netherlands

Christianne Verhaak, PhD Department of Medical Psychology, Radboud University Medical Center, Nijmegen, The Netherlands

M. Caroline Vos, MD, MSc Department of Obstetrics and Gynecology, Elisabeth Tweesteden Hospital, Tilburg, The Netherlands

P.T.M. Weijenborg, MD, PhD Department of Gynecology, Leiden University Medical Centre, Leiden, The Netherlands

Barbro Wijma, MD, PhD Unit of Gender and Medicine, Department of Clinical Experimental Medicine, Faculty of Medicine and Health Sciences, Linköping University, Linköping, Sweden

Klaas Wijma, PhD Unit of Medical Psychology, Department of Clinical and Experimental Medicine, Faculty of Medicine and Health Sciences, Linköping University, Linköping, Sweden

Beate Wimmer-Puchinger, PhD Department of Applied Psychology, University of Salzburg, Salzburg, Austria

Tewes Wischmann Institute of Medical Psychology, University Hospital Heidelberg, Heidelberg, Germany

Jan C. Wouda, PhD Ahmas Foundation, Groningen, The Netherlands

Part I

Obstetrics, Gynecology, Fertility and Sexology

A Woman Afraid to Deliver: How to Manage Childbirth Anxiety

1

Klaas Wijma and Barbro Wijma

1.1 Introduction and Aims

A woman has severe childbirth anxiety (CA) when she is so afraid of a delivery that it considerably impairs her personal, social, relational, and occupational life, her willingness to become pregnant, and/or her competence to give birth. Severe CA turns into a (specific) phobia when it is so intense that the woman earnestly wants to avoid pregnancy, delivery, or when a delivery will be endured with intense anxiety. A pregnant woman with severe CA suffers from anxious apprehension, which pursues her to actively avoid places, cognitions, emotions, and physical reactions connected to her CA. In the end she can feel trapped in her situation, dreading the delivery to come.

A conservative estimation gives prevalence numbers of about 10 % for severe CA, including 2.5 % for phobic CA. In this chapter we discuss CA in women and concentrate on those who want to become, are, or have been pregnant and who are handicapped by this mental state in daily life. Since this chapter is only about women, we use the feminine form in case of pronouns.

K. Wijma, PhD (✉)
Unit of Medical Psychology, Department of Clinical and Experimental Medicine,
Faculty of Medicine and Health Sciences, Linköping University, SE-58183 Linköping, Sweden
e-mail: klaas.wijma@liu.se

B. Wijma, MD, PhD
Unit of Gender and Medicine, Department of Clinical Experimental Medicine,
Faculty of Medicine and Health Sciences, Linköping University, SE-58183 Linköping, Sweden
e-mail: barbro.wijma@liu.se

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_1

1.2 Definition in Lay Terms

When a woman is afraid of the situation where a child will or is to be born, she has "childbirth anxiety" (CA). CA covers the whole continuum from a little fear that is easy to cope with to phobic fear, when the woman wants to avoid the situation by all means. CA is mostly discussed when it regards a pregnant woman, but this phenomenon can also exist in nonpregnant women and in men.

1.3 Didactic Goals

After reading this chapter you:

- Are familiar with the classification of childbirth anxiety into no, moderate, severe, and phobic
- Are familiar with the diagnosis of childbirth phobia and have knowledge of other mental disorders and problems of relevance in a differential diagnostic assessment
- Are able to describe the procedure of how to trace clinical forms (severe and phobic) of childbirth anxiety by means of screening and a diagnostic interview
- Are familiar with risk factors for and consequences of severe childbirth anxiety
- Are familiar with the best practice procedure for the treatment of severe childbirth anxiety
- Are familiar with the pitfalls in the communication with women with severe childbirth anxiety
- Are familiar with practical arrangements for the care of women with severe CA during pregnancy and delivery and postpartum

Case History

A 30-year-old teacher, Anne Jade has been happily married for 5 years with her 6 years older husband. Anne had postponed a pregnancy for many years because she could not imagine being able to deliver. Finally, she pandered to her partner's strong wish to have a child.

After 15 weeks of gestation, during which she has consulted her midwife many times for various ailments, she meets an obstetrician who has been informed by the midwife that Anne is very anxious. It becomes clear that Anne cannot see herself going through a vaginal delivery, and at the same time she is extremely scared of having a cesarean section (CS). The obstetrician suggests extra consultations to the midwife, for additional information and reassurance, but these visits do not comfort Anne. When Anne is in her 20th week of gestation, the obstetrician and midwife decide to recommend that Anne start participating in antenatal classes as soon as possible "to counter her mistrusts with realistic information."

1.4 Facts and Figures: Definitions, Assessment, and Prevalence

1.4.1 What Is the Definition of Childbirth Anxiety?

The concept of childbirth anxiety concerns anxiety over the situation where a child will be or is born. Such anxiety exists more or less in all women. In this chapter, we use the term CA mostly in a clinical sense to indicate severe CA, when a woman is so afraid of the delivery situation that it considerably impairs her personal, social, relational, and occupational life, her willingness to become pregnant, and/or her competence to give birth. In a woman with phobic CA, her CA is so intense that she wants to avoid the delivery or she endures the delivery in a state of intense anxiety (see section 1.6.2.1 Clinical Criteria).

1.4.2 How Is Childbirth Anxiety Assessed?

With the publication of the Wijma Delivery Expectancy/Experience Questionnaire (W-DEQ) [1] and its translation into many languages, a measure exists not only to study the prevalence of CA, but also to screen for CA [2].

Although the W-DEQ is more or less the international standard measure for CA, the use of the W-DEQ can only be a part of an assessment to identify women with severe CA. The procedure has to be completed with history taking and diagnostics. In addition, a differential diagnostic evaluation is needed to separate those women who manifest themselves as having CA but whose fear has its pathogenesis in other problems/illnesses. Such completion should be done by a mental health professional with proper competence, such as a clinical psychologist or a psychiatrist.

1.4.3 What Is the Prevalence of Childbirth Anxiety?

Various studies in different Western countries have shown that nulliparous and multiparous women have about the same prevalence of CA [3–9]. The prevalence of severe CA at a cutoff ≥85 W-DEQ sum score varies in samples with both primiparous and multiparous women from 7.5 to 15.6% [5, 10–16]. In such samples, the prevalence for phobic CA (W-DEQ cutoff ≥100) was found to be 2.4–7.7% [5, 7, 11, 17].

1.5 Etiology and Pathogenesis

1.5.1 Where Does Childbirth Anxiety Come From?

The mechanisms governing CA are exactly the same as those for anxiety problems in general. Therefore we start this section with a summary of the mechanisms of anxiety in general and its development into disorders. This information is then applied to CA.

1.5.1.1 Evolutionary Developed Reaction Tendencies

Anxiety is a system developed during evolution, comprising action tendencies as appropriate measures in case of emergency or threat. The system becomes dysfunctional (disordered) when it is long-lastingly overactive (acts too intensively and/or too often). The consequence is not only that there is a lot of "false alarm" (the actual threat is gone, but the alarm signal is still going on) but also that the individual's life functions and abilities are becoming more and more restricted. In the end the individual may become severely handicapped.

The anxiety reaction is a normal, but complex biopsychosocial process. Essential for the development of dysfunctional anxiety in a person is a state of helplessness when she appraises danger, which makes her more or less constantly on her guard [18], i.e., her anxious apprehension has become an integrated part of her daily life.

1.5.2 How Do Anxiety Problems in General Develop?

Most likely the aim of fundamental anxiety action tendencies, such as fight or flight, is to parry threat. Anxiety problems start when the individual gets stuck in a reaction pattern with anxious apprehension even when the threat is gone. Particularly strong emotions are released at the judgment of being trapped [18]. This is especially the case in phobic reactions, when the basic action tendency to escape is blocked, whether the alarm is true or false, and all attention is narrowed to finding a way out, impeding effective performance of current tasks.

Classical (Pavlovian) conditioning [19] is fundamental in the development of anxiety reactions, when threatening stimuli become associated (conditioned) with alarm reactions, which then also easily become connected (generalized) to other, previously neutral, stimuli that appear closely in time.

Such learning can go extremely fast. In a person's attempt to handle the situation, often inadequate coping strategies become strengthened as they offer the person momentary—although short-lasting—relief from her anxiety. In addition, the person struggles to avoid her unpleasant emotions, thoughts, and physical arousal symptoms that are part of her anxiety. From then on she is actively avoiding places, cognitions, emotions, and physical reactions connected to anxiety.

1.5.3 What Makes the Difference Between People Who Develop an Anxiety Disorder and Those Who Do Not?

The difference between those who develop anxiety reaction patterns and those who do not is probably that the latter group neither interprets the situation that evoked fear, nor their own anxiety reactions, as problematic and therefore can turn their attention away from them [20].

1.5.4 What Are the Basic Contributors to the Origin of Anxiety Disorders?

What are the mechanisms of action in people who develop anxiety disorders? In his description of the origin of anxiety disorders, Barlow [18] mentions three necessary contributors:

1. A *generalized biologic vulnerability* that is inherited. There is evidence that certain families have a genetic predisposition (vulnerability) for experiences of general distress [21–24], often called by its generic name "negative affect" [25].
2. A *generalized psychological vulnerability*. This is created when early life experiences contribute to a diminished sense of control (easily started helplessness) and a heightened sense of threat and danger.
3. A *specific psychological vulnerability.* Certain life experiences become interlocked with the heightened sense of threat and danger (alarm), and those experiences determine which kind of specific anxiety disorder the individual will develop.

In summary, a person who develops an anxiety disorder has (1) hereditary susceptibility for feeling stress/nervousness/insecurity, especially in unknown situations; (2) during her growing up, had life experiences with threat and danger in situations where she had diminished control; and (3) an intense anxiety reaction in specific stimulus situations to which the disordered anxiety will be connected.

In a person who develops an anxiety disorder, all three contributors are in place. Therefore, for instance, only experiencing a trauma or a traumatic situation, such as a traumatic delivery, will not cause posttraumatic stress disorder (PTSD) or a phobia [20].

Case History: Continued

After her parents' divorce, when Anne Jade was 4, she grew up with her beloved grandparents, because her mother severely suffered from periods of depression and anxiety. Since she grew older, Anne was more and more worried about her grandfather, the most important person in her life. He was old and sick and she feared the moment he would die. Her grandfather was ill in periods, which made Anne feel restless and gave her disturbed sleep with nightmares. Therefore, Anne probably already had, before she got pregnant, a generalized biological as well as a psychological vulnerability that possibly is the basis for the specific phobia she now has developed.

1.5.5 How Does Specific Phobia Develop?

Conditioning is a well-defined mechanism in the development of specific phobias. According to Barlow's theory [18], three different events can start the first alarm—all having a common basis in a generalized biologic vulnerability. The first possibility

to develop a phobia is when the person is in a special situation or confronted with a certain object that *falsely* is interpreted as dangerous, has an intense reaction, and becomes convinced of the stimulus' danger, resulting in learned alarm (conditioning). Then, the person develops an apprehension for the specific object or situation. The second opportunity to develop a phobia starts with meeting *a real threat* that evokes an alarm reaction (true alarm) that is supported by specific and generalized psychological vulnerability and leads to a specific phobia. The third way to develop a specific phobia is when the person becomes anxious by observing another person in danger in the specific situation or in confrontation with the specific object (*vicarious learning*). After that she follows the same path of learning as described for the other two lines.

In a phobic situation, a person can feel trapped, when the possibility to flee is restricted. A severe fear reaction (panic or panic-like) with high arousal intensifies narrowing of attention and minimizes cognitive creativity. After such an experience, the situation has become so frightening that it instantly triggers anxiety and strong urges of flight or avoidance.

Case History: Continued

Anne Jade starts to take part in the antenatal classes. She could manage the first session, but during the second she starts to tremble, she feels that her heart starts pounding, and she has problems breathing and has to leave the room. She cancels the rest of the course, as she "cannot stand hearing more details about deliveries." Moreover, the positive atmosphere the midwife conveys about labor and delivery is unrealistic to Anne. Anne feels that she and the other women in the course live mentally in completely different worlds, and she is not able to handle the other women's happy expectations. She thinks that the others are naïve, as they do not realize that they finally will be cornered by their bodily task to deliver without having any control and under the command of strangers.

Anne has experienced a panic attack during this second session of the antenatal classes. In the following week, she is very upset and angry and terribly regrets that she at all has agreed to a pregnancy. She worries that a panic attack will happen again. She feels locked up in her state and eager to avoid all reminders of her pregnancy. In despair she visits her midwife again, accusing her for her suggestion to follow the classes and wishing for more help, as she feels more and more unsafe and insecure and having difficulties in handling her situation.

The midwife and the obstetrician decide to refer Anne to the clinical psychologist, connected to the obstetric department, for further examination, possible treatment, and advice for a joint strategy to help Anne.

1.6 Specific Diagnostic Aspects

1.6.1 When Does a Woman Screen Positive on the W-DEQ?

No formal criteria specifically for CA exist. We offer a description of CA by means of psychometric, clinical, and *Diagnostic and Statistical Manual of Mental Disorders*, *Fifth Edition* (DSM-5) conditions as follows.

1.6.1.1 Psychometric Criteria

The Wijma Delivery Experience/Expectancy Questionnaire (W-DEQ) [1] is a self-assessment scale including 33 items measuring fear about the object or situation of childbirth; each item is rated from "not at all" (zero) to "extremely" (five). The sum score can vary from zero to 165. The higher the score, the more severe is the CA. W-DEQ version A measures [1] CA before or during pregnancy; version B measures postpartum CA. CA, as expressed by a sum score on the W-DEQ, has been shown to be normally distributed in the population of pregnant women, both before and after delivery [5], i.e., most women experience a certain amount of CA, and there are also women with extremely low and extremely high levels of CA. When screening with the W-DEQ, primiparous women with severe CA (see next section on "Clinical Criteria") mostly have a sum score of ≥85, and those with phobic CA (see next section on "Clinical Criteria") mostly a sum score of ≥100 [2].

1.6.2 What Are the Clinical Criteria for Childbirth Anxiety?

1.6.2.1 Clinical Criteria

In clinical practice it is helpful to distinguish the following four categories of CA in terms of intensity or severity:

1. Low CA. The woman does not see any or almost no problems with, and is not bothered about, giving birth.
2. Moderate CA. The woman can imagine that problems may appear during labor and delivery but expects that those can be handled and are implicit risks she has to take when giving birth.
3. Severe CA. The fear is so intense that it makes the woman dysfunctional with abundant consequences for her personal, social, and work life on the one hand and for her willingness to become pregnant and/or ability to give birth on the other hand.
4. Phobic CA. The fear fulfills the criteria for a specific phobia according to DSM-5 [26], i.e., the woman wants to avoid delivery or the delivery is endured with intense anxiety (see later Sect. 1.6.3).

Only women in categories 3 and 4 can be seen as having CA in *a clinical sense*, i.e., need extra care by obstetric and mental health-care professionals.

Case History: Continued

When visiting the clinical psychologist in gestation week 22, *some* of the psychologist's questions generate the following answers (P = clinical psychologist; A = Anne):

P: "What can you tell me about your present situation?"
A: "I know that the delivery will become a catastrophe, although my midwife and obstetrician have tried to reassure me. Apparently the statistics seem to show a low risk for problems… They tell me I am in good physical shape without any risks as far as they can see. But I cannot believe them. All the good figures apply to other women, but you will see, I belong to the exceptions. Another thing that disturbs me extremely is that wherever I go I am reminded of my pregnancy and delivery, by what people talk about: in the news, in advertisements. I need to be constantly on my guard."
P: "What do you think of mostly when you imagine the delivery?"
A: "I am convinced that I and my child will die during the delivery; I will be bleeding to death and the child will be torn into pieces. Only thinking of the situation in which unknown people will have complete control over me, while I have no way out, frightens me."
P: "When you become afraid thinking of the delivery, how do you cope?"
A: "As soon as I think of the delivery, I consciously try to calm down and to distract myself as these thoughts frighten me."
P: "Have you had any information about pregnancy and delivery?"
A: "I avoid everything that can remind me of the delivery. The information booklet my midwife has given me to read I have passed to my husband and asked him either to throw it away or to hide it. He has read the booklet and keeps it, thinking that it could be good to have it in case I will ask for it later on, which is very unlikely. It annoys me that he thinks that I ever will read it."
P: "What do you think of meeting the staff?"
A: "I have forced my husband to accompany me at my visits to the midwife and the doctor; I don't want to be there alone. These people are important, I am literally in their hands, but they frighten me at the same time, because they are a clear reminder of what will come. Why do they wear white clothes other than that they work with bleeding people?"
P: "Can you tell about your reactions from the moment on when you knew you were pregnant?"
A: "In the beginning of my pregnancy, I could take pleasure in my husband's happiness that we will have a child. Soon my anxiety grew and since then the pregnancy is a burden. I actually can long for the child, but my anxiety about the delivery spoiled all my positive expectations of becoming a mother."
P: "How does your anxiety influence your life in general?"
A: "More and more I avoid meeting others (visiting friends, choir rehearsals, etc.) to prevent questions about my pregnancy and to reduce confrontation with other pregnant women. I can do my work as a teacher, but I have made my husband cancel his business journeys, as I do not want to be alone the moment I cannot handle my anxiety."

The psychological examination of Anne makes clear that she suffers from a phobic CA. Although she does not fulfill criteria for other diagnoses, Anne's mental condition in general is impoverished. In her daily life, she becomes more and more preoccupied with what she thinks awaits her when the child finally will be born. She has become restless and develops sleeping problems. In her work as a teacher, she experiences concentration difficulties, is stressed, and feels that it is harder to manage the children's high sound levels in the classroom. The psychologist suggests cognitive behavioral therapy (CBT) for childbirth phobia (Table 1.1 [27]), and Anne finally accepts the treatment that will start immediately and take place during the coming months. Anne also agrees with the psychologist to discuss her situation with midwives and obstetricians, in order to coordinate her care as optimally as possible.

At assessment Anne's W-DEQ A sum score is 134.

Table 1.1 Outline of the modules week by week in a cognitive behavioral therapy (CBT) program for severe childbirth anxiety

Information path[a]		CBT path[a]
Module 1	Normal pregnancy: first trimester	CBT as treatment method. Psychoeducation concerning fear and anxiety in general and related to childbirth. How different physical conditions (e.g., sleep deprivation, hunger, etc.) can influence persons differently. Description of own expectations of the imminent labor and delivery
Module 2	Normal pregnancy: second trimester	Goal setting—what can be realistic to expect during labor and delivery. Participants set their own goals for the therapy. Exposure to other women's stories about labor and delivery
Module 3	Normal pregnancy: third trimester	Instruction in and practice with tools to deal with the physical reactions to fear, e.g., breathing retraining, focusing techniques. Testing the tools in everyday situations
Module 4	Normal labor: preparations and start	Difference between thoughts and feelings and how they interact. Participants identify and challenge own fearful thoughts and then create alternative, more helpful thoughts about labor and delivery
Module 5	Normal labor: pain relief	Instructions for exposure in vivo (in the woman's natural milieu)
Module 6	Normal labor: first and second stage	How to manage situations one cannot influence. What is control? How to control one's own thoughts?
Module 7	Normal labor and delivery: acute situations	Advantages of different modes of delivery for one's own situation. Summary of the program
Module 8	Normal labor and delivery: third stage	How to deal with setbacks. Participants work out an individual program for maintaining their progress. Description of own expectations of the imminent labor and delivery

Used with permission of Taylor and Francis from Nieminen et al. [27]

[a]Every module has a section with information about pregnancy and delivery (the information path) and a section dealing more strictly with the management of the phobic anxiety (the CBT path)

1.6.3 When Does a Woman Have a Childbirth Phobia According to DSM-5?

1.6.3.1 Criteria for Phobic CA According to DSM-5 Criteria for Specific Phobia

If a woman fulfills DSM-5 criteria A-G (please see the DSM-5 manual), she has phobic CA according to the DSM-5 criteria for specific phobia [26]. However, if a woman does not fulfill all the diagnostic criteria required for the diagnosis of phobic CA, she can nonetheless suffer seriously from CA symptoms.

1.6.3.2 The DSM System

The DSM is a system to describe mental disorders in objective, explicit terms. It helps clinicians to operationalize and facilitate communication about patients' mental problems, which makes it easier to decide about treatment possibilities. DSM neither offers an explanation of the origin of mental disorders nor an instruction for care management (see also Chap. 24).

1.6.4 Which Other Mental Problems Are Important to Differentiate from Severe/Phobic Childbirth Anxiety in a Differential Diagnosis for CA?

1.6.4.1 Differential Diagnosis of CA

Like all other anxiety problems, phobic and severe CA are highly comorbid with other anxiety disorders [26] and also with other mental problems [28]. In the context of a differential diagnosis for severe and phobic CA, some disorders need special attention because they easily can misguide the health-care workers who are the first to meet these patients. It is necessary and appropriate to evaluate other diagnoses, not only anxiety disorders but also mental problems in general, to find out which mental condition the woman is suffering from and which help (treatment) fits best for her actual situation. See Box 1.1 for a short overview of the most important problems [29, 30].

Box 1.1. Differential Diagnosis for Severe and Phobic Childbirth Anxiety

Blood-Injection-Injury Phobia

Many with a specific phobia also have other types of phobias. In case a woman is severely suffering from a blood-injection-injury phobia, she should be treated for that first with cognitive behavioral therapy (CBT), which is very effective [29]. Afterward the patient's CA can be reviewed and treatment for CA added if needed.

Other Situational Phobias

Hospital Phobia

A woman with augmented CA, planning to give birth at a hospital, could have a hospital phobia, whereas she is not afraid of giving birth. When this is assessed in time, therapy can be offered before she has to give birth.

Vaginismus and Dyspareunia

The content of fear in these women most likely concerns fear of pain and penetrations in the genital area (see below). This type of treatment is special and different from that of women with CA. At intake in antenatal care, caregivers should routinely ask patients about special concerns regarding contact with obstetric care during the time to come.

Fear of the Pelvic Examination

As the pregnancy and delivery include several pelvic examinations, these women may have great problems with obstetric care during pregnancy and the routine examinations during delivery. Since it is not the delivery in itself that is feared, these women need to be treated in another way than those suffering from CA.

Somatic Symptom Disorder and Illness Anxiety Disorder

A person with somatic symptom disorder has one or more somatic symptoms that cause disproportionate and persistent anxiety. Someone with illness anxiety disorder has excessive worries about her health and is easily alarmed by bodily signals about her health status. These disorders exist already before gestation, but can intensify in connection to the challenges of pregnancy and delivery.

Social Anxiety Disorder

Social anxiety disorder does not specifically concern pregnancy and delivery, but more the confrontation with unfamiliar people and the feeling of being inspected. The period of pregnancy and the delivery is an awkward situation for these women as it involves many confrontations with midwives and other members of the obstetric staff, which they may prefer to avoid as far as possible.

Panic Disorder

A woman with severe or phobic CA may be struck by a full or limited symptom panic attack when confronted with childbirth stimuli, such as objects, persons, places, words, thoughts, or images that have to do with delivery. Therefore severe/phobic CA and panic disorder can easily be mixed up and can also coexist. It is of great value to assess a panic disorder differentiated from severe/phobic CA since in the first case, a special treatment focused on panic disorder is required. If the woman has both panic disorder and severe/phobic CA, both problems need attention.

The delivery is usually accompanied by many physical and psychological symptoms. The extreme levels of physical stress may aggravate these symptoms during the course of delivery. Because physical panic symptoms can easily be mistaken by staff as normal, standard symptoms during the course of labor and delivery, panic attacks are hardly detected during childbirth, especially when the focus is on the woman's belly and the child to be born. This means that after a delivery where a panic attack occurred, this anxiety disorder may pass undiagnosed, and the woman as well as the health-care staff may focus on a traumatic delivery experience without getting hold of the essence of it and thereby delaying proper diagnostics and treatment.

Posttraumatic Stress Disorder

Posttraumatic stress disorder (PTSD) is a common disorder in the population. When a woman has PTSD and severe/phobic CA, her PTSD should be assessed and, if possible, treated before handling her phobia. Especially PTSD related to sexual abuse or a previous delivery needs urgent attention since after such events, trauma anxiety easily is provoked by pregnancy and delivery.

Depression

It is well known that depressive symptoms can be a consequence of suffering from serious anxiety problems over a long time. Therefore, it is important to also examine for anxiety problems when a woman shows up with depressive symptoms in connection to pregnancy and childbirth. On the other hand, depression is a risk factor for severe/phobic CA [30].

Other Problems that Can Cause Fear and Anxiety in Connection to Pregnancy and Delivery

Except for the differentiation between CA and the aforementioned disorders, the situation of pregnancy and the forthcoming delivery may include aspects that worry the woman to such an extent that she experiences fear that is not strictly related to the delivery to come. These are, e.g., incomplete mourning for a lost child, pathological shyness, and guilt for an earlier abortion or one considered during the actual pregnancy, relationship problems, and intimate partner violence or drug abuse by a partner.

Case History: Continued

Although Anne Jade has had a panic attack recently, she does not fulfill the diagnosis for panic disorder. She also has a great need for control and planning and "likes to do and have things in her way," but not in clinical terms, i.e., not fulfilling DSM-5 criteria, for example for obsessive-compulsive disorder.

1.7 Clinical Features and Comments

1.7.1 Patients with Childbirth Anxiety

1.7.1.1 What Are the Clinical Features of Childbirth Anxiety During Pregnancy?

In almost all other phobic situations than childbirth phobia, the phobic person is able to avoid a great part of what she fears. However, the pregnant woman with severe CA is constantly "trapped" until the child is born [31]. In phobic situations, the idea of being trapped without the ability to flee is an indispensible trigger for intense anxiety. Moreover, the progressing pregnancy brings her closer to the feared, unavoidable situation. Women with childbirth phobia can experience their status as

mental torture when they have to endure a seemingly endless time in constant horror for what will come [32]. On the other hand, this same phenomenon is favorable for the woman's motivation to take part in treatment of her phobic CA, as she has minimal chances to postpone the final confrontation with the phobic situation.

During pregnancy, many women with severe CA can only imagine the approaching delivery as an upcoming disaster and have the same PTSD symptoms as those who already have experienced a trauma in reality [30]. In case of CA, one could speak of a "Pre-TSD" [33].

Unfortunately, we found that the delivery experience for most women will turn out as expected [3, 8, 34]. The pregnancy confronts the woman with massive bodily changes that influence her physical functioning. Simultaneously, such changes can be appraised as real symptoms of *abnormal* physical phenomena. Anxious persons have a tendency to be observant of their body functions, which makes the anxious pregnant woman more vulnerable to alarms from all physical changes. Thus, whereas most pregnant women see their physical changes as belonging to pregnancy, in women with severe CA, these changes instead easily add to their suspicion that their body functions are abnormal (a false alarm).

Pregnancy has been called "a healthy illness," which in many countries is underpinned by societal service, such as regular obstetric controls to confirm that the woman and her fetus are all right. A woman with CA may interpret these controls as indications that pregnancy and delivery are combined with serious risks for complications. Extended consultations as means of alleviating anxiety rarely work [35], which is further exemplified in illness anxiety (Box 1.1).

In all other forms of phobias, the phobic person only needs to care for herself, while a pregnant woman, suffering from CA, is forced to think both of her own and the fetus' well-being. This means that the potential origin of her anxiety is widened extensively.

In many societies the advent of a new child is socially highly appreciated, and an observed pregnancy is freely favored. Therefore, it is not easy for a woman with CA to get approval for her problems, and when expressed, she often feels minimized. She may also feel an enormous social pressure, as she has to fulfill one of the most appreciated societal tasks and on top of that "feel happy."

1.7.1.2 What Are the Clinical Features of Childbirth Anxiety During Delivery?

During delivery the woman with severe CA is finally trapped in the situation she has feared for a long time, and all ways to flee are blocked. Then valuable matters are at stake. She has the task to contribute, maximizing the options of delivering a healthy child, even if this means physical and mental suffering for her personally. In the end, she is often locked up within some square meters, and while enduring pain, she has to yield to prerequisite performances while her efforts are closely observed. In extreme cases it is about life and death for both herself and her child.

Giving birth is for all women a strenuous effort, physically and psychologically. An important point is that during this process, most women experience moments with a more or less altered state of awareness. The woman has to endure extreme levels of physical stress and pain, which she probably otherwise never experiences in her life, that influence her awareness. Moreover, many women breathe quickly

when they have contractions, thus hyperventilate, which also affects their state of consciousness.

Therefore, during labor and delivery there are several elements that stimulate a temporary change in awareness; some women can even welcome this as a way to cope with extreme pain.

Such states are normal in daily life, like during daydreaming, when extremely tired, when fasting, having slept too little or too long, or when influenced by fever or a medicine or another external agent, which by no means is pathologic in a psychiatric sense. The decisive factor for how she experiences this phenomenon emotionally is her cognitive labeling of what happens. Therefore, helping the woman to interpret the process correctly is meaningful. However, during this process, and especially in critical moments when the child's or her own health is in danger, much of the staff's attention is concentrated on the woman's and the child's physical conditions, even if that is at the expense of their attentiveness toward the mother's mental state. In any case, even when she receives correct information, in connection with labor and delivery, the stress can become so intense that she dissociates in a pestiferous sense, e.g., when it is part of extreme anxiety like during a panic attack. See DSM-5 for the description of the symptoms of a panic attack [26].

Dissociation can be summarized in simple words as when the woman experiences either or both:

- A feeling of being outside her body and its feelings (depersonalization)
- A feeling that everything is unreal—like in a dream (derealization)

Although dissociation is seen as a way to escape from extreme stress and anxiety, reality testing is intact, and thus dissociation can at the same time in itself be very frightening, as absolutely any control is lost, and the woman can think that she has become crazy. Postpartum, such an experience can become a part of a childbirth-linked posttraumatic stress disorder (PTSD). Therefore, it is recommended to notice dissociation during delivery as possibly harmful when it goes together with severe anxiety, and/or postpartum is seen by the woman as (part of) a traumatic experience.

Severe CA does not automatically disappear after the delivery and becomes most alive when a woman considers a new pregnancy. Nor does a psychologically perfect accomplished delivery, following a traumatic delivery that gave postpartum phobic CA, "treat" the phobic CA. The intensity of a phobic anxiety, also of severe CA, varies with the distance to the phobic stimulus. Thus, an untreated phobic CA re-intensifies when a woman considers a new pregnancy or is pregnant again.

1.7.1.3 What Are the Risk Factors for Childbirth Anxiety?

Risk Factors and Consequences: Vicious Cycles Everywhere

We found that women with the highest levels of CA during gestation, as measured by the W-DEQ, also had the highest CA during and after delivery [3, 36], which was unrelated to obstetric complications [8]. A vicious cycle phenomenon also seems to be the pattern for mental health problems connected to pregnancy and delivery at large. Many women with severe CA have already had mental problems in their lives

[37–40], and consequently even during pregnancy, several also have other anxiety disorders [11]. In general, mental disorders such as anxiety and depression are most noticeable during the reproductive age for women [40–42]. This means that during this life period, negative affect is widespread among women, making them extra vulnerable for developing severe CA when pregnant. Consequently, previous mental problems such as anxiety and depression are risk factors for severe CA during pregnancy.

1.7.1.4 How Much Does Childbirth Anxiety Influence the Process of Labor?

Some studies show that severe CA is associated with obstetric complications such as prolonged labor, instrumental vaginal deliveries, and cesarean sections [10, 43, 44], although this is not found in all studies [4, 6].

As we have argued [45], very little is known about possible links between the level of fear women experience and the physiological functioning during the process of labor and delivery. As the endocrine system is essential for the well functioning of the different steps in the delivery process, we measured CA and stress hormones hourly during the process of labor and delivery, but could not find a systematic correlation between the two variables [34].

However, women's CA may influence deliveries in another way, i.e., by the reaction to her fear by obstetric health providers. Already in the 1980s [46] and three decades later [34], we found that during delivery, a staff's standard response to CA is offering pain relief, which may conceal the problem of fear. Throughout the last decade, CA is regarded as the main reason for the increasing number of cesarean sections (CS) on maternal request [47–49].

In Western countries, severe CA has caused a significant increase of CS without medical reasons [50, 51]. This trend is not without concern, since CS implies higher short- and long-term risks for both mother and infant as compared to vaginal delivery [52–56].

In many delicate situations, where obstetric caregivers are confronted with a pregnant woman panicking when only thinking of a vaginal delivery, an elective CS seems to be an easy way out. As it implies the greatest possible reinforcement for these women's urges to escape delivery, most also will wish to end a following pregnancy by means of a CS [5, 49].

Sometimes, in acute situations, CS may be an emergency solution also for psychological reasons, but for handling a woman's severe anxiety, this is an insufficient treatment. Moreover, pregnant women with severe CA, who get a CS on maternal request but do not have a treatment for their CA, run a risk to have a negative experience of their delivery anyway [46]. Therefore, such actions have to be completed with proper care for the woman's CA, which will be discussed later.

After delivery, severe CA more often is found in women having had complications such as an instrumental vaginal delivery, emergency CS, or fetal compromise [6, 7, 10, 33, 57].

CA during labor and delivery is a risk factor for postpartum PTSD [30, 33, 58, 59]: Extreme fear (panic) can be so overwhelming that women experience the delivery as a trauma. Then, anxiety-vulnerable women may develop postpartum PTSD [60].

For many women, pregnancy, labor, and delivery are a challenge, and for some women the endeavors carry a price by affecting their mental condition with a risk for postpartum psychiatric problems [37] and difficulties in a healthy mother-child bonding [46]. It has been found that for a notable number of women with panic disorder, their panic started during pregnancy or soon after delivery [61].

Although it earlier has been hard to show how anxiety during gestation is related to delivery outcome and the condition of the child, the study results of Andersson et al. [62] revealed no differences in neonatal outcome between women with antenatal depressive disorders and/or anxiety disorders and healthy subjects. The authors conclude that neonatal outcome did not deteriorate despite the women's impaired mental health during pregnancy.

It is unclear if and how CA directly influences the biologic process of labor and delivery. According to recent reviews, it becomes increasingly evident that at least there might be a relation between anxiety during pregnancy and preterm birth [63, 64].

1.7.2 Caregivers' Communication and Collaboration with Women with Childbirth Anxiety

Most likely, obstetric caregivers have generally spoken have difficulties in handling severe CA, which in Western countries probably has been the reason for an increasing number of elective CS [50].

1.7.2.1 What Can Be Expected from Obstetrical Health-Care Providers in Diagnostic and Assessment Procedures of Severe Childbirth Anxiety?

Diagnostic and Assessment Procedures: For Whom to Carry Through?

In the preceding sections, we have shown in depth the details of anxiety and anxiety disorders and the place of severe and phobic CA among them. Severe CA is a serious mental problem and phobic CA a psychiatric disorder, even though the situation regards pregnancy and delivery—the field of obstetrics.

Severe CA is often strongly related to other mental difficulties that are easily overlooked when the caregiver does not have the right clinical psychological or psychiatric competence, although by now it is well known that such problems greatly affect the patient's mental condition during pregnancy and, if not properly treated, implies at least for the patient herself a great risk for serious mental problems for a long time after delivery. Therefore, it is advised that the obstetric staff routinely screen for CA and that those women who are screened positive are further diagnosed by caregivers with appropriate competence. This means that obstetricians and midwives need to collaborate with clinical psychologists and psychiatrists. In addition, measurements such as the W-DEQ are useful tools in finding women with CA, but they cannot replace proper diagnostics.

1.7.2.2 What Are the Problems in Disclosure of Severe CA?

We have classified CA in its extreme form as a specific phobia. Among the mental problems, specific phobia is probably the most widespread with a lifetime prevalence of 11 % [65] and of all anxiety disorders, probably the best understood [66] and best treatable [29, 67, 68]. In general, persons with phobias hardly seek help for their problems, possibly because they can find ways to avoid the object they fear. It is also probable that phobia, and even more so subclinical fear, is so common that sufferers get used to its existence and find strategies to live with it and confine themselves to living with their phobia. Nevertheless specific phobia can have serious consequences, especially in its severe form and when the phobic stimulus cannot be avoided.

These general aspects also count for women with childbirth phobia who turn up in obstetric care when pregnant. However, here the phobic patient often expresses her *anxiety* by means of *worries about her physical condition and all the bodily dangers and suffering* that might occur during labor and delivery. These, in interaction with the caregivers' reactions, develop a kind of *obstetrification* of CA, where the patient seems to demand from caregivers measures to ensure her and her fetus' health, and caregivers try to answer the woman's anxiety with (inappropriate/insufficient) obstetric measures.

In addition, this interaction comes with the woman's way of expressing her need for help by rephrasing her anxiety as fear of pain [36, 46]. It is well known that help-seeking patients try to formulate their questions in such a way that they think the care system will understand and for which the system is able to offer remedies [35]. Concentration on pain can be a manner for an anxious woman to win approval for her apprehension and helplessness, as pain is a topic that is often discussed before and during labor. For both the woman with CA and her caregiver, pain is a rewarding topic. The woman can formulate a clear question about a topic that fits the frame of reference of the caregiver, not the least being that obstetrics in Western countries nowadays can offer advanced pain relief, and thus the staff can feel reassured that the woman's request has been adequately met. Interestingly, severe pain almost always reflexively generates an acute panic-like reaction that can be sedated by means of pain relief. Thus, during the delivery, psychologically and pain-generated panic easily can be mixed up. Accordingly, in various studies we have found that during childbirth women with severe CA get significantly more pain relief than others [34, 46].

In obstetric care, practically all service is concentrated on the physical condition of the mother and the fetus. Even childbirth-preparing classes focus on these aspects. Generally spoken, this is logical and adequate. Midwives and obstetricians are educated to attend to the care of the pregnant woman and her fetus, with responsibility for the gestational aspects of the well-being of the woman and her child. As the physical condition of the woman is the main goal for obstetrics, CA may easily be marginalized. When midwives and obstetricians are preoccupied with the woman's physical condition, her CA is easily overlooked, as "a certain amount of CA is normal and should be tolerated," thereby minimizing the communication about fear when a woman signals CA.

But also the reverse can be the case. For a pregnant woman, statistically speaking, there are risks for real dangers for her own and the child's well-being, and

therefore she may think that her fears are appropriate, and she will focus on medical assistance. A caregiver's rewording of such worries into a discussion about the woman's anxiety can easily be experienced as a playdown of her concerns. There is a real risk for a conflict between the patient expressing her beliefs and the caregivers' more accurate estimation of these threats. In that case it will be difficult to motivate the patient for psychological treatment. Moreover, to center upon her mental state would also mean a confrontation with the discomfort she wants to reduce and preferably manages by means of avoidance.

Consequently, proper discussions of the patient's CA easily go astray in concord between staff and patient. When a patient expresses her worry, caregivers use to literally concentrate on the content of the patient's questions, answering with comforting reassurance, which often may be helpful for subclinical fear, but is no effective remedy for clinical anxiety. There is plenty of experience with patients who somatisize, that frequent medical consultations met with reassurances or even physical tests can make the patient even more eager to come back for new consultations, as these actions only give temporary relief [35].

At least in Western countries, women trust obstetric staff and expect to get all the service they need in connection with their pregnancy and delivery. Staff, doing their best to reassure the woman, promotes this impression. And therefore this idea is nurtured in harmony. This is particularly suitable for those women who want to avoid getting in touch with their CA until the last minute, telling themselves that "it's going to work out." An additional aspect is the belief that childbirth anxiety only exists during pregnancy and automatically vanishes after delivery, only she endures until she has given birth. At the end of gestation, these women can find themselves in a situation where their CA finally erupts in full swing, while time for psychological treatment has run out. The risk for a traumatic delivery is then impending, with negative consequences for the woman's postpartum mental health.

1.8 Specific Therapeutic Aspects

1.8.1 What Methods of Treatment of Childbirth Anxiety Have Been Evaluated Scientifically?

1.8.1.1 Treatment of Maternal Anxiety

During the last decades, various trials to manage CA have been published. In 1997, Astbury offered information about the process of labor and delivery, without an effect on "maternal anxiety" [69]. Mehl-Madrona tested hypnosis as a preparation for the delivery. By means of hypnosis, depression, anxiety, and life stress decreased, which was associated with fewer complicated births [70].

Except for the Astbury and Mehl-Madrona studies, all other treatment trials, with very diverse content and duration, have had the main aim to improve the willingness of pregnant women to have a vaginal delivery [17, 71–76]. Randomized controlled trials (RCTs) testing new treatment programs, with the aim to treat CA as such, are underway [77, 78].

1.8.2 What Is the Main Aim for the Treatment of Severe and Phobic Childbirth Anxiety?

1.8.2.1 Specific Treatment of Severe and Phobic Childbirth Anxiety

In our view, the central aim of a psychological treatment of severe CA should be improvement of the woman's mental health by reduction of her anxiety. Such treatment should be given by qualified people, as it otherwise may be without the aspired effect [79]. When anxiety is effectively reduced by therapy, a traumatic delivery may be averted, which can prevent worsening of the patient's future mental health. Therefore women with severe and phobic CA should be helped according to best practices for the treatment of phobia, i.e., CBT. Women with severe CA should be offered such treatment, even when the staff cannot see any obstetric risks for the woman to give birth, as the aim for the therapy at first hand is the woman's mental condition. Ideally, for the best care of women with severe CA, like for proper diagnostics and psychotherapy, obstetric staff should collaborate with mental healthcare professionals.

1.8.3 What Are the Ingredients of a CBT Treatment Program for Severe and Phobic Childbirth Anxiety?

During the last years, our group has developed a CBT treatment program comprised of eight modules, preferably worked through in 8 weeks (Table 1.1). The program has a module with psychoeducation and homework for each of the 8 successive weeks. The program is now tested for both vis-à-vis therapy and treatment via the Internet. Studies are ongoing, and preliminary results are promising [27, 32].

Case History: Continued

During the first 4 weeks, Anne Jade has a positive feeling about the treatment program, but when she has to start with exposure, her anxiety increases significantly (W-DEQ 152).

Anne tells her midwife that she is considering calling off her therapy. The psychologist advises the staff at the antenatal clinic to stay calm and support Anne to continue therapy, as such an increase in anxiety is a normal reaction when the patient starts with exposure therapy.

It appears that Anne has avoided reading the information part of the treatment modules, as she fears its content. The psychologist suggests to Anne that this part will be a component of the exposure section of the therapy.

In the exposure section of the therapy, Anne is gradually confronted with what frightens her, which helps her to cope with her anxiety. As she has a strong urge to avoid these topics, they are divided into a hierarchy from those that trigger a little anxiety (e.g., pictures of pregnant women) to those that Anne absolutely cannot consider to be confronted with (e.g., instruments used

during a delivery, a film about labor and delivery). Anne needs several confrontations with every topic in the hierarchy to have a decrease in her anxiety. For every topic, the first exposure trials take place together with the psychologist at the clinic, after which she continues the exposures at home every day.

When Anne has completed about one-third of her list of exposure tasks, her CA decreases quickly and substantially.

At the end of the therapy, she is amazed that she can look forward to the delivery, still feeling nervous but anyhow seeing it as a challenge (W-DEQ sum score 78).

1.9 Critical Reflection and Conclusive Remarks

Severe CA varies in characteristics and expression according to the person it affects, her situation, other possible problems she may have, and the phase of her pregnancy. How CA appears in the individual woman depends partly on the character of the phenomenon—an anxiety problem—and partly on other aspects such as the content of her anxious thoughts, a hampered communication and collaboration with the staff, and difficulties for her in the health-care system, including aftercare. These aspects will be summarized here briefly.

1.9.1 Anxiety Disorder

Severe CA in its clinical form is first of all an anxiety disorder. This has a number of logical consequences, however difficult to manage, such as:

- Severe CA can make women avoid pregnancy or repeatedly seek abortion.
- Pregnant women with severe CA can try to hide their anxiety problems as long as possible; mostly the problem manifests itself as full blown at the end of pregnancy or, at worst, not until during the delivery.
- Women with severe CA can experience anxiety so intense that it provokes sheer panic.
- Their apprehension can make them apply for extra consultations for examination and reassurance regarding physical symptoms, sleeping problems, fatigue, etc.
- Many women with severe CA avoid proper information about gestation, labor, and delivery, which makes them badly prepared for the delivery to come. Their fantasies can become the only images they have when they finally give birth, which may unintentionally restrict their ability to behave adequately during labor and delivery.
- Because the woman is dominated by her anxiety, severe CA can seriously complicate the birthing process.
- During delivery, symptoms of panic anxiety can resemble normal symptoms of the process of labor and delivery, and therefore they are neither noticed during delivery nor correctly diagnosed later on and properly treated after delivery.

1.9.2 Content of Thinking

On a content level, women with severe CA live in constant worry about all that can go wrong during gestation, labor, delivery, and the time after.

1.9.3 Communication and Collaboration

The greatest problem in communication with women with severe CA can be the staff's concentration on the obstetric aspects of gestation, labor, and delivery while such women are preoccupied with their anxiety. Thus, patient and staff may not communicate properly, although they can seem to talk about the same topics.

1.9.4 Disease and Patient Management

Many women with low and moderate CA are relieved by means of reassurance about their ability to deliver and standard information about labor and delivery. By contrast, in women with severe CA, such information does not relieve them from their anxiety, even though this information may be profitable for them in other aspects.

1.9.5 Aftercare

For health-care givers in obstetrics, it is important to realize the following:

- An obstetrically correct delivery without medical complications can be endured with extreme anxiety. In that case a great risk exists that the woman will develop severe mental problems, mostly starting with trauma anxiety-like reactions or panic attacks, gradually accompanied by depression. Such reactions can start immediately postpartum but can also appear a long time after delivery. A traumatic delivery can also initiate a childbirth phobia.
- After a distressing delivery, women can suffer mentally for a long time, which influences their contact with the baby, the relationship with their partner, and their social and professional contacts in a negative way. In case they have developed severe CA or their previous severe CA is still present, it is beneficial for such women to have their CA treated as soon as possible. It is a mistake to wait for treatment until a next pregnancy.
- Treatment for postpartum PTSD cannot replace a treatment for CA as these problems and its treatments are not identical.
- A postpartum treatment for severe CA is insufficient as therapy for posttraumatic stress disorder (PTSD) after childbirth. In case a woman has developed PTSD, such treatment is recommended to start 4 weeks postpartum.

Tips and Tricks

During pregnancy

Check whether the woman has severe CA:

1. When the woman has a history with depression or anxiety or an actual depression or anxiety
2. When during the consultation the woman is restless, nervous, and tense; in a hurry as if she wants to break away from you; or, on the contrary, finds it difficult to leave you
3. When the woman asks for extra consultations, has many extra questions, seems in need of extra reassurance, considers an abortion where you have difficulties seeing why, is more than normally worrying about her physical state and her pregnancy symptoms, or on the contrary wants to avoid you and the clinic

In case you wonder if a woman has severe CA:

1. Let the woman complete the W-DEQ version A. In case of a sum score ≥85, the woman most probably has severe CA.
2. In addition ask questions such as:
   - "How do you feel about your pregnancy?"
   - "What do you think will happen during the rest of your pregnancy?"
   - "What do you think will happen during the upcoming delivery?"
   - "Many women are more or less afraid of their upcoming delivery. Some fear their delivery very much. What about you?"

When your questions confirm what the W-DEQ sum score and your suspicions suggest, discuss the CA with her and offer her a referral to a clinical psychologist/CBT psychotherapist for further assessment.

During delivery

When a woman has extreme anxiety during delivery, this can turn into a panic attack. Many symptoms of panic anxiety can easily be mistaken for normal phenomena of labor and delivery.

When a woman panics or dissociates during delivery, it is helpful, whenever possible:

- To try to create a break in the situation.
- To be determined.
- To sit down at the headboard (if she is in bed) and speak distinctly and in a clear voice with her.
- To have eye contact.
- To take her hand steadily in yours and caress; try to give her a feeling that you are real and there.
- To ask her where she is, what she experiences.
- To ask her what she thinks is happening and give her honest and correct information in simple words.
- To explain in simple words what is happening to her concerning the delivery (repeat).
- To repeat what is happening according to your view.
- Not to dismiss the woman's concerns as trivial.

- Not to dispute with the woman or downplay the situation.
- To encounter the woman with compassion and approval.
- In case you have to continue physical work with the delivery, to have someone else taking over your task and let this person keep direct contact with the woman.
- If a partner is present, give him a place to sit down at the headboard (if she is in bed) and address him now and then.

After the delivery

1. Let the woman complete the W-DEQ version B. In case of a sum score ≥85, the woman most probably has severe CA.
2. In addition, and surely when you suspect postpartum CA, start a discussion with her about her delivery.

Ask about the delivery experience, whether or not the woman has been in trouble during labor and delivery. Ask direct questions about how she experienced the delivery. The same questions can be repeated at successive meetings, as some traumatized women instantly want to avoid being reminded of the delivery. Examples of simple questions are:

- How did you experience the delivery?
- What do you think of when you recall the delivery?

If she answers with dislike, disgust, and horror or such questions seem to be inconvenient, let her tell what she thinks.

If she reacts with defense, irritation, aggression, and refusal, tell her that she may address you later and get back to the topic.

Women, who appear to suffer from trauma anxiety during the first weeks postpartum, should have a checkup at about 4 weeks postpartum. Many women manage to cope with traumatic events, but some get stuck in their traumatic experiences. If they still suffer from trauma anxiety after 4 weeks, a referral to a mental care specialist such as a clinical psychologist or a psychiatrist is recommended.

In some women trauma anxiety becomes a mental problem much later than during the first months. Note that posttraumatic stress disorder (PTSD) is discussed in Chap. 2 of this book.

Notice that treatment for postpartum PTSD cannot replace a treatment for CA as these problems and its treatments are not identical.

In case of a postpartum severe CA/childbirth phobia, treatment is recommended to start within some months postpartum (the sooner the better) as her suffering may disturb her relationship with the newborn child considerably, the child being a constant reminder of the traumatic event. Never should such treatment be postponed until an eventual next pregnancy, as untreated women never may dare to become pregnant again.

Test Your Knowledge and Comprehension

1. Severe and phobic CA are basically the same anxiety problem, be it that a phobic CA fulfills the criteria for a specific phobia.
   (a) True
   (b) False

2. In fact, when anxiety concerns life or death (like in severe CA), by innate forces, a very anxious person often gradually develops adequate effective coping strategies.
   (a) True
   (b) False
3. Phobic and severe CA are so specifically related to pregnancy and delivery that they are not comorbid with other mental problems.
   (a) True
   (b) False
4. Women with a postpartum severe/phobic CA can be treated by another delivery with maximal care by the staff.
   (a) True
   (b) False
5. Severe CA is intact when the delivery is over.
   (a) True
   (b) False
6. A conservative estimation of the prevalence of severe (including phobic) CA is:
   (a) 1 %
   (b) 5 %
   (c) 10 %
   (d) 15 %
7. A person who develops an anxiety disorder has
   (a) Hereditary susceptibility for feeling stress/nervousness/insecurity, especially in unknown situations
   (b) During her growing up life, experiences with threat and danger in situations where she had diminished control
   (c) An intense anxiety reaction in a specific stimulus situations to which her anxiety will be connected
   (d) All of the above
8. An effective method to decrease severe and phobic CA during pregnancy is
   (a) Assurance and correct information
   (b) Agreement about a detailed birth plan
   (c) Promising maximum pain relief during delivery
   (d) None of the above
9. What is, according to literature, the best practice for the treatment of a phobia?
   (a) Psychotherapy by means of CBT
   (b) Psychotherapy by means of the PLISSIT model
   (c) SSRI medication
   (d) None of the above
10. What is the main aim for the treatment of severe and phobic CA?
   (a) Improvement of knowledge as a preparation for labor and delivery
   (b) Improvement of the woman's mental health by reduction of her anxiety
   (c) Improvement of the woman's ability to make use of her physical capacity to deliver
   (d) Improvement of the woman's abilities to interact with staff during labor and delivery

Answers

1. True
2. False
3. False
4. False
5. True
6. (c)
7. (d)
8. (d)
9. (a)
10. (b)

1.10 Additional Reflection

Which Can Be Done Individually or in Group Work

1. Please imagine one or two difficult clinical situations you have experienced as a professional that are related to this chapter. Please write down the situation for yourself to remember it more clearly.
2. Then ask yourself the following questions and reflect on them while imagining that you are back in that situation again:
   - When you are there, what will be your immediate reaction? What do you feel, think, say, and tell with your body language?
   - On what knowledge are those reactions based?
   - What would be the probable consequences of your actions for the woman?
   - Can you think of other ways of acting? What would their consequences be? Why would those be more suitable for the situation—or less suitable?
3. Please write down your reflections.
4. When you do this reflection in a group, every group member can illustrate his/her situation and reflect on it in the group. After the contribution of the individual group member, the group can ask additional questions in order to find the best way of acting in a similar situation in the future.

References

1. Wijma K, Wijma B, Zar M. Psychometric aspects of the W-DEQ; a new questionnaire for the measurement of fear of childbirth. J Psychosom Obstet Gynecol. 1998;19(2):84–97.
2. Zar M. Diagnostic aspects of fear of childbirth. PhD thesis. Linköping: Linköping University; 2001.
3. Zar M, Wijma K, Wijma B. Pre- and postpartum fear of childbirth in nulliparous and parous women. Scand J Behav Ther. 2001;30:75–84.
4. Johnson R, Slade P. Does fear of childbirth during pregnancy predict emergency caesarean section? BJOG Int J Obstet Gynaecol. 2002;109(11):1213–21.
5. Nieminen K, Stephansson O, Ryding EL. Women's fear of childbirth and preference for cesarean section – a cross-sectional study at various stages of pregnancy in sweden. Acta Obstet Gynecol Scand. 2009;88(7):807–13.

6. Fenwick J, Gamble J, Nathan E, Bayes S, Hauck Y. Pre- and postpartum levels of childbirth fear and the relationship to birth outcomes in a cohort of Australian women. J Clin Nurs. 2009;18(5):667–77.
7. Rouhe H, Salmela-Aro K, Halmesmäki E, Saisto T. Fear of childbirth according to parity, gestational age, and obstetric history. BJOG. 2009;116(1):67–73.
8. Sluijs A-M, Cleiren MPHD, Scherjon SA, Wijma K. No relationship between fear of childbirth and pregnancy-/delivery-outcome in a low-risk Dutch pregnancy cohort delivering at home or in hospital. J Psychosom Obstet Gynecol. 2012;33(3):99–105.
9. Toohill J, Fenwick J, Gamble J, Creedy DK. Prevalence of childbirth fear in an Australian sample of pregnant women. BMC Pregnancy Childbirth. 2014;14:275.
10. Ryding EL, Wijma B, Wijma K, Rydhstrom H. Fear of childbirth during pregnancy may increase the risk of emergency cesarean section. Acta Obstet Gynecol Scand. [Research Support, Non-U.S. Gov't]. 1998;77(5):542–7.
11. Zar M, Wijma K, Wijma B. Relation between anxiety disorders and fear of childbirth during late pregnancy. Clin Psychol Psychother. 2002;9:122–30.
12. Kjærgaard H, Wijma K, Dykes AK, Alehagen S. Fear of childbirth in obstetrically low-risk nulliparous women in Sweden and Denmark. J Reproduct Infant Psychol. 2008;26(4):340–50.
13. Spice K, Jones SL, Hadjistavropoulos HD, Kowalyk K, Stewart SH. Prenatal fear of childbirth and anxiety sensitivity. J Psychosom Obstet Gynecol. 2009;30(3):168–74.
14. Adams S, Eberhard-Gran M, Eskild A. Fear of childbirth and duration of labour: a study of 2206 women with intended vaginal delivery. BJOG. 2012;119(10):1238–46.
15. Nordeng H, Hansen C, Garthus-Niegel S, Eberhard-Gran M. Fear of childbirth, mental health, and medication use during pregnancy. Arch Womens Ment Health. 2012;15(3):203–9.
16. Storksen HT, Eberhard-Gran M, Garthus-Niegel S, Eskild A. Fear of childbirth; the relation to anxiety and depression. Acta Obstet Gynecol Scand. 2012;91(2):237–42.
17. Rouhe H, Salmela-Aro K, Toivanen R, Tokola M, Halmesmäki E, Saisto T. Obstetric outcome after intervention for severe fear of childbirth in nulliparous women – randomised trial. BJOG. 2013;120(1):75–84.
18. Barlow DH. Anxiety and its disorders. 2nd ed. New York: Guilford Press; 2004.
19. Robbins SJ, Schwartz B, Wasserman EA. Psychology of learning and behavior. 5th ed. New York: W. W. Norton & Company; 2001.
20. Ryding EL, Wijma K, Wijma B. Experiences of emergency cesarean section: a phenomenological study of 53 women. Birth. 1998;25(4):246–51.
21. Torgersen S. The nature and origin of common phobic fears. Br J Psychiatry [Journal Article]. 1979;134(4):343–51.
22. Gottesman II. Schizophrenia genesis: the origins of madness. San Francisco: Freeman; 1991.
23. Plomin R, DeFries JC, McClearn GE, McGuffin P. Behavioral genetics. 4th ed. New York: Worth Publishers; 2001.
24. Kendler KS, Karkowski LM, Prescott CA. Fears and phobias: reliability and heritability. Psychol Med. 1999;29(3):539–53.
25. Mineka S, Watson D, Clark LA. Comorbidity of anxiety and unipolar mood disorders. Annu Rev Psychol. 1998;49(1):377–412.
26. American-Psychiatric-Association. Diagnostic and statistical manual of mental disorders. 5th ed. Washington, DC: APA; 2013.
27. Nieminen K, Andersson G, Wijma B, Ryding E-L, Wijma K. Treatment of severe fear of childbirth via the internet. J Psychosom Obstet Gynaecol. 2016;26:1–7.
28. Andersson L, Sundström-Poromaa I, Wulff M, Åström M, Bixo M. Depression and anxiety during pregnancy and six months postpartum: a follow-up study. Acta Obstet Gynecol Scand. 2006;85(8):937–44.
29. Öst L-G. One-session treatment for specific phobias. Behav Res Ther. 1989;27(1):1–7.
30. Söderquist J, Wijma B, Thorbert G, Wijma K. Risk factors in pregnancy for post-traumatic stress and depression after childbirth. BJOG. 2009;116(5):672–80.

31. Wijma K, Alehagen S, Wijma B. Development of the Delivery Fear Scale. J Psychosom Obstet Gynecol. 2002;23(2):97–107.
32. Nieminen K, Malmquist A, Wijma B, Ryding EL, Andersson G, Wijma K. Nulliparous pregnant women's narratives of imminent childbirth before and after internet-based cognitive behavioural therapy for severe fear of childbirth: a qualitative study. BJOG. 2015;122(9): 1259–65.
33. Söderquist J, Wijma B, Wijma K. The longitudinal course of post-traumatic stress after childbirth. J Psychosom Obstet Gynecol. 2006;27(2):113–9.
34. Alehagen S, Wijma K, Lundberg U, Wijma B. Fear, pain and stress hormones during the process of childbirth. J Psychosom Obstet Gynecol. 2005;26:153–65.
35. Salkovskis PM. The cognitive approach to anxiety: threat beliefs, safety-seeking behavior, and the special case of health anxiety and obsessions. In: Salkovskis PM, editor. Frontiers of cognitive therapy. New York: The Guilford Press; 1996. p. 48–74.
36. Alehagen SIW, Wijma B, Wijma K. Fear of childbirth before, during, and after childbirth. Acta Obstet Gynecol Scand. 2006;85(1):56–62.
37. Ross LE, McLean LM. Anxiety disorders during pregnancy and the postpartum period: a systematic review. J Clin Psychiatry. 2006;6(9):1285–98.
38. Salomonsson B, Gullberg MT, Alehagen S, Wijma K. Self-efficacy beliefs and fear of childbirth in nulliparous women. J Psychosom Obstet Gynecol. 2013;34(3):116–21.
39. Andersson L, Sundström-Poromaa I, Wulff M, Åström M, Bixo M. Implications of antenatal depression and anxiety for obstetric outcome. Obstet Gynecol. 2004;104(3):467–76.
40. Martini J, Petzoldt J, Einsle F, Beesdo-Baum K, Höfler M, Wittchen H-U. Risk factors and course patterns of anxiety and depressive disorders during pregnancy and after delivery: a prospective-longitudinal study. J Affect Disord. 2015;175:385–95.
41. Kessler RC, Petukhova M, Sampson NA, Zaslavsky AM, Wittchen H-U. Twelve-month and lifetime prevalence and lifetime morbid risk of anxiety and mood disorders in the United States. Int J Methods Psychiatr Res. 2012;21(3):169–84.
42. Wittchen HU, Jacobi F, Rehm J, Gustavsson A, Svensson M, Jönsson B, et al. The size and burden of mental disorders and other disorders of the brain in europe 2010. Eur Neuropsychopharmacol. 2011;21(9):655–79.
43. Johnson RC, Slade P. Obstetric complications and anxiety during pregnancy: is there a relationship? J Psychosom Obstet Gynecol. 2003;24(1):1–14.
44. Laursen M, Johansen C, Hedegaard M. Fear of childbirth and risk for birth complications in nulliparous women in the Danish National Birth Cohort. BJOG. 2009;116:1350–5.
45. Wijma K. Why focus on "fear of childbirth"? J Psychosom Obstet Gynecol. 2003;24:141–3 (Editorial).
46. Areskog B, Uddenberg N, Kjessler B. Experience of delivery in women with and without antenatal fear of childbirth. Gynecol Obstet Invest. 1983;16(1):1–12.
47. Gamble JA, Creedy DK. Women's preference for a cesarean section: incidence and associated factors. Birth. 2001;28(2):101–10.
48. Waldenström U, Hildingsson I, Ryding EL. Antenatal fear of childbirth and its association with subsequent caesarean section and experience of childbirth. BJOG. 2006;113(6):638–46.
49. Melender HL. Experiences of fears associated with pregnancy and childbirth: a study of 329 pregnant women. Birth. 2002;29(2):101–11.
50. Fenwick J, Staff L, Gamble J, Creedy DK, Bayes S. Why do women request caesarean section in a normal, healthy first pregnancy? Midwifery. 2010;26(4):394–400.
51. Karlström A, Rådestad I, Eriksson C, Rubertsson C, Nystedt A, Hildingsson I. Cesarean section without medical reason, 1997 to 2006: a Swedish register study. Birth. 2010;37(1): 11–20.
52. Bodner K, Wierrani F, Grünberger W, Bodner-Adler B. Influence of the mode of delivery on maternal and neonatal outcomes: a comparison between elective cesarean section and planned vaginal delivery in a low-risk obstetric population. Arch Gynecol Obstet. 2011;283(6): 1193–8.

53. Irion O, Hirsbrunner Almagbaly P, Morabia A. Planned vaginal delivery versus elective caesarean section: a study of 705 singleton term breech presentations. BJOG. 1998;105(7):710–7.
54. Fisher J, Astbury J, Smith A. Adverse psychological impact of operative obstetric interventions: a prospective longitudinal study. Aust N Z J Psychiatry. 1997;31(5):728–38.
55. Håkansson S, Källén K. Caesarean section increases the risk of hospital care in childhood for asthma and gastroenteritis. Clin Exp Allergy. 2003;33(6):757–64.
56. Wiklund I, Edman G, Andolf E. Cesarean section on maternal request: reasons for the request, self-estimated health, expectations, experience of birth and signs of depression among first-time mothers. Acta Obstet Gynecol Scand. 2007;86(4):451–6.
57. Saisto T, Ylikorkala O, Halmesmäki E. Factors associated with fear of delivery in second pregnancies. Obstet Gynecol. 1999;94(5, Part 1):679–82.
58. Ryding EL, Wijma K, Wijma B. Psychological impact of emergency cesarean section in comparison with elective cesarean section, instrumental and normal vaginal delivery. J Psychosom Obstet Gynecol. 1998;19(3):135–44.
59. Söderquist J, Wijma K, Wijma B. Traumatic stress in late pregnancy. J Anxiety Disord. 2004;18(2):127–42.
60. Ayers S, Pickering AD. Do women get posttraumatic stress disorder as a result of childbirth? A prospective study of incidence. Birth. 2001;28(2):111–8.
61. Roth M. The phobic anxiety-depersonalization syndrome. Proc R Soc Med. 1959;52(8):587–95.
62. Andersson L, Sundström-Poromaa I, Wulff M, Åström M, Bixo M. Neonatal outcome following maternal antenatal depression and anxiety: a population-based study. Am J Epidemiol. 2004;159(9):872–81.
63. Shapiro Gabriel D, Fraser William D, Frasch Martin G, Séguin JR. Psychosocial stress in pregnancy and preterm birth: associations and mechanisms. J Perinat Med. 2013;41(6):631–45.
64. Ding X-X, Wu Y-L, Xu S-J, Zhu R-P, Jia X-M, Zhang S-F, et al. Maternal anxiety during pregnancy and adverse birth outcomes: a systematic review and meta-analysis of prospective cohort studies. J Affect Disord. 2014;159:103–10.
65. Eaton WW, Kessler RC, Wittchen HU, Magee WJ. Panic and panic disorder in the United States. Am J Psychiatry. 1994;151(3):413–20.
66. Antony MM, Swinson RP. Phobic disorders and panic in adults: a guide to assessment and treatment. Washington, DC: American Psychological Association; 2000.
67. Öst L-G, Salkovskis PM, Hellström K. One-session therapist-directed exposure vs. self-exposure in the treatment of spider phobia. Behav Ther. 1991 Summer;22(3):407–22.
68. Öst L-G, Brandberg M, Alm T. One versus five sessions of exposure in the treatment of flying phobia. Behav Res Ther. 1997;35(11):987–96.
69. Astbury J. The crisis of childbirth: can information and childbirth education help? J Psychosom Res. 1980;24(1):9–13.
70. Mehl-Madrona LE. Hypnosis to facilitate uncomplicated birth. Am J Clin Hypnosis. 2004;46(4):299–312.
71. Ryding EL. Investigation of 33 women who demanded a cesarean section for personal reasons. Acta Obstet Gynecol Scand. 1993;72(4):280–5.
72. Sjögren B, Thomassen P. Obstetric outcome in 100 women with severe anxiety over childbirth. Acta Obstet Gynaecol Scand. 1997;76(10):948–52.
73. Saisto T, Salmela-Aro K, Nurmi J-E, Könönen T, Halmesmäki E. A randomized controlled trial of intervention in fear of childbirth. Obstet Gynecol. 2001;98(5, Part 1):820–6.
74. Nerum H, Halvorsen L, Sorlie T, Oian P. Maternal request for cesarean section due to fear of birth: can it be changed through crisis-oriented counseling? Birth. 2006;33:221–8.
75. Saisto T, Toivanen R, Salmela-Aro K, Halmesmäki E. Therapeutic group psychoeducation and relaxation in treating fear of childbirth. Acta Obstet Gynaecol Scand. 2006;85(11):315–1319.

76. Rouhe H, Salmela-Aro K, Toivanen R, Tokola M, Halmesmäki E, Ryding E-L, et al. Group psychoeducation with relaxation for severe fear of childbirth improves maternal adjustment and childbirth experience-a randomised controlled trial. J Psychosom Obstet Gynecol. 2015;36(1):1–9.
77. Fenwick J, Gamble J, Creedy DK, Buist A, Turkstra E, Sneddon A, et al. Study protocol for reducing childbirth fear: a midwife-led psycho-education intervention. BMC Pregnancy Childbirth. 2013;13(1):190.
78. Klabbers G, Wijma K, Paarlberg KM, Emons WHM, Vingerhoets AJJM. Treatment of severe fear of childbirth with haptotherapy: design of a multicenter, randomized trial. BMC Complement Altern Med. 2014;14:385.
79. Ryding EL, Persson A, Onell C, Kvist L. An evaluation of midwives' counseling of pregnant women in fear of childbirth. Acta Obstet Gynecol Scand. 2003;82(1):10–7.

A Woman Afraid of Becoming Pregnant Again: Posttraumatic Stress Disorder Following Childbirth

2

Claire Stramrood and Pauline Slade

2.1 Introduction and Aims

Some women experience the delivery of a child as so traumatic that they develop a posttraumatic stress disorder (PTSD). PTSD may occur after events in which a person experienced or witnessed (threatened) death or serious injury to the body and suffers from a range of symptoms as a result of it [1]. People with PTSD frequently report nightmares, unwanted intrusions of negative emotions and cognitions, avoidance behavior, irritability, generally being on edge, poor concentration, guilt, and agitation. Since the late 1990s, scientific articles have been published related to childbirth as a potential traumatic event. Because of the possible implications for mother, infant, and family, it is important that obstetric care professionals and those providing care in the first postnatal year in community settings recognize and acknowledge PTSD following childbirth and that they are aware of possible risk factors, consequences, and treatment options.

2.2 Definition in Lay Terms

Some women experience so much stress and anxiety during childbirth that they find it a traumatic experience. If they afterward have symptoms such as nightmares, flashbacks, irritability, and feelings of guilt and when they try to avoid conversations or

C. Stramrood, MD, PhD (✉)
Department of Obstetrics and Gynecology, University Medical Center Utrecht, Utrecht, The Netherlands
e-mail: info@drstramrood.nl

P. Slade, BSc, MSc, PhD
Institute of Psychology Health and Society, University of Liverpool, Liverpool, UK
e-mail: Pauline.slade@liverpool.ac.uk

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_2

places that remind them of labor and delivery, they may be suffering from a condition called posttraumatic stress disorder (PTSD).

2.3 Didactical Goals

After reading this chapter, you know:

- How often PTSD following childbirth occurs
- That the level or number of complications/interventions during childbirth does not determine whether a delivery was a traumatic experience
- Which women are particularly vulnerable for developing PTSD following childbirth
- That PTSD following childbirth often co-occurs with (postpartum) depression
- How to recognize (women with) PTSD following childbirth
- Possible treatment options for women with PTSD (symptoms)

Case History

Lisa Gray is a 33-year-old woman. She is 28 weeks pregnant and already has a 4-year-old daughter. The pregnancy is medically uncomplicated thus far. During a routine visit, she mentions to the midwife that for the past few weeks she has been having difficulty falling asleep and that she feels exhausted during the day. She reveals there is also quite some tension between her and her partner lately, and she has been yelling at her daughter over minor things. She worries a lot about soon having two young children to take care of and whether she will be a good-enough mother. As her due date is coming closer, she frequently thinks back to her first delivery, which upsets her. She thinks it may be one of the reasons she has difficulty falling asleep at night and of waking up terrified in the middle of the night.

Midwife Alicia Crimson figures that part of what Lisa describes is what many mothers (and fathers) experience, during or outside of pregnancy: feeling tired, not getting enough sleep, an intimate partner relationship that has its ups and downs, and doubts and frustrations about one's own parenting skills. However, Lisa has mentioned that a number of these issues have begun recently: she has negative thoughts and feelings and relates part of her feeling miserable to thoughts of both the past and upcoming deliveries. Therefore, Alicia asks Lisa about the experience of her first delivery, how she anticipates the upcoming delivery, her general current mood, and possible explanations for her complaints.

2.4 Facts and Figures: Definitions, Classification, and Prevalence

2.4.1 How Often Do Women Experience the Delivery as Traumatic?

A traumatic delivery experience is generally reported by 29–44 % of women [2–5].

2.4.2 When May a Delivery Be Experienced as Traumatic?

In order to classify an event like giving birth as a "traumatic event" in line with the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5) criteria, a woman would have to have experienced or witnessed death, threatened death, actual or threatened serious injury, or actual or threatened sexual violence, in this case referring to herself or the baby. It is important to realize that the perception of "threatened death or injury" is subjective and determined by the person experiencing it. Whether the life of a woman or her baby was actually in danger, from a medical (objective) point of view, is interestingly not relevant enough in the context of determining whether the delivery was traumatic for the patient. It must also be noted that indications of fetal distress or the experience of tears, episiotomy, or hemorrhage are not uncommon in childbirth.

Case History: Continued

Midwife Alicia Crimson looks into Lisa Gray's medical chart of her first delivery. It is noted: "Healthy, 29-year-old primigravida, 40 + 6 weeks gestation. Admitted to the obstetrician-led unit for failure to progress at 2 cm and desire for pain relief. Received epidural analgesia. After 70 min in second stage, instrumental delivery (ventouse) for failure to progress and suspected fetal distress. Healthy girl born with 1 min APGAR of 7 and 5 min APGAR of 9, weighing 3855 g. Postpartum hemorrhage of 1400 cc. Re-admitted on day 8 postpartum for suspected endometritis, treated with IV antibiotics."

At the following visit Lisa tells her, "After 12 h of painful contractions, I was exhausted. The pains were irregular, so the midwife only came to check on me once during the whole night. She told me to give it some time and try to relax, but I was so overwhelmed already. At 9 in the morning, I only had 2 cm dilatation, and I couldn't take it anymore. They gave me the epidural and also put me on an oxytocin drip, but then left me alone again for several more hours. I failed at everything. I couldn't do the contractions by myself, I

couldn't handle the pain, and I couldn't push hard enough. By the time I had been pushing for over an hour, the baby's heartbeat dropped with every contraction. They needed that horrible, painful suction thing to get her out quickly. I can still remember the look on the face of the obstetrician pulling it. I was terrified, and when she came out, the first thing I thought was 'I hope she's still alive.' Then I started bleeding; people started panicking. I know my husband was really afraid I would die, but I don't remember most of that part. I feel such a failure for not being able to birth my own child and asking for pain relief even though I was convinced I could do without. Right now, I don't feel extremely depressed or sad. I just cannot handle failing a second time and am terrified when I think of this upcoming delivery. Every time I pass the hospital, my heart is racing, and I am on the verge of hyperventilating."

2.4.3 How Common Is PTSD Following Childbirth?

The prevalence of PTSD following childbirth is approximately 3.1 % in unselected populations [5–7]. In high-risk groups (see later for risk factors), the prevalence is up to 15.7 %.

2.4.4 When Does a Woman Suffer from PTSD Following Childbirth?

Next to having experienced a traumatic event, the DSM-5 lists four categories of symptoms as part of the PTSD diagnosis, a number of which from each category should be present to meet the criteria for the disorder (as outlined in the DSM-5 [1]):

- Intrusions (1 required)
  - Recurrent, involuntary, and intrusive memories
  - Nightmares
  - Dissociative reactions (e.g., flashbacks)
  - Psychological distress after exposure to traumatic reminders
  - Physiological reactivity after exposure to traumatic reminders
- Avoidance (1 required)
  - Effortful avoidance of trauma-related thoughts, feelings, people, places, conversations, etc.
- Negative cognitions and mood (2 required)
  - (Dissociative) amnesia about the traumatic event
  - Negative beliefs and expectations about oneself
  - Blame of others or self about causing the traumatic event and its consequences
  - Negative trauma-related emotions
  - Diminished interest in previously significant activities

  - Detachment or estrangement from others
  - Inability to experience positive emotions
- Alterations in arousal and reactivity (2 required)
  - Irritable or aggressive behavior
  - Self-destructive or reckless behavior
  - Hypervigilance
  - Exaggerated startle response
  - Problems in concentration
  - Sleep disturbance

Furthermore, the symptoms should cause distress and/or impairment and be present for at least 1 month. Nonetheless, it is widely recognized that levels of distress at sub-diagnostic levels are of sufficient salience for intervention, not the least because of the important developmental consequences of women's well-being for the fetus and infant [8].

Case History: Continued
In this case history, Lisa has mentioned a number of things that are concurrent with the criteria for PTSD. Firstly, she has described a traumatic delivery experience, in particular being afraid that her baby would die ("I hope she's still alive"). She also uses terms such as "horrible, painful suction thing" and "being terrified." She has reported several symptoms of PTSD in three of the four clusters. As intrusions, she describes nightmares, has frequent upsetting thoughts about the delivery, and has physical reactions when faced with something that reminds her of the birth (racing heart and hyperventilating when passing by the hospital). She has not explicitly reported avoidance. As for negative cognitions and mood, she describes feelings of failure ("I failed at everything") and fear of failing again with the upcoming birth, partial amnesia ("I don't remember most of that part"), and guilt and self-blame related to the course of labor and delivery ("I couldn't push hard enough"). For hypervigilance, she describes sleep disturbance and irritable behavior. She mentioned significant impairment of her daily functioning. Before considering a PTSD diagnosis, one would still need to know how long she is experiencing these symptoms and if she also has symptoms of avoidance.

2.5 Etiology and Pathogenesis

When an event has been experienced as very frightening, then the traumatic memories made are stored in a different part of the brain from normal memories [9]. These are primitive sensory memories. It can be quite normal for people to experience intrusive images and thoughts in the early days post trauma as the person attempts to assimilate this new information and its meaning into their personal life history.

However, if the material is very distressing and painful, then the person may seek to avoid and block these memories. Unfortunately, this blocks the processing, or adaptation, of making sense of material and linking this with other meaning that would normally occur [10]. These patterns lead to the development of PTSD. The ability to form and have available supportive relationships (i.e., secure attachment patterns) facilitates both the tolerance of stressful events without high levels of fear and the normal processing of difficult experiences and resolution of memories. Some work has suggested that experiences such as early abuse that undermine trust in others and lead to insecure attachment lay the foundations for low stress tolerance and difficulty processing distressing material [11, 12].

2.5.1 Can You Identify Risk Factors for the Development of PTSD Following Childbirth?

Some women are more likely to develop PTSD following childbirth than others. Generally, risk factors can be divided according to their chronological occurrence or according to the type of risk factor. A common distinction is between predisposing factors (present prepregnancy or during pregnancy), precipitating factors (aspects of the childbirth event itself and how this is experienced), and maintaining factors (postpartum factors, including how well a woman is supported and the sense she makes of her early responses) [13]. Another division is between psychological factors, obstetric factors, and situational factors that occur during labor and delivery. Predisposing psychological risk factors include a history of PTSD, depression during pregnancy, and fear of childbirth. Women with poor coping skills or postpartum depression also experience PTSD more often. While women may develop PTSD following deliveries that are considered normal, physiological, or uncomplicated in medical terms, PTSD is more common after obstetric interventions and complications. Pregnancy complications (e.g., preterm birth, preeclampsia), obstetric emergencies, unplanned caesarean section, instrumental delivery (ventouse/forceps), neonatal morbidity, and perinatal mortality all increase the risk of developing PTSD. However, it is the way in which women appraise the delivery that plays a key role in the development of PTSD. Negative subjective birth experiences, lack of (perceived) control (autonomy), dissociation, lack of (perceived) support, and negative emotions are associated with traumatic delivery experiences and PTSD postpartum [6, 14]. Finally as indicated previously, how a woman responds to early intrusive experiences and whether she is supported to discuss these postpartum so that she can face and assimilate them into her life story rather than try to control distress through avoidance is also important.

2.5.2 What Is the Natural Course of PTSD Following Childbirth?

Not all women who found labor and delivery unpleasant also perceived it as traumatic. And not all women who found childbirth traumatic develop (symptoms of) PTSD or acute stress disorder. However, evidence shows that in most women who

have developed PTSD postpartum, without treatment, spontaneous recovery is rare, and significant distress may continue for years [15, 16].

2.5.3 What Are Possible Consequences of PTSD Following Childbirth?

The implications of PTSD can be considered at the level of the individual, her relationships, and in healthcare systems. Firstly, PTSD has a negative impact on women's own functioning. Secondly, there is the potential for significant negative impact on mother-infant bonding, even more so with comorbid depression [17], and difficulties in the partner relationship may develop [18]. Infants may also have feeding difficulties and show excessive crying [19]. Early posttraumatic stress symptoms are also associated with later parenting stress [20].

It is not uncommon that women with PTSD following childbirth change their plans for future pregnancies [7], in some case even leading to a decision not to pursue another pregnancy due to the previous traumatic experience, despite strong wishes to have more children. Where women do go on to become pregnant again, then subsequent maternity care is likely to be affected. Obstetricians and midwives may also encounter women with PTSD requesting an elective caesarean section. Different national guidelines vary in the extent and the conditions by which these requests may or should be honored. Some women present wishes that very much oppose national guidelines (e.g., home birth after 2 caesareans (HBA2C)) or draft lengthy and often inflexible birth plans including detailed directions for labor and delivery staff. The avoidance behavior that is part of PTSD can often lead women to miss appointments or fail to report problems. Other women, however, show a pattern of multiple consultations and nonspecific physical complaints/somatization.

Healthcare more generally may also be adversely affected. Clinical experience shows that many women with PTSD following childbirth resent and fail to attend routine gynecological examinations such as for cervical cancer screening.

2.6 Specific Diagnostic Aspects

2.6.1 How Can PTSD (Following Childbirth) Be Diagnosed?

The diagnosis of PTSD should be made by a licensed healthcare professional with extensive background in psychopathology and psychodiagnostics, such as a psychologist or psychiatrist. Formal diagnosis can be made, for example, by making use of clinical interviews such as the Clinician-Administered PTSD Scale (CAPS), the Structured Clinical Interview for DSM Disorders (SCID), and the Mini International Neuropsychiatric Interview (M.I.N.I.) [21–23]. However, it is very important to recognize that there can be high levels of distress requiring psychological intervention even where a woman does not fully fulfill diagnostic criteria.

2.6.2 What Can Obstetricians and Midwives Do to Facilitate the Diagnosis of PTSD Following Childbirth?

Awareness of the symptoms and risk factors for PTSD following childbirth is essential, as well as asking follow-up questions when women report somatic complaints (fatigue, concentration problems, insomnia), in order to distinguish between physical and psychological causes of these symptoms.

The simple question "how did you experience the (previous) delivery" is likely to reveal a lot of information about a woman's appraisal of the event. Obstetricians, midwives, health visitors, social workers, family (general) practitioners, and others can make use of self-report questionnaires to screen for PTSD. Validated screening instruments include the PTSD checklist for DSM-5 (PCL-5), Trauma Screening Questionnaire (TSQ), and PTSD Symptom Scale Self-Report (PSS-SR) [24–26].

2.6.3 Should We Screen for PTSD Following Childbirth?

Experts in the field do not provide a straightforward answer to this question [27]. While awareness of PTSD following childbirth is increasing among healthcare professionals and women themselves, the condition still often goes unrecognized. In order to detect more women with PTSD, with the intention to offer treatment and prevent further harm, one could decide to screen all women at a given point in time (e.g., 6 weeks postpartum), or to screen those with identified (obstetric and/or psychological) risk factors, or to screen at the discretion of the care provider (i.e., when PTSD is suspected). Screening requires adequate instruments (a number of which are available) and the local infrastructure to refer to suitable treatment facilities.

2.6.4 What Do You Want to Know in Order to Distinguish Between PTSD and Other Conditions, i.e., What Is the Differential Diagnosis?

It is important to elaborate on possible causes for vague or nonspecific symptoms such as fatigue and irritability, in order to distinguish between predominantly physi(ologi)cal and psychological causes. The list is much more extensive, but one should consider anemia, hypothyroidism or other thyroid disorders, vitamin D or B12 deficiency, infectious mononucleosis (Pfeiffer's disease), or cytomegalovirus (CMV) infection. As for psychiatric conditions, research estimates that 20–75 % of the women with PTSD following childbirth also suffer from (postpartum) depression [5, 16, 28]. At the same time, women with PTSD are commonly misdiagnosed with (postpartum) depression. Experts in the field have the impression that depression is often secondary to the traumatic experience [27]. It is also possible that women meet the DSM criteria for PTSD, but that this is (partly) as a result of previous trauma and PTSD symptoms, such as sexual or childhood abuse. The key elements for consideration are women's experiences of intrusive experiences either

Table 2.1 Treatment options for PTSD

Intervention	Key elements and therapeutic processes
EMDR	Intervention that involves standardized procedures that include focusing simultaneously on (1) spontaneous associations of traumatic images and the accompanying feelings, thoughts, and physical responses and (2) bilateral stimulation, usually repeated eye movements. The hypothesis is that negative thoughts, feelings, and behaviors are the result of unprocessed memories. The working memory is taxed simultaneously by recalling the event and the bilateral stimulation, thereby causing the memory to be reconsolidated less vividly. Unlike trauma-focused CBT, EMDR does not involve detailed descriptions of the event
CBT with exposure	CBT aims to modify dysfunctional (inaccurate or unhelpful) thinking and behavior. Trauma-focused CBT is an intervention aimed at (1) preventing the avoidance of the troubling images and thoughts by actively re-experiencing the events in a controlled and safe environment and (2) cognitive restructuring by identifying the meaning of the particular "hot spots" (worst part of the events for the person): What did it make them think about themselves at that point? Is there any new information that they could use to challenge that now? The goal is to update the memory with new information

EMDR eye movement desensitization and reprocessing, *CBT* cognitive behavioral therapy

through imagery thoughts or nightmares. There is little research about the comorbidity of PTSD following childbirth with other psychiatric conditions.

2.7 Specific Therapeutic Aspects

2.7.1 How Can PTSD Following Childbirth Be Treated?

General PTSD literature clearly favors trauma-focused cognitive behavioral therapy (CBT) and eye movement desensitization and reprocessing (EMDR) therapy as the interventions with the best available evidence for their effectiveness [29–32] (Table 2.1). Only a limited number of smaller studies have been published pertaining specifically to women with postpartum PTSD, yielding positive results for both types of interventions [33–35]. Literature does not favor either of the therapies in terms of effectiveness. When to choose either of these therapeutic approaches is therefore largely a matter of personal preference of the woman for either type of approach and of experience and availability of qualified therapists. EMDR does not involve homework, and there is evidence that with EMDR faster symptom reduction is seen and fewer sessions are necessary in the case of a single traumatic event [36]. Treating women with a history of abuse or neglect will often take more time and/or require additional types of therapy. Compared to EMDR, which is a technique used for just over 25 years, more studies have been published demonstrating the effectiveness of CBT. Both these approaches require high levels of training, and women are advised to seek treatment from mental health professionals with experience in treating psychopathology related to the peripartum period. In case of comorbid depressive disorder and/or insufficient response to psychological therapy, one may

also consider pharmacological treatment. In that case, selective serotonin reuptake inhibitors (SSRIs) are most frequently used. As with any medication use postpartum, expert advice should be sought in case a woman is breastfeeding.

2.7.2 Can Women Be Treated During Pregnancy?

Very little research has thus far been published involving pregnant women with PTSD following childbirth. From a theoretical point of view, treatment can result in increased stress, with unknown consequences for the fetus. Both trauma-focused CBT and EMDR require women to direct their attention to the traumatic event, which can be stress provoking. A key element for consideration is therefore the level of current distress that a woman is experiencing. For example, if a woman is exhausted because she keeps waking up after 2 h of sleep with disturbing dreams and she is too fearful to go back to sleep, she is already highly stressed. While the safety of interventions during pregnancy is not well established, we should assume a potential harm of ongoing stress during pregnancy, which may even increase as the due date draws closer. This may have therapists and women decide together that treatment during pregnancy is desired. An alternative approach, with emerging evidence that does not require reliving, is a metacognitive therapy [37]. This involves understanding how we think about and respond to our distress and symptoms of PTSD, rather than focusing on the traumatic event itself. So this intervention is not about what images or thoughts we have in response to a traumatic situation but *how we think about our thoughts*. The premise is that certain patterns of response maintain symptoms rather than allowing natural processing and resolution. So it is what we *make* of the fact that we have distressing images and thoughts, rather than their existence that exacerbates problems and prevents natural resolution. Identifying, understanding, and challenging these patterns of response to symptoms and developing alternatives have shown promise. These alternative approaches and their implications need to be discussed with the woman so she can indicate her own preferences and provide informed consent.

2.7.3 What Should Be Done to Minimize the Risk of Another Traumatic Experience During a Subsequent Delivery?

Traumatic experiences and PTSD can never be completely avoided, because complications and interventions are sometimes inevitable, and some women are more vulnerable to psychopathology than others. However, if women feel well supported throughout childbirth and experience a sufficient degree of autonomy and communication between woman, partner, and obstetric staff is optimal, the risks of experiencing even an obstetrically complex birth as traumatic will be very significantly reduced [38]. It is important to be aware of symptoms of mental disorders during pregnancy and offer adequate counseling, support and/or intervention, and careful preparation for the next birth.

Many women report having felt a complete loss of autonomy and control during the traumatic delivery, and providing tools for them to feel prepared, heard, and in

charge may help. These may include things such as discussing pain relief options, agreeing on scheduling or avoiding induction of labor, offering elective caesarean section in some cases, agreeing to avoid instrumental deliveries unless for fetal distress, etc. It may help for women to write down general birth preferences for how they are supported and wish to be cared for in childbirth, rather than rigid plans in order for the professionals attending their delivery to be aware of their background. Psychoeducation should help women to understand and prepare for the need for flexibility in response to the course of labor and the fact that aspects of childbirth are not all a function of their preparation and efforts but are also affected by unpredictable factors. Whether a traumatic experience or fear of childbirth is a legitimate reason for obstetricians to consent to an elective caesarean (in the absence of a medical necessity) is a topic of debate, and guidelines vary between countries. Aside from the medical risks associated with major abdominal surgery, for some women a successful vaginal delivery with adequate staff and partner support is incredibly empowering. On the other hand, for other women the decision not to go through the labor and delivery process again, but to opt for a controlled and planned caesarean section instead, provides them with a sense of autonomy that they felt lacking during the previous (traumatic) delivery and leads to tremendous stress reduction.

2.7.4 Can We Prevent PTSD Following Childbirth?

The simplest answer is that we do not know, meaning that no good quality research with well-designed prevention strategies have been published. However, Slade's model [13], through providing a conceptual etiological framework that focuses on understanding how (1) predisposing factors (preexisting attributes or patterns of relating that a woman brings with her into the pregnancy), (2) precipitating factors (what actually happens in the events of childbirth), and (3) maintaining factors (how a woman responds to her early postpartum experiences) interact to determine whether a woman develops PTSD, provides testable hypotheses that future research can explore. Based on extrapolation of other studies and the experience of many experts in this field, a number of suggestions can be made. Obviously, healthcare professionals should strive to minimize the number of emergency situations, unnecessary interventions, and obstetric complications. Whether screening for and treating anxiety and depression during pregnancy leads to fewer cases of PTSD postpartum has never been studied, although this would benefit women's general well-being.

There is ample evidence that the degree and quality of perceived support during labor is associated with women's appraisal of the delivery, having a traumatic experience, and developing PTSD. This works both ways: positive support during birth is associated with reduced PTSD, especially in case of interventions and in women with a history of trauma [38], partly by improving women's perceived control [39]. Conversely, many women point to a lack of (perceived) support, feeling ignored and abandoned, and uncaring staff as crucial factors in their traumatic experience [40]. It is known from general childbirth literature that continuous one-on-one support influences a variety of factors, such as the duration of labor and the incidence of caesarean section, instrumental deliveries, and epidural anesthesia [41]. It seems

that the quantity and quality of staff interaction and communication during labor and delivery also affect the development of PTSD, and hence improved support should theoretically be useful.

Negative, bad, or traumatic experiences are often associated with a discrepancy between expectations and reality. Therefore, it is crucial that women are prepared (by healthcare professionals, antenatal classes, reading, or otherwise) for what to expect during labor and delivery. All too often, usually with good intentions, women end up being educated on all the possibilities and benefits of natural, drug-free labor, but know very little about what to expect in terms of pain, duration of labor, induction, and chances of having a caesarean section or postpartum hemorrhage. In their preparation, having or developing a reasonable degree of cognitive flexibility is imperative. Rather than focusing on a birth plan with a single well-defined outcome (usually an idealistic picture of childbirth), women should be encouraged to consider their wishes in the light of different possible scenarios (e.g., induction, preterm birth, caesarean section) and may call this a birth flow chart instead of a birth plan [42].

Certainly early postpartum identification of women at risk and intervention can theoretically have the potential to prevent posttraumatic stress disorder, although definitive evidence is awaited. There is some evidence to suggest that a "childbirth review"—a meeting to discuss the birth with a professional who can clarify and answer queries—may help women to make sense of their experiences. However, neither universal debriefing nor critical incident debriefing is indicated by the literature [43].

Case History: Continued

As midwife Alicia Crimson suspected PTSD, she asked Lisa Gray to complete three screening questionnaires (PTSD, depression, and fear of childbirth). The questionnaires indicated a possible PTSD and strong fear of childbirth, while clinical depression seemed unlikely. Lisa was referred to a psychologist with experience in maternal mental health for diagnosis and treatment. He confirmed the diagnosis of PTSD. Over the course of the next 8 weeks, a weekly therapy session took place. The therapist used EMDR during two sessions. Lisa and her therapist extensively talked about Lisa's tendency for self-blame from early childhood onward. EMDR helped Lisa to feel less upset and emotional when talking about the birth of her daughter and altered her view on her supposed failure; instead, she realized that part of what happened was bad luck, and during all of the delivery, she did the best she could for herself and her baby. Lisa and her husband had two extra visits with midwife Alicia and the consultant obstetrician. They drafted a birth plan that included a number of wishes and agreements (early access to pain relief if requested, Lisa's desire for direct communication, and her wish to be kept informed and involved in decisions during labor) and a mention of her previous traumatic experience for hospital staff to be aware of. With this combined approach, Lisa felt confident about herself and the staff to face the upcoming birth. She went into spontaneous labor at 38 weeks, received an epidural, and delivered a healthy boy 6 h later. She looks back at the delivery positively.

2.8 Critical Reflection and Conclusive Remarks

Approximately 3 % of women meet the DSM-5 diagnostic criteria for PTSD, a larger proportion reports and suffers from sub-diagnostic PTSD symptoms, and at least one-third of women report having experienced the delivery as traumatic. There is increasing recognition for the occurrence and consequences of traumatic delivery experiences and PTSD following childbirth. Some women are more prone to develop postpartum PTSD, based on their psychological vulnerability and previous trauma, the (objective) nature of the course of their labor and delivery, and maintaining factors after birth. Early identification of these women at risk is crucial for timely intervention/treatment. Obstetric staff should be(come) aware of their role in women's appraisal of labor and delivery, both positively and negatively. Future research should include further investigating prevention strategies to reduce the likelihood of women reporting childbirth to be traumatic, which may lead to the development of postpartum PTSD.

Tips and Tricks

1. Always ask multiparous women how they experienced and appraised previous deliveries. Traumatic delivery experiences are very common (29–44 %). PTSD much less so (3 %).
2. Note the difference between postpartum posttraumatic stress disorder and postpartum depression, both in etiology, symptomatology, and treatment options. While there is considerable comorbidity of PTSD following childbirth with (postpartum) depression, they are two distinct conditions.
3. Obstetric staff and others with no formal psychological/psychiatric (diagnostic) training need educative input to understand the relevant constructs before routinely administering self-report screening questionnaires for PTSD following childbirth.
4. PTSD is a condition that is usually not self-limiting but requires treatment. In case of (suspected) PTSD following childbirth, refer to a psychologist or psychiatrist who has experience with trauma and mental health disorders related to the postpartum/pregnancy/reproduction.

Check Your Knowledge and Comprehension

1. 3 % of women develop PTSD following childbirth.
   (a) True
   (b) False
2. PTSD following childbirth is a severe type of postpartum depression.
   (a) True
   (b) False
3. Women with PTSD following childbirth often delay subsequent pregnancies or do not dare becoming pregnant again.
   (a) True
   (b) False

4. After a few years, women usually spontaneously recover from PTSD following childbirth.
   (a) True
   (b) False
5. First choice of treatment for women with PTSD following childbirth is medication (often SSRIs).
   (a) True
   (b) False
6. The gynecologist determines whether a delivery has been traumatic, based on the number of complications and interventions.
   (a) True
   (b) False
7. Key elements for the consideration of PTSD following childbirth, and the difference with, for example, postpartum depression, are the occurrence of intrusive experiences such as nightmares or flashbacks.
   (a) True
   (b) False
8. Which of the following is *not* a risk factor for the development of PTSD following childbirth?
   (a) Preterm birth
   (b) Emergency caesarean section
   (c) Educational level
   (d) Depression during pregnancy
9. Which of the following is/are a common behavioral pattern in women with PTSD following childbirth who are pregnant again?
   (a) Frequent consultations for somatic complaints (e.g., abdominal pains, trouble sleeping, nausea) for which no probable physical cause is found
   (b) Missing appointments, denying routine procedures and screening (blood tests, ultrasounds), and generally avoiding the hospital
   (c) Over-preparedness, including lengthy birth plans and high demands and requests related to labor and delivery that are unusual or not in line with guidelines or protocols
   (d) All of the above
10. The application of EMDR therapy and trauma-focused cognitive behavioral therapy (including exposure) is contraindicated during pregnancy.
    (a) True
    (b) False

Answers

1. True
2. False
3. True
4. False
5. False
6. False
7. True

8. (c)
9. (d)
10. False

References

1. American Psychiatric Association. Diagnostic and statistical manual of mental disorders, 5th edition (DSM-5). Washington, DC: APA; 2013.
2. Soet JE, Brack GA, DiIorio C. Prevalence and predictors of women's experience of psychological trauma during childbirth. Birth. 2003;30:36–46.
3. Stramrood CA, Paarlberg KM, Huis In 't Veld EM, Berger LW, Vingerhoets AJ, Weijmar Schultz WC, van Pampus MG. Posttraumatic stress following childbirth in homelike- and hospital settings. J Psychosom Obstet Gynaecol. 2011;32:88–97.
4. Boorman RJ, Devilly GJ, Gamble J, Creedy DK, Fenwick J. Childbirth and criteria for traumatic events. Midwifery. 2014;30:255–61.
5. Alcorn KL, O'Donovan A, Patrick JC, Creedy D, Devilly GJ. A prospective longitudinal study of the prevalence of post-traumatic stress disorder resulting from childbirth events. Psychol Med. 2010;40:1849–59.
6. Grekin R, O'Hara MW. Prevalence and risk factors of postpartum posttraumatic stress disorder: a meta-analysis. Clin Psychol Rev. 2014;34:389–401.
7. Czarnocka J, Slade P. Prevalence and predictors of post-traumatic stress symptoms following childbirth. Br J Clin Psychol. 2000;39:35–51.
8. NICE. Antenatal and postnatal mental health: Clinical management and service guidance (CG 45); 2007.
9. Brewin CR. A cognitive neuroscience account of posttraumatic stress disorder and its treatment. Behav Res Ther. 2001;39:373–93.
10. Horowitz M, Wilner N, Alvarez W. Impact of event scale: a measure of subjective stress. Psychosom Med. 1979;41:209–18.
11. Iles J, Slade P, Spiby H. Posttraumatic stress symptoms and postpartum depression in couples after childbirth: the role of partner support and attachment. J Anxiety Disord. 2011;25:520–30.
12. Quinn K, Spiby H, Slade P. A longitudinal study exploring the role of adult attachment in relation to perceptions of pain in labor, childbirth memory and acute traumatic stress responses. J Reprod Infant Psychol. 2015;33:256–67.
13. Slade P. Towards a conceptual framework for understanding post-traumatic stress symptoms following childbirth and implications for further research. J Psychosom Obstet Gynaecol. 2006;27:99–105.
14. Andersen LB, Melvaer LB, Videbech P, Lamont RF, Joergensen JS. Risk factors for developing post-traumatic stress disorder following childbirth: a systematic review. Acta Obstet Gynecol Scand. 2012;91:1261–72.
15. Soderquist J, Wijma B, Wijma K. The longitudinal course of post-traumatic stress after childbirth. J Psychosom Obstet Gynaecol. 2006;27:113–9.
16. Stramrood CA, Wessel I, Doornbos B, Aarnoudse JG, van den Berg PP, Schultz WC, van Pampus MG. Posttraumatic stress disorder following preeclampsia and PPROM: a prospective study with 15 months follow-up. Reprod Sci. 2011;18:645–53.
17. Righetti-Veltema M, Conne-Perreard E, Bousquet A, Manzano J. Postpartum depression and mother-infant relationship at 3 months old. J Affect Disord. 2002;70:291–306.
18. Ayers S, Eagle A, Waring H. The effects of childbirth-related post-traumatic stress disorder on women and their relationships: a qualitative study. Psychol Health Med. 2006;11:389–98.
19. Pierrehumbert B, Nicole A, Muller-Nix C, Forcada-Guex M, Ansermet F. Parental post-traumatic reactions after premature birth: implications for sleeping and eating problems in the infant. Arch Dis Child Fetal Neonatal Ed. 2003;88:F400–4.

20. McDonald S, Slade P, Spiby H, Iles J. Post-traumatic stress symptoms, parenting stress and mother-child relationships following childbirth and at 2 years postpartum. J Psychosom Obstet Gynaecol. 2011;32:141–6.
21. First MB, Spitzer RI, Gibbon M, Williams JBW. Structured clinical interview for DSM-IV axis I disorders, research version, non-patient edition (SCID-I/NP). New York: Biometrics Research Department, New York State Psychiatric Institute; 1997.
22. Sheehan DV, Lecrubier Y, Sheehan KH, Amorim P, Janavs J, Weiller E, Hergueta T, Baker R, Dunbar GC. The Mini-International Neuropsychiatric Interview (M.I.N.I.): the development and validation of a structured diagnostic psychiatric interview for DSM-IV and ICD-10. J Clin Psychiatry. 1998;59 Suppl 20:22–33.
23. Blake DD, Weathers FW, Nagy LM. The development of a clinician administered PTSD scale. J Trauma Stress. 1995;8:75–90.
24. Foa EB, Riggs DS, Dancu CV, Rothbaum BO. Reliability and validity of a brief instrument for assessing post-traumatic stress disorder. J Trauma Stress. 1993;4:459–73.
25. Brewin CR, Rose R, Andrews B, Green J, Tata P, McEvedy C, Turner S, Foa EB. Brief screening instrument for post-traumatic stress disorder. Br J Psychiatry. 2002;181:158–62.
26. Weathers FW, Litz BT, Keane TM, Palmieri PA, Marx BP, Schnurr PP. The PTSD checklist for DSM-5 (PCL-5); National Center for PTSD, 2013.
27. McKenzie-McHarg K, Ayers S, Ford E, Horsch A, Jomeen J, Sawyer A, Stramrood CA, Thomson G, Slade P. Post-traumatic stress disorder following childbirth: an update of current issues and recommendations for future research. J Reprod Infant Psychol. 2015;33:219–37.
28. White T, Matthey S, Boyd K, Barnett B. Postnatal depression and post-traumatic stress after childbirth: prevalence, course and co-occurrence. J Reprod Infant Psychol. 2006;24:107–20.
29. NICE. Post-traumatic stress disorder; the management of PTSD in adults and children in primary and secondary care. London: NICE guidelines; 2005.
30. American Psychiatric Association (APA). Practice guidelines for the treatment of patients with acute stress disorder and posttraumatic stress disorder. Arlington: American Psychiatric Association Practice Guidelines; 2004.
31. International Society for Traumatic Stress Studies, Foa EB, Keane TM, Friedman MJ, Cohen JA. Effective treatments for PTSD: practice guidelines from the International Society for Traumatic Stress Studies. 2nd ed. New York: The Guilford Press; 2005.
32. Landelijke Stuurgroep Multidisciplinaire Richtlijnontwikkeling in de GGZ. Multidisciplinaire Richtlijn Angststoornissen. http://www.ggzrichtlijnen.nl/.
33. Ayers S, Kenzie-McHarg K, Eagle A. Cognitive behaviour therapy for postnatal post-traumatic stress disorder: case studies. J Psychosom Obstet Gynaecol. 2007;28:177–84.
34. Stramrood CA, van der Velde J, Doornbos B, Paarlberg KM, Weijmar Schultz WC, van Pampus MG. The patient observer: eye-movement desensitization and reprocessing for the treatment of posttraumatic stress following childbirth. Birth. 2012;39:70–6.
35. Sandstrom M, Wiberg B, Wikman M, Willman AK, Hogberg U. A pilot study of eye movement desensitisation and reprocessing treatment (EMDR) for post-traumatic stress after childbirth. Midwifery. 2008;24:62–73.
36. Ironson G, Freund B, Strauss JL, Williams J. Comparison of two treatments for traumatic stress: a community-based study of EMDR and prolonged exposure. J Clin Psychol. 2002; 58:113–28.
37. Wells A, Sembi S. Metacognitive therapy for PTSD: a preliminary investigation of a new brief treatment. J Behav Ther Exp Psychiatr. 2004;35:307–18.
38. Ford E, Ayers S. Support during birth interacts with prior trauma and birth intervention to predict postnatal post-traumatic stress symptoms. Psychol Health. 2011;26:1553–70.
39. Ford E, Ayers S. Stressful events and support during birth: the effect on anxiety, mood and perceived control. J Anxiety Disord. 2009;23:260–8.
40. Harris R, Ayers S. What makes labor and birth traumatic? A survey of intrapartum 'hotspots'. Psychol Health. 2012;27:1166–77.

41. Hodnett ED, Gates S, Hofmeyr GJ, Sakala C. Continuous support for women during childbirth. Cochrane Database Syst Rev. 2012;(10):CD003766.
42. Thomson G, Downe S. Changing the future to change the past: women's experiences of a positive birth following a traumatic birth experience. J Reprod Infant Psychol. 2010;28:102–12.
43. Sheen K, Slade P. The efficacy of 'debriefing' after childbirth: is there a case for targeted intervention? J Reprod Infant Psychol. 2015;33:308–20.

A Woman Who Cannot Enjoy Her Pregnancy: Depression in Pregnancy and Puerperium

3

Mijke P. Lambregtse-van den Berg and Inge L. van Kamp

3.1 Introduction and Aims

Depressive symptoms during pregnancy and after delivery are common. Overall 7–13% of women suffer from major depression during their pregnancy and/or in the first 3 months after delivery. Perinatal depression is associated with both maternal and child adverse outcomes, but often remains unrecognized. Therefore, early detection and treatment of depression during pregnancy and in the postpartum period is crucial.

3.2 Definition in Lay Terms

Perinatal depression is a specifier of a depression with an onset of mood symptoms during pregnancy or in the first 4 weeks following delivery. A diagnosis of major perinatal depression requires a depressed mood or a loss of interest or pleasure in daily activities for more than 2 weeks, along with a fixed number of emotional, somatic or cognitive symptoms. The severity of these symptoms should impair social, occupational, and/or educational functioning.

M.P. Lambregtse-van den Berg, MD, PhD (✉)
Department of Psychiatry/Child and Adolescent Psychiatry, Erasmus Medical Center, Rotterdam, The Netherlands
e-mail: Mijke.vandenberg@erasmusmc.nl

I.L. van Kamp, MD, PhD
Department of Obstetrics, Leiden University Medical Center, Leiden, The Netherlands
e-mail: i.l.van_kamp@lumc.nl

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_3

3.3 Didactic Goals

After reading this chapter, you will be able to:

- Describe the criteria for perinatal depression
- Distinguish perinatal depression from pregnancy-related symptoms and maternity blues
- Mention risk factors and possible etiologies of perinatal depression
- Identify women with perinatal depression
- Consider pharmacological and non-pharmacological options for treating perinatal depression
- Weigh the risks and benefits of antidepressant medication during pregnancy and lactation period

Case History
Nadia Teal, 29 years old, presents for her pregnancy booking with her midwife at 10 weeks gestation. She is pregnant for the first time. The pregnancy was unplanned and unexpected. Although she is not confident about her relationship, she is willing to keep the baby. She tells her midwife that since she learned she was pregnant, she feels tired and sick, is easily irritated, has a lack of appetite, suffers from insomnia, and has problems concentrating at work. Currently she is at home, because she is not able to work. She asks whether these symptoms are related to pregnancy and if the midwife could help her to feel better.

3.4 Facts and Figures: Definitions, Classification, and Prevalence

3.4.1 What Is the Definition of Perinatal Depression?

See DSM-5 for the criteria for a major depressive disorder. According to the DSM-5, a specifier "with peripartum onset" can be applied to a major depressive episode if the depressive symptoms start during pregnancy or in the first 4 weeks after delivery. The diagnostic criteria for a depression in pregnancy and postpartum ("perinatal depression") do not differ from a depression outside the perinatal period. However, the presentation of depressive symptoms might differ from a "normal" depression. Women with perinatal depression often present with impaired bonding to their (unborn) child and feelings of guilt and insufficiency toward both their child and their partner.

3.4.2 How to Distinguish Postpartum Depressive Symptoms from Postpartum Blues

In the first week after delivery, about half of women experience symptoms such as crying, mood lability, irritability, anxiety, and insomnia. These symptoms, often referred to as "postpartum blues," "maternity blues," or "baby blues," typically start

Table 3.1 Point prevalence of major and minor perinatal depression

Point prevalence	Major and minor depression (%)	Major depression (%)
First trimester	11.0	3.8
Second trimester	8.5	4.9
Third trimester	8.5	3.1
1 month postpartum	9.7	3.8
3 months postpartum	12.9	4.7
6 months postpartum	10,6	5.6
12 months postpartum	6.5	3.9

Data from Ref. [2]

around the 3rd or 4th day after delivery and should resolve within 2 weeks [1]. This is considered to be a physiological phenomenon, often assumed to be related to hormonal readjustment after delivery. If postpartum blues do not resolve within 2 weeks, women are at risk for developing depression and should be evaluated by their general practitioner (GP) or a psychologist.

3.4.3 What Is the Prevalence of Depression During Pregnancy and Postpartum?

Although traditionally it was assumed that women were at highest risk for depression in the postpartum "puerperal" period, increasing research has shown that the rates of postpartum depression do not significantly differ from those of the reproductive years in general or during pregnancy. The prevalence of perinatal depression varies depending upon the method of assessment and the period over which prevalence is determined. Overall, 18.4% of women suffer from depression during their pregnancy, of whom 12.7% have major depression. In the first 3 months after delivery, 19.2% of women have depression, of whom 7.1% suffer from major depression [2]. Point prevalence estimates for minor and major depression are presented in Table 3.1 [2].

3.5 Etiology and Pathogenesis

3.5.1 What Is the Pathogenesis of Perinatal Depression?

The pathogenesis of perinatal depression is largely unknown. As is true for depression in general, the causes of perinatal depression are likely to be a combination of biological, psychological, and environmental factors.

3.5.2 What Are Risk Factors for Perinatal Depression?

Psychological and environmental risk factors for perinatal depression that are reported in separate studies are [3]:

1. Past history of psychiatric disorders

2. Depression/anxiety during current pregnancy
3. Maternity blues
4. Recent adverse life events
5. Low socioeconomic status
6. Insufficient emotional/social support
7. Poor marital relationship
8. Unplanned pregnancy
9. Immigration/pre-migration stress
10. Personality traits
11. Unfavorable obstetric/pregnancy outcomes
12. Unfavorable neonatal outcomes
13. Chronic/current physical illness
14. History of Premenstrual Mood Disorder (PMD)
15. History of physical/sexual abuse
16. Multiple births
17. Domestic violence
18. Childcare stress/infant temperament

Table 3.2 shows the effect sizes of risk factors associated with depression during pregnancy and postpartum, based on systematic reviews [4, 5]. In summary, there are many risk factors or indicators for depression.

3.5.3 Do Hormonal Factors Play a Role in the Pathogenesis?

Since levels of the reproductive hormones estrogen and progesterone increase during pregnancy and fall rapidly after delivery, perinatal depression is often hypothesized to be related to hormonal fluctuations. However, clinical studies

Table 3.2 Risk factors for perinatal depression and their effect sizes

Risk factor	Depression during pregnancy	Postpartum depression
History of depression	+++	++++
Anxiety	++++	++++
Life stress/events	+++	++++
Neuroticism	?	+++
Lack of support	++++	++++
Poor partner relationship	+++	+++
Domestic violence	+	?
Unintended pregnancy	+++	?
Obstetric factors	–	+
Smoking	+	?
Socioeconomic status	–	+

Data from Refs. [4, 5]
– no association, + small association, ++ small-to-medium association, +++ medium association, ++++ medium-to-large association, ? no studies available (based on Cohen's definitions of standardized effect sizes)

investigating the effect of hormonal interventions to prevent or reduce perinatal depression are limited and inconclusive [6].

More evidence exists for hypothalamic-pituitary-adrenal (HPA) axis dysfunction in women with perinatal depression. Patients with depression, both during and outside the perinatal period, have higher baseline levels of cortisol and a hyperactivity in reaction to stress. For example, a double-blinded study in which the rapid withdrawal of reproductive hormones after delivery was simulated in euthymic, nondepressed women outside the puerperal period with and without a history of postpartum depression showed that women with a history of perinatal depression were at much higher risk to develop significant mood symptoms in the withdrawal period [7]. Also, some studies found an association between lower levels of serum free triiodothyronine (FT3) and free thyroxine (FT4) and an increased incidence of mood disturbances in the postpartum period [8, 9]. However, these studies do not give evidence and/or indications for prevention or treatment of perinatal depression. Therefore, hormone substitution in women with—or at risk for—perinatal depression should be avoided until more evidence is available.

3.6 Specific Diagnostic Aspects

Early detection and diagnosis of perinatal depression can be complicated by the shame and burden most women feel at presenting with depressive symptoms to their healthcare professional in a period that is traditionally considered cheerful. Therefore, one should be particularly aware of the emotional and social isolation that women with depressive feelings often experience. Even if women do not appear depressed, they could significantly suffer from their symptoms. Another difficulty in identifying women with perinatal depression is that depressive symptoms could mimic pregnancy-related symptoms, such as altered weight, insomnia or hypersomnia, fatigue or loss of energy, and problems with concentration. In contrast to women with only pregnancy-related symptoms, women with perinatal depression also suffer from one of the core symptoms: depressed mood and/or loss of interest/pleasure (anhedonia).

3.6.1 How Can Women at Risk for Perinatal Depression Be Screened?

As recommended by the National Institute for Health and Care Excellence (NICE) guidelines in the UK, healthcare professionals (including midwives, obstetricians, health visitors, and GPs) should ask two questions at a woman's first contact with primary care, at her booking visit, and postnatally (usually at 4–6 weeks and 3–4 months) to identify a possible depression:

1. During the past month, have you often been bothered by feeling down, depressed, or hopeless?

2. During the past month, have you often been bothered by having little interest or pleasure in doing things?

If the woman answers "yes" to either of the above, then a third question should be asked:

3. Is this something you feel you need or want help with?

For further assessment of perinatal depression, the most widely accepted Edinburgh Postnatal Depression Scale (EPDS) could be used, which takes 2–5 min to complete [10]. In this validated 10-item self-report questionnaire, the somatic symptoms are excluded because they do not differentiate well between depressed and nondepressed pregnant and postpartum women. This questionnaire is also validated for use during pregnancy [11]. A cutoff score of ≥10 is indicative for clinically relevant depressive symptoms. Women who score above this threshold should be referred to a general practitioner or psychologist for further evaluation and eventual treatment of perinatal depression.

Case History: Continued
When the midwife asks Nadia whether she felt depressed or has been bothered by having little interest or pleasure in doing things during the past month, Nadia answers "yes" to both questions. Further assessment of the severity of depressive symptoms by means of the EPDS reveals a score of 15, which is above the cutoff score for clinically relevant depressive symptoms. The midwife, who closely collaborates with a perinatal psychologist, arranges a consultation in the next week.

3.7 Specific Therapeutic Aspects

3.7.1 What Are Evidence-Based Treatments for Perinatal Depression?

There is growing notice of the importance of screening for depression during pregnancy. However, evidence-based treatment algorithms for depression during pregnancy are limited. In general there is no reason to assume that evidence-based treatments for "normal" depression would not be as effective in the perinatal period.

However, in decisions about treating perinatal depression, the risks and benefits to the unborn child must also be taken into account. Leaving depression untreated may be hazardous to the unborn child. At present, it is well known that children of women who suffered from depression during pregnancy have an increased risk of adverse perinatal health outcomes and behavioral, emotional, cognitive, and motor problems in early childhood [12, 13].

An important first step in treating perinatal depression is explaining to the woman and her partner that depression is a frequently occurring condition that can effectively be treated. Second, it is important to discuss ideas about the disorder, including stigma and feelings of guilt and shame, and expectations about treatment. If possible, also the partner, family, and other nearby people should be actively involved in the decisions about treatment and their role in supporting the woman.

3.7.1.1 Non-pharmacological Treatment

Pregnant women express a strong preference for non-pharmacological depression treatment over antidepressant medication, because of the possible harm to their child [14]. In pregnancy and in the postpartum period, the efficacy of psychotherapy is empirically supported. Interpersonal psychotherapy (IPT) and cognitive behavioral therapy (CBT) have been shown to be effective for perinatal depression across the spectrum from mild to severe depression [15]. The results of the latter study stress the importance of implementing preventive CBT as a first-choice treatment for relapse of depression/anxiety during pregnancy.

IPT is a time-limited psychotherapy that targets reduction of depressive symptoms, improved interpersonal functioning, and increased social support. The underlying theory is that changes in interpersonal relationships trigger depression in sensitive women [16]. Especially in the perinatal period, relationships with the partner, employer, and the woman's own parents are changing and often stressful. The first phase in IPT is identifying the major loss or losses that are related to the interpersonal role changes that occur during pregnancy or after childbirth. For example, a woman who used to have an active social life before becoming pregnant has to give up going out during nights as frequently as before pregnancy. First she could be helped with realizing and accepting that life will never be like before pregnancy again and that this is a major loss that may cause feelings of mourning. After discussing the loss and feeling the grief, the therapist will help this woman to identify possibilities to adjust to the new situation of pregnancy. For example, she could discuss with her partner to find other distractions that are more compatible with her pregnancy or aim at ways of getting to know other pregnant women with whom she could meet during the day and share feelings that are typically related to pregnancy and becoming a mother.

CBT has mainly been studied, and shown to be effective, in the prevention and treatment of postpartum depression [15]. CBT addresses dysfunctional thoughts and beliefs, e.g., "I will never be a good mother" or "other women do much better than I." These often automatically generated negative thoughts will first be identified and secondly challenged and replaced with alternative more helpful thoughts and activities. Registration of thoughts and feelings during the day and goal-oriented exercises provide women with insight and tools to change their maladaptive behaviors.

Other non-pharmacological treatments that might be considered are summarized in Table 3.3 [16–22]. These effect sizes are mainly based on randomized controlled trials (RCTs). However, a placebo response could not be ruled out because in most non-pharmacological treatments, blinding is not possible, except for bright light therapy.

3.7.1.2 Pharmacological Treatment

When the direct availability of psychotherapists is limited and/or when the depression is severe (e.g., in case of psychotic features and suicidal ideation), antidepressant medication should be actively considered. This should be carefully evaluated and monitored by a psychiatrist. Research is still equivocal on the effect of antidepressant medication use during pregnancy. In Table 3.4 the known effects of depression and antidepressant medication use during pregnancy, birth outcome, and child development are presented. Only data from meta-analyses are presented [13, 23–28].

Table 3.3 Non-pharmacological treatments for perinatal depression and their effect sizes

Treatment	Effect size
Interpersonal psychotherapy [16]	++++
Cognitive behavioral therapy [17]	++++
Relational therapy [18]	++
Bright light therapy [19]	+++
Mindfulness [20]	?
Acupuncture [21]	+
Massage [22]	+
e-Health	?

Data from Refs. [16–22]
– no association, + small association, ++ small-to-medium association, +++ medium association, ++++ medium-to-large association, ? no studies available (based on Cohen's definitions of standardized effect sizes)

Table 3.4 Effects of depression and antidepressant medication during pregnancy

Treatment	Depression	Antidepressant medication
Spontaneous abortion	–	–
Preeclampsia	+	–
Premature birth (<37 weeks)	+	+
Low birth weight	+/–	+
Small for gestational age	+/–	+
Overall congenital malformations	–	–
Cardiovascular malformation	–	+[a]
Poor neonatal adaptation	–	+++
Persistent pulmonary hypertension	–	++[b]
Child developmental problems	+	+/–

Data from Refs. [13, 23–28]
– no association, +/– inconclusive, + OR 1.00–2.00, ++ OR 2.00–3.00, +++ OR >3.00
[a]Mainly cardiac septal defects and occasionally right ventricular outflow tract obstruction
[b]The effect was only significant for the third trimester, and the absolute risk of PPHN is very low (2.9–3.5 per 1000 infants)

3.7.2 What Are the Risks and Benefits of Antidepressant Medication During Pregnancy?

It should be noted that both treated and untreated depression are associated with adverse outcomes. Also, the meta-analyses are based on studies with generally low levels of evidence due to a lack of randomization and uncontrolled confounders (e.g., actual level of depression, substance use, comorbidity, and co-medication). If antidepressant medication has an increased risk for adverse outcomes at all, this risk is generally not clinically relevant and for some outcomes (e.g., birth outcomes) is comparable to untreated depression.

In clinical practice, the clinician must carefully discuss the risks and benefits of antidepressant use during pregnancy. The decision to use antidepressants must be weighed against the risks of untreated maternal depression, including poor self-care, suboptimal food intake, increased risk of relational problems, and potential self-harm, including suicide. As shown in Fig. 3.1, Yonkers et al. presented a helpful algorithm for decision-making in women with major depression in obstetric care [29].

3.7.3 Is Breastfeeding Contraindicated When Antidepressant Medication Is Continued?

There is no methodologically sound literature on the effects of antidepressant medication during breastfeeding on child outcomes. Some small studies did not find any adverse child outcomes for which they may or may not have sought medical attention [30, 31]. Most tricyclic antidepressants and the selective serotonin reuptake inhibitors (SSRIs) sertraline, fluvoxamine, and paroxetine have low transfer rates to breast milk. For venlafaxine, (es)citalopram, and fluoxetine, higher levels are found in breast milk. In general, breastfeeding with antidepressant medication is not contraindicated unless the child is born prematurely or in a poor condition after childbirth.

Case History: Continued

As suggested, Nadia Teal consulted a psychologist in the same week. Her partner Donald, who was invited as well, accompanied her. During the consultation Nadia showed no suicidal ideations and there were no psychotic symptoms. Nadia explained she was never treated for depression before. After discussing the different treatment options, she showed highest motivation for a non-pharmacological treatment. Because of the problems adjusting to pregnancy and the relational stress, the psychologist started with interpersonal psychotherapy. Donald appeared to be very willing to work on their relationship and agreed to join some sessions.

After 12 weekly sessions, the depression and the relationship significantly improved. Nadia delivered a healthy baby, was able to adjust to motherhood well, and felt supported by Donald.

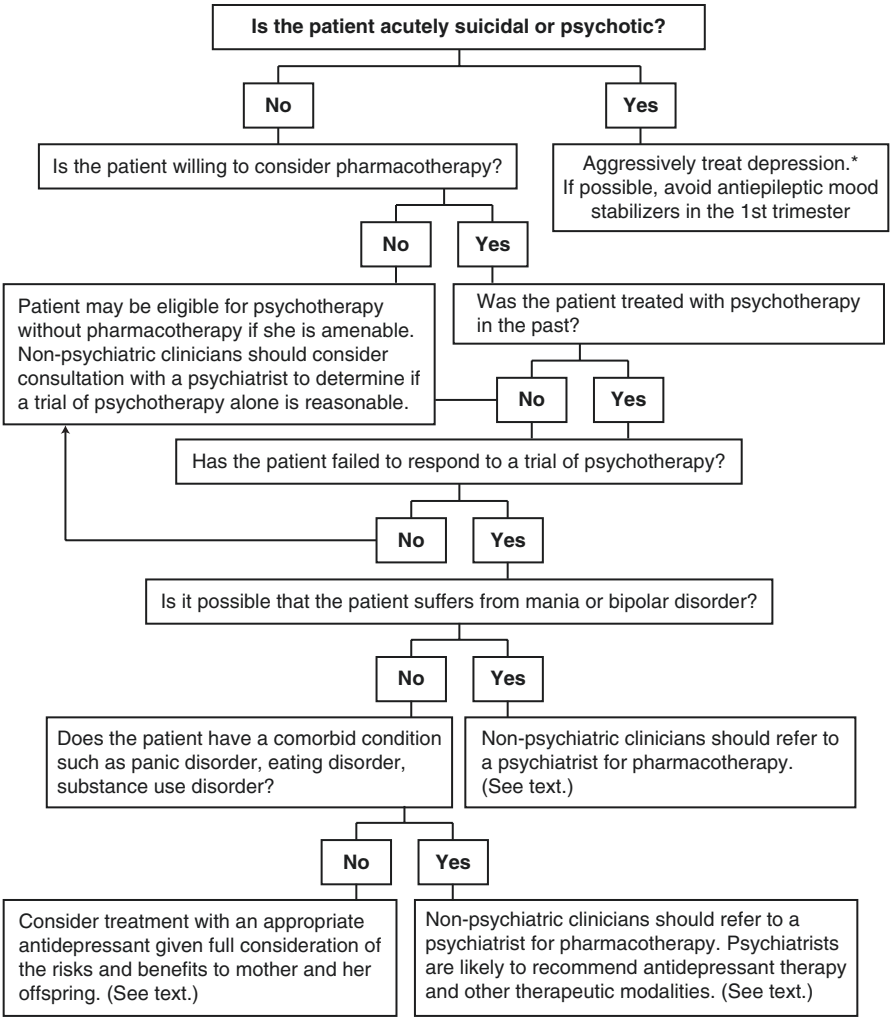


Fig. 3.1 Algorithm for treating depression in an obstetric setting (Used with permission of Wolters Kluwer from Yonkers et al. [29])

3.8 Critical Reflection and Conclusive Remarks

Depression is a very heterogeneous disorder with a complex etiology involving biological, psychological, and environmental risk factors. It is still under debate whether a typical perinatal or postpartum depression exists. The symptoms, prevalence, and risk factors associated with perinatal depression are not significantly different from those of nonpregnant women of reproductive age. However, it is important to realize that women with depressive symptoms are probably underdiagnosed because of the burden professionals and women feel about discussing

negative feelings in a period that is traditionally considered as a cheerful period. Therefore, healthcare professionals should ideally address and discuss both positive and negative feelings of pregnancy. Also, depressive symptoms show overlap with pregnancy-related symptoms, making it more difficult to recognize depression at an early stage. On the other hand, the perinatal period offers a unique opportunity for early detection and lifetime prevention for depression. In this period in which scheduled pregnancy visits take place, midwives and obstetricians should routinely ask about depressed feelings and/or decreased pleasure in doing things since the last visit. If positive, the EDS can be used to detect and if necessary refer women at risk for depression.

With respect to treatment, the window of opportunity is small, and therefore treatment options should be weighed against the motivation of the woman, availability of non-pharmacological therapy, and severity of the depression. If the woman is motivated and the depression does not require immediate treatment with antidepressant medication (e.g., in case of suicidal ideation or psychotic features), then the treatment of first choice is psychotherapy (e.g., cognitive behavioral therapy or interpersonal psychotherapy).

Tips and Tricks

- Since depression is prevalent, often not recognized, and associated with serious adverse outcomes for both mother and child, routine screening for perinatal depression in obstetric practice is advocated. When signs of depression are found while taking history during intake, the EDS can be used as an easy-to-administer and validated questionnaire to detect women at risk for perinatal depression. The EDS can easily be found as an online screening tool on websites such as the Australian "Beyond Blue" site (http://www.beyondblue.org.au/the-facts/depression/signs-and-symptoms/anxiety-and-depression-checklist-k10).
- Since the time window of treatment for perinatal depression is small, obstetricians and midwives should closely collaborate with mental healthcare professionals to provide prompt and efficient treatment.
- Ideally the partner and family should be involved in the management and treatment of perinatal depression, for a better understanding and optimizing of their supportive role.

Test Your Knowledge and Comprehension

1. The diagnostic criteria for a depression in pregnancy and postpartum period do not differ from a depression outside the perinatal period.
   (a) True
   (b) False
2. The diagnosis of a perinatal depression requires a depressed mood and a loss of interest or pleasure in daily activities.
   (a) True
   (b) False

3. Hormonal therapy is effective in preventing postpartum depression.
   (a) True
   (b) False
4. Postpartum blues is a physiological phenomenon that should be finished in the first 2 weeks after delivery.
   (a) True
   (b) False
5. Antidepressant medication should be avoided during pregnancy.
   (a) True
   (b) False

Five closed book questions and answers based on the chapter:

6. Perinatal depression (minor and major) occurs in approximately ____% of women
   (a) 5%
   (b) 10%
   (c) 15%
   (d) 20%
7. Which of the following factors is most strongly associated with perinatal depression?
   (a) Smoking
   (b) Lack of support
   (c) Obstetric factors
   (d) Low socioeconomic status
8. Which of the following outcomes is *not* associated with depression during pregnancy?
   (a) Preeclampsia
   (b) Premature birth
   (c) Spontaneous abortion
   (d) Child developmental problems
9. Which of the following outcomes is associated with perinatal depression?
   (a) Food supplements
   (b) Bright light therapy
   (c) Cognitive psychotherapy
   (d) Interpersonal psychotherapy
10. Which of the following antidepressant medication should be avoided during breastfeeding?
    (a) Paroxetine
    (b) Escitalopram
    (c) Tricyclic antidepressants
    (d) None of the above

Answers

1. True
2. False
3. False

4. True
5. False
6. (b)
7. (b)
8. (c)
9. (a)
10. (d)

References

1. O'Hara MW, Schlechte JA, Lewis DA, Wright EJ. Prospective study of postpartum blues. Biologic and psychosocial factors. Arch Gen Psychiatry. 1991;48(9):801–6.
2. Gavin NI, Gaynes BN, Lohr KN, Meltzer-Brody S, Gartlehner G, Swinson T. Perinatal depression: a systematic review of prevalence and incidence. Obstet Gynecol. 2005;106(5 Pt 1):1071–83.
3. Paschetta E, Berrisford G, Coccia F, Whitmore J, Wood AG, Pretlove S, et al. Perinatal psychiatric disorders: an overview. Am J Obstet Gynecol. 2014;210(6):501–9.e506.
4. Lancaster CA, Gold KJ, Flynn HA, Yoo H, Marcus SM, Davis MM. Risk factors for depressive symptoms during pregnancy: a systematic review. Am J Obstet Gynecol. 2010;202(1):5–14.
5. Robertson E, Grace S, Wallington T, Stewart DE. Antenatal risk factors for postpartum depression: a synthesis of recent literature. Gen Hosp Psychiatry. 2004;26(4):289–95.
6. Dennis CL, Ross LE, Herxheimer A. Oestrogens and progestins for preventing and treating postpartum depression. Cochrane Database Syst Rev. 2008(4):CD001690.
7. Bloch M, Schmidt PJ, Danaceau M, Murphy J, Nieman L, Rubinow DR. Effects of gonadal steroids in women with a history of postpartum depression. Am J Psychiatry. 2000;157(6):924–30.
8. Pedersen CA, Johnson JL, Silva S, Bunevicius R, Meltzer-Brody S, Hamer RM, et al. Antenatal thyroid correlates of postpartum depression. Psychoneuroendocrinology. 2007;32(3):235–45.
9. Lambrinoudaki I, Rizos D, Armeni E, Pliatsika P, Leonardou A, Sygelou A, et al. Thyroid function and postpartum mood disturbances in greek women. J Affect Disord. 2010;121(3):278–82.
10. Cox JL, Holden JM, Sagovsky R. Detection of postnatal depression. Development of the 10-item edinburgh postnatal depression scale. Br J Psychiatry. 1987;150:782–6.
11. Bergink V, Kooistra L, Lambregtse-van den Berg MP, Wijnen H, Bunevicius R, van Baar A, et al. Validation of the edinburgh depression scale during pregnancy. J Psychosom Res. 2011;70(4):385–9.
12. Talge NM, Neal C, Glover V, Early Stress TR, Prevention Science Network F, Neonatal Experience on C, et al. Antenatal maternal stress and long-term effects on child neurodevelopment: how and why? J Child Psychol Psychiatry. 2007;48(3–4):245–61.
13. Field T. Prenatal depression effects on early development: a review. Infant Behav Dev. 2011;34(1):1–14.
14. Battle CL, Salisbury AL, Schofield CA, Ortiz-Hernandez S. Perinatal antidepressant use: understanding women's preferences and concerns. J Psychiatr Pract. 2013;19(6):443–53.
15. Stuart S, Koleva H. Psychological treatments for perinatal depression. Best Pract Res Clin Obstet Gynaecol. 2014;28(1):61–70.
16. Miniati M, Callari A, Calugi S, Rucci P, Savino M, Mauri M, et al. Interpersonal psychotherapy for postpartum depression: a systematic review. Arch Womens Ment Health. [Review]. 2014;17(4):257–68.
17. Stuart S, Koleva H. Psychological treatments for perinatal depression. Best Pract Res Clin Obstet Gynaecol. [Review]. 2014;28(1):61–70.

18. Claridge AM. Efficacy of systemically oriented psychotherapies in the treatment of perinatal depression: a meta-analysis. Arch Womens Ment Health. 2014;17(1):3–15.
19. Crowley SK, Youngstedt SD. Efficacy of light therapy for perinatal depression: a review. J Physiol Anthropol. 2012;31:15.
20. Woolhouse H, Mercuri K, Judd F, Brown SJ. Antenatal mindfulness intervention to reduce depression, anxiety and stress: a pilot randomised controlled trial of the mindbabybody program in an australian tertiary maternity hospital. BMC Pregnancy Childbirth. 2014;14(1):369.
21. Manber R, Schnyer RN, Lyell D, Chambers AS, Caughey AB, Druzin M, et al. Acupuncture for depression during pregnancy: a randomized controlled trial. Obstet Gynecol. 2010;115(3):511–20.
22. Field T, Diego MA, Hernandez-Reif M, Schanberg S, Kuhn C. Massage therapy effects on depressed pregnant women. J Psychosom Obstet Gynaecol. 2004;25(2):115–22.
23. Grote NK, Bridge JA, Gavin AR, Melville JL, Iyengar S, Katon WJ. A meta-analysis of depression during pregnancy and the risk of preterm birth, low birth weight, and intrauterine growth restriction. Arch Gen Psychiatry. 2010;67(10):1012–24.
24. Grigoriadis S, VonderPorten EH, Mamisashvili L, Tomlinson G, Dennis CL, Koren G, et al. The impact of maternal depression during pregnancy on perinatal outcomes: a systematic review and meta-analysis. J Clin Psychiatry. 2013;74(4):e321–41.
25. Grigoriadis S, VonderPorten EH, Mamisashvili L, Roerecke M, Rehm J, Dennis CL, et al. Antidepressant exposure during pregnancy and congenital malformations: is there an association? A systematic review and meta-analysis of the best evidence. J Clin Psychiatry. 2013;74(4):e293–308.
26. Grigoriadis S, VonderPorten EH, Mamisashvili L, Eady A, Tomlinson G, Dennis CL, et al. The effect of prenatal antidepressant exposure on neonatal adaptation: a systematic review and meta-analysis. J Clin Psychiatry. 2013;74(4):e309–20.
27. Grigoriadis S, Vonderporten EH, Mamisashvili L, Tomlinson G, Dennis CL, Koren G, et al. Prenatal exposure to antidepressants and persistent pulmonary hypertension of the newborn: systematic review and meta-analysis. BMJ. 2014;348:f6932.
28. Ross LE, Grigoriadis S, Mamisashvili L, Vonderporten EH, Roerecke M, Rehm J, et al. Selected pregnancy and delivery outcomes after exposure to antidepressant medication: a systematic review and meta-analysis. JAMA Psychiatry. 2013;70(4):436–43.
29. Yonkers KA, Wisner KL, Stewart DE, Oberlander TF, Dell DL, Stotland N, et al. The management of depression during pregnancy: a report from the american psychiatric association and the american college of obstetricians and gynecologists. Obstet Gynecol. 2009;114(3):703–13.
30. Lee A, Woo J, Ito S. Frequency of infant adverse events that are associated with citalopram use during breast-feeding. Am J Obstet Gynecol. 2004;190(1):218–21.
31. Heikkinen T, Ekblad U, Kero P, Ekblad S, Laine K. Citalopram in pregnancy and lactation. Clin Pharmacol Ther. 2002;72(2):184–91.

New Mothers with Disturbing Thoughts: Treatment of Obsessive-Compulsive Disorder and of Psychosis in Postpartum

4

Vesna Pirec and Agnieszka Grabowski

4.1 Introduction and Aims

Psychiatric symptoms in postpartum tend to vary in severity and presentation. As a result, they may be challenging to adequately recognize and treat. In this chapter, we will focus on postpartum obsessive-compulsive disorder and postpartum psychosis. Both of these psychiatric illnesses can have intrusive thoughts of hurting the child as a central theme. It is imperative to promptly identify them, determine severity of presentation, and assist women in obtaining treatment. If symptoms remain undetected, serious and sometimes lethal consequences for both mother and child could follow.

4.2 Definition in Lay Terms

Obsessive-compulsive disorder (OCD) is a mental illness in which an afflicted person experiences repetitive, anxiety-provoking thoughts and behaviors she feels unable to stop.

V. Pirec, MD, PhD (✉)
Insight Behavioral Health Centers, Department of Psychiatry, University of Illinois at Chicago, Chicago, IL, USA

Department of Psychiatry, Rush University Medical School, Chicago, IL, USA
e-mail: psychvp@gmail.com

A. Grabowski, MA, LCSW
Wildflower Center for Emotional Health LLC, Chicago, IL, USA
e-mail: agrabowski@wildflowerllc.com

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_4

Postpartum psychosis (PP) is an uncommon and severe mental illness that usually starts a few days after the delivery and in which an afflicted woman loses contact with reality while exhibiting bizarre thoughts and behaviors.

4.3 Didactic Goals

After reading this chapter, you will:

- Be familiar with presentation, etiology, course, and treatment of postpartum obsessive-compulsive disorder and postpartum psychosis
- Be able to identify symptoms of postpartum OCD and PP
- Understand the differences between these disorders and their unique presentations
- Know how to identify and refer patients manifesting OCD or PP symptomatology
- Have an understanding of treatment and prognosis for each disorder

Case Histories

An Obsessive-Compulsive Disorder Case

Vera Gold is a married African-American primipara in her early 30s admitted to an inpatient psychiatric unit at 2 weeks postpartum due to obsessive thoughts and images of killing her baby. Upon admission, the patient experienced insomnia, poor appetite, mood lability, and tearfulness. She stated that she did not wish to hurt her baby and was distressed by her obsessions. She recognized that the thoughts were a creation of her mind but they felt very real. She ruminated on them. She feared being alone with her baby and felt she could not be trusted taking care of it. Her pregnancy was unremarkable. She delivered vaginally without complications. She had no prior psychiatric history.

A Psychosis Case

Malia Sapphire is a married Hispanic primipara in her early 30s admitted to an inpatient psychiatric unit at 6 weeks postpartum with psychotic presentation. At admission she was delusional, agitated, and restless; insomnia was persisting and she had no appetite. Her delusions had a religious connotation and also contained a belief that her husband was unfaithful to her. Her behavior was unpredictable and she was paranoid. Occasionally she was aggressive toward staff. She had episodes during which she would close her eyes and scream, appearing as if she were in a delirium-like state. Patient's recollection of the events that occurred while she was psychotic was limited. Her pregnancy was unremarkable. She delivered vaginally without complications. She had no prior psychiatric history.

Table 4.1 Definition of postpartum obsessive-compulsive disorder

Formal definition of OCD [1]	Additional features specific to postpartum OCD
Obsessive thoughts and/or compulsive acts present most days for at least 2 successive weeks that are a source of distress or interfere with activities Obsessive thoughts: repetitive ideas, images, or impulses. Often violent, obscene, or perceived to be senseless, the person cannot dismiss them The patient recognizes them as her own thoughts or impulses. Compulsive acts: stereotyped behaviors that are repeated to reduce anxiety caused by obsessions. For instance, a sufferer who has obsessive thoughts of her baby dying of sudden infant death syndrome (SIDS) may engage in compulsively checking of baby's breathing numerous times at night	Rapid onset [2]. Mean time of onset is 2 to 4 weeks after delivery but may be as early as the second postpartum day [3–5] Non-postpartum OCD typically has a gradual onset The presence of aggressive obsessions is more common in postpartum than in non-postpartum women [5] Aggressive obsessions in the postpartum period are frequently linked to the theme of harming the newborn, i.e., dropping, suffocating, molesting, or becoming sexually aroused when caring for the baby [5–8] Obsessions in non-postpartum OCD are highly heterogeneous in content

Data from Refs. [1–8]

4.4 Facts and Figures: Definitions, Classifications, and Prevalence

4.4.1 Postpartum Obsessive-Compulsive Disorder

4.4.1.1 What Is the Definition of Postpartum Obsessive-Compulsive Disorder?

Obsessive-compulsive disorder (OCD) is an anxiety disorder characterized by constant and intrusive thoughts, images, or impulses (*obsessions*) and/or repetitive behaviors (*compulsions)* the person feels driven to perform in response to obsessions.

In the postpartum period, OCD typically presents as obsessive thoughts or images about contamination of, harm coming to, and aggression toward the baby.

In Table 4.1 the most relevant characteristics of OCD are summarized [1–8].

4.4.1.2 How to Distinguish Normative Intrusive Thoughts in Postpartum from Clinically Significant Symptoms That Warrant Further Assessment?

More than half of women report mild and transient intrusive thoughts upon giving birth [9]. The content of these thoughts may be similar to those seen in postpartum OCD, such as fears of harming the infant or the infant dying of sudden infant death syndrome (SIDS), yet they are never that intense nor do they trigger dysfunction or behavioral modifications [9]. Most new mothers check on the newborn to ensure his or her well-being. This is normal behavior. In women with postpartum OCD, excessive checking eventually impairs the mother's ability to take care of the newborn

due to distressing symptoms. When symptoms negatively interfere with the person's regular activities and functioning in the social, occupational, and family spheres, further assessment is necessary.

4.4.1.3 What Is the Incidence and Prevalence of Obsessive-Compulsive Disorder?

In Table 4.2, incidence and prevalence of postpartum OCD is summarized [7–16].

4.4.1.4 What Are the Most Common Themes of Postpartum Obsessions and Compulsions?

Women may experience one or several themes of obsessive thoughts at the same time. These are the most common types of obsessive symptoms:

- Thoughts, images, or urges of intentional harm to the infant such as:
  - Dropping the baby from a high place
  - Putting the baby in a microwave
  - Choking or shaking the baby
  - Pressing the baby's soft spot on the head (fontanel)
  - Drowning the baby while giving bath
  - Stabbing the baby
  - Molesting the baby
  - Experiencing sexual arousal when caring for the baby
- Other thoughts:
  - Baby suffocating or dying of SIDS
  - Accidents
  - Losing the baby, images of the baby being dead
  - Baby contracting an infectious disease or getting poisoned by harmful substances (such as mercury, lead) via touch and contact with improperly washed foods, bottles, or other objects

The most common types of compulsions in postpartum OCD:

Overt:

- Cleaning/washing and related rituals to prevent contamination of the baby
- Checking behaviors to prevent harm to the baby

Table 4.2 Incidence and prevalence of postpartum OCD

Incidence of new-onset OCD after childbirth	1.7–4.0 % [7, 8, 10, 11]
Prevalence of postpartum OCD	1–9 % [7, 8, 10, 12–14] (prevalence not as well studied)
Prevalence of subclinical, transient obsessive thoughts in the postpartum	Majority of women [9, 15, 16]

Data from the United States and selected countries in Europe
Data from Refs. [7–16]
OCD obsessive-compulsive disorder

- Avoidance of the baby or of objects associated with aggressive images or thoughts, i.e., avoidance of kitchen knives when obsessive thoughts center on stabbing the baby

Covert:

Mental rituals, i.e., praying, attempts to suppress the thought, and counting

4.4.1.5 What Are the Differences Between Postpartum OCD and Postpartum Depression (PPD)?

Postpartum OCD is highly correlated with postpartum depression [15, 16]. To avoid mistaking obsessive content for depressive symptoms, distinction between the two needs to be made (Table 4.3).

4.4.2 Postpartum Psychosis

4.4.2.1 What Is the Definition of Postpartum Psychosis?

PP is the most severe type of postpartum mental illness that requires immediate treatment. Onset of PP most often takes place within the first week after delivery. Hospitalization is warranted. Some symptoms of PP are the same as in non-postpartum psychosis. These are:

- False beliefs not based in reality (*delusions*) such as fear of being followed or watched, thoughts broadcasting, thoughts insertion, and conviction that thoughts and/or actions are controlled by outside forces
- Hearing, seeing, or feeling unreal things (*hallucinations*)
- Disorganized thinking patterns

Additional symptoms specific to PP include severe insomnia, agitation, bizarre, disorganized behavior, thoughts of harming the baby, incoherent and illogical speech, and rapid mood changes.

4.4.2.2 How to Distinguish Normal Cognitive Disturbances or Dysfunctions (Confusion, Memory Problems, Loss of Insight) in Postpartum from Clinically Significant Symptoms That Warrant Further Assessment?

Cognitive disturbances in the postpartum period could, in rare occasions, occur as a consequence of inflammatory, autoimmune, or metabolic causes. It is imperative to rule out any potential medical causes that could trigger cognitive distortions.

Table 4.3 Differences between obsessive and depressive thoughts

Obsessive	Depressive
Repetitive, specific, and fixed themes Center on events that may be realistic but have low probability of occurring Primarily induce fear and anxiety	Broad, nonspecific, and changing themes Center on actual circumstances Primarily induce sadness

The first steps are to obtain a comprehensive laboratory panel and, rarely, complete brain imaging. Several symptoms distinguish PP from other potential causes of cognitive distortion in postpartum; these are insomnia coupled with agitation, fluctuating mood symptoms, and rapid changes in the clinical presentation as well as insight into the illness. Other illnesses that may induce cognitive disturbances have a steady progression and lack mood fluctuations.

4.4.2.3 What Is the Incidence and Prevalence of Postpartum Psychosis?

See Table 4.4 for incidence and prevalence of PP [17–22].

4.4.2.4 What Are the Most Common Themes of Delusions in Postpartum Psychosis?

Delusional themes in PP are heterogeneous in nature. The following types of delusions have been identified:

- Of altruistic homicide in which the woman is convinced that she needs to kill her baby to save it from a fate worse than death [23]
- Of religious nature in which the woman believes she or her baby has a special relationship with God or the devil [24]
- Of grandeur (often related to religion) in which the woman believes she has special powers or authority [25]
- Of paranoia and/or persecution in which the woman believes that the baby is not hers or that someone wants to hurt her or the baby (among other things) [25]
- Of influence/control in which the woman feels she is being controlled by an outside force [25]

4.4.2.5 What Are the Differences Between Postpartum Psychosis and Postpartum Depression?

In Table 4.5, the key differences between PPD and PP are summarized.

Table 4.4 Incidence and prevalence of postpartum psychosis (Data from the United States and selected countries in Europe)

Incidence and prevalence of postpartum psychosis	
Incidence/prevalence	1–2 per 1000 childbirths [17, 18] Rate is up to 100 times higher for women with personal history of bipolar disorder [19, 20] Rate is seven times higher for women with personal history of postpartum psychosis [21, 22]

Data from Refs. [17–22]

Note: Published literature on PP refers to 1–2 per 1000 childbirths interchangeably as incidence or prevalence. No additional data exist

Table 4.5 Key differences between postpartum depression and postpartum psychosis

Features	Postpartum depression	Postpartum psychosis
Onset	Gradual	Abrupt
Mood	Persistent sadness and/or loss of interest	Rapidly fluctuating depressive and manic symptoms
Reality testing	Intact	Disturbed
Psychotic symptoms	Occasionally present, mood congruent, and develop gradually	Always present, mood incongruent, and develop abruptly

Table 4.6 Differences between symptoms of postpartum and non-postpartum psychosis

Non-postpartum	Postpartum
Can occur in a variety of psychiatric diagnoses, such as schizophrenia, schizoaffective disorder, and mood disorders, and in many medical conditions	Most commonly seen as a manifestation of bipolar disorder precipitated by childbirth [18, 26, 27]
Hallucinations most often affect one sensory system at a time	Hallucinations affect all senses (tactile, visual, olfactory, and auditory) [25]
Affective symptoms of one type (depression and/or mania) may or may not be present	Interchangeable and fluctuating mood symptoms, both elation and depression [27]
Lack of obvious confusion	Disturbance of consciousness marked by confusion, bewilderment, or perplexity [20, 28]
Symptoms develop gradually	Symptoms develop abruptly after delivery (2 to 7 days) [27]
In the acute phase, symptoms progress in a mostly steady manner	Rapid changes in intensity and symptom presentation [29, 30]

Data from Refs. [18, 20, 25–30]

4.4.2.6 What Are the Symptoms Distinguishing Non-postpartum Psychosis from Postpartum Psychosis?

In Table 4.6, the key differences between non-PP and PP are described [18, 20, 25–30].

4.4.2.7 What Is the Postpartum Psychosis Classification in Leading Mental Health Diagnostic Manuals?

As is depicted in Table 4.3, in practice there is a distinct clinical presentation and treatment of postpartum psychosis. However, neither the *International Statistical Classification of Diseases and Related Health Problems, 10th Revision* (ICD-10) [1], nor the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (DSM-5) [31], recognizes it as a separate diagnosis. This has been subject to ongoing debate. Women with PP are formally diagnosed with mental behavioral disorders associated with the puerperium, not elsewhere classified per ICD-10, and with unspecified bipolar and related disorders with peripartum onset per DSM-5.

4.4.2.8 What Is the Differential Diagnosis of Postpartum Psychosis?

The differential diagnoses of PP are:

- Acute confusion due to medical conditions
- Alcohol withdrawal
- Psychotic disorders such as schizophrenia, schizoaffective, and schizophreniform disorder
- Major depressive disorder with psychotic features

4.4.2.9 What Are the Differences Between Postpartum Psychosis and Postpartum Obsessive-Compulsive Disorder?

It is imperative to distinguish obsessive thoughts from psychotic process due to different treatment approaches for each diagnostic entity [3–5, 16, 27, 32] (Table 4.7). Notably, in severe, persistent postpartum OCD, obsessions may take on a delusional quality.

4.4.2.10 What Are the Potential Consequences of Untreated Postpartum Psychosis?

Potential consequences of untreated PP are:

- Suicide (in up to 5 % of women with PP) [33]
- Infanticide (in up to 4 % of women with PP) [32, 33]
- Impaired mother-child bonding
- Recurrent psychiatric illness
- Infant abuse and neglect

4.5 Etiology and Pathogenesis

4.5.1 Postpartum Obsessive-Compulsive Disorder

4.5.1.1 What Are the Main Theories That Explain the Emergence of Obsessive-Compulsive Symptoms in Postpartum?

Many theories seek to explain the etiology and pathogenesis of postpartum OCD (Table 4.8) [5, 6, 15, 34–37]. Consensus exists that the causes are multifactorial and include cognitive, psychosocial, and biological factors. Dysfunctional cognitive beliefs (conviction that normal, albeit unwelcome, thoughts about the infant are

Table 4.7 Key differences between postpartum psychosis and obsessive-compulsive disorder

Features	Obsessive-compulsive disorder	Postpartum psychosis
Onset	2 to 4 weeks after childbirth [3–5]	Within 1 week after childbirth [27]
Risk of harm to the infant	Low to none [15, 16]	High [32]
Disturbance in sensory perception	None	Hallucinations affect all senses
Insight into symptoms	Present	Absent

Data from Refs. [3–5, 15, 16, 27, 32]

Table 4.8 Main etiological theories of postpartum obsessive-compulsive disorder

Cognitive behavioral theory	Symptoms triggered by (1) stressors associated with motherhood, (2) misinterpretation of normal thoughts and worries, and (3) ensuing emergence of maladaptive coping responses [34, 35] Risk increased by cognitive tendencies, such as overestimation of threat/inflated responsibility; importance of, and need to control, intrusive thoughts; perfectionism and intolerance of uncertainty [35]
Biological theory	Role of neurotransmitters or hormones [36] Abrupt drop in estrogen and progesterone levels following childbirth adversely affects serotonin functioning [6, 15, 37] Higher concentration of oxytocin in the postpartum has been linked to OCD severity [37] Possible genetic component that is not fully understood [5]
Evolutionary theory	Intrusive thoughts about the infant evolved to ensure sensitivity to infant safety. This adaptive pattern may trigger obsessive-compulsive symptoms in vulnerable women [15] The theory lacks evidence but would explain why healthy postpartum women report subclinical obsessive thoughts
Sociobiological theory	Susceptibility to anxiety and stress [15]

Data from Refs. [5, 6, 15, 34–37]

dangerous and significant and need to be suppressed or otherwise gotten rid of) give rise to OCD symptoms and impairment. Psychosocial stresses of new motherhood (such as sleep deprivation, changes in role, identity, priorities and routines, responsibility of caring for the infant, etc.) may create pressures that render the woman less able to cope with disturbing thoughts. Additionally, some women appear to be particularly vulnerable to change in levels of serotonin effected by abrupt postchildbirth drop in estrogen and progesterone.

4.5.1.2 What Are the Risk Factors for Postpartum Obsessive-Compulsive Disorder?

Risk factors for postpartum OCD are:

- Preexisting obsessive-compulsive symptoms
- Dysfunctional cognitive beliefs linked to frequent intrusive worries in new mothers
- History of:
  - Major depressive disorder
  - Generalized anxiety disorder
  - Premenstrual dysphoric disorder
  - Personality disorders (obsessive-compulsive or avoidant personality disorder)
- Primiparity
- First several weeks after the birth

Other biological risk factors for postpartum OCD are:

- Significant drop of estrogen and progesterone in postpartum leading to dysregulation of serotonergic transmission

- Specific brain morphology (hyperactivity of the anterior cingulated cortex)
- Genetic vulnerability (family history of OCD) activated by transition to motherhood

Risk factors alone are not sufficient to detect the presence of the disorder. They must be coupled with thorough assessment of current symptomatology and associated impairment; adequate diagnostics are essential.

4.5.2 Postpartum Psychosis

4.5.2.1 What Are the Potential Causes of Postpartum Psychosis?

Proposed etiological theories focus on biological mechanisms:

- Immune system dysregulation [38]
- Thyroid dysfunction [39]
- Sleep deprivation or insomnia [40, 41]
- Decreased melatonin [42]
- Abrupt drop in estrogen and progesterone after childbirth [43]
- Genetic predisposition [19, 41]

To this day it is not clear which of these mechanisms has a leading role in the development of PP. PP is most likely triggered by the combination of all proposed factors. It appears that severe sleep deprivation in biologically vulnerable individuals triggers the cascade of previously described symptoms. Most but not all of those women have previous history of bipolar disorder. Therefore, it is imperative to educate vulnerable women about the importance of uninterrupted sleep and often requires involving the partner and/or social system in establishing it. In some cases, it is necessary to introduce pharmacotherapy at the time of delivery in order to prevent mood dysregulation and PP.

4.5.2.2 What Are the Risk Factors for Postpartum Psychosis?

The most common risk factors for PP are:

- Abrupt discontinuation of mood stabilizers in women with bipolar disorder
- History of bipolar disorder
- Previous psychotic episode in history
- Family history of PP

Risk factors that may contribute to PP are:

- Primiparity
- Difficult labor and obstetric complications
- Inadequate social support
- Medications such as corticosteroids, narcotics (meperidine), sympathomimetics, antibiotics (gentamicin, sulfonamides, isoniazid, vancomycin), anticholinergics, and antiviral (acyclovir, interferon)

Additional biological risk factors:

- Sleep loss
- Change in sleep architecture
- Sudden withdrawal of estrogen
- Hypersensitivity of dopamine receptors due to hormonal changes

4.6 Specific Diagnostic Aspects

4.6.1 Postpartum Obsessive-Compulsive Disorder

4.6.1.1 What Are the Barriers to Symptom Disclosure?

Barriers to symptom disclosure of patients are:

- Shame, sense of failure
- Worry that the provider will call child protective services, especially when symptoms involve aggressive obsessions toward the baby
- Confusion and lack of education about symptoms
- Worry that symptoms are signs that the patient is "going crazy" and/or will hurt the baby

4.6.1.2 What Are the Steps in Assessment and Referral Process on the Part of an Obstetrician?

- Be empathic.
- Ask questions such as "Many women experience troubling, repetitive thoughts, or images after having a baby. Have you been having any thoughts or images that are worrisome or concerning?" If the patient endorses symptoms, inquire about distress and degree of functional impairment to determine if symptoms warrant referral to a psychiatrist.
- Provide education about symptoms and normalize obsessions when appropriate.
- Consider administering screening tools to help detect psychiatric symptoms in the postpartum (such as Yale-Brown Obsessive-Compulsive Scale or Perinatal Obsessive-Compulsive Scale) [44].
- Refer to a perinatal psychiatrist and ensure ongoing communication (with patient's written permission).
- Educate the woman and her partner (if she consents) about treatment and recovery process to enhance motivation and compliance.

4.6.2 Postpartum Psychosis

4.6.2.1 What Are the Steps in Diagnosis and Referral Process?

A brief prodromal period occurs right after delivery and prior to the onset of PP during which the patient frequently presents with hypomanic symptoms such as severe insomnia (unrelated to having a newborn), agitation, restlessness, and mild

cognitive impairment. During that brief period, mood lability is extreme and women cannot be consoled. This period is at times mistaken for normal experience of becoming a new mother. Full-blown symptoms of PP usually occur a couple days later. Typically, the patient presents as confused and unaware of symptom gravity. PP may become manifested while the woman is still in the obstetric ward. Alternatively, a patient is brought to the emergency room by a family member or ambulance. The clinical picture may fluctuate rapidly, which makes diagnosis challenging.

Diagnostic steps to be completed by the assessing physician:

1. Managing acute agitation (if present) via injectable antipsychotic and/or benzodiazepines
2. Obtaining collateral information from family, support network, and treatment providers
3. Ruling out metabolic causes and/or medical illnesses (Table 4.9)
4. Referring to a psychiatric hospital if medical illness is ruled out

4.7 Specific Therapeutic Aspects

4.7.1 Postpartum Obsessive-Compulsive Disorder

Effective treatment must target the three domains of etiologic importance in postpartum OCD:

- Cognitive, i.e., changing dysfunctional beliefs that create/maintain distress and impair functioning
- Psychosocial, i.e., assisting the woman in coping with psychological and environmental stresses of postpartum period
- Biological, i.e., prescribing psychotropic medication in case of moderate to severe symptoms

Table 4.9 Procedures to rule out other causes that could induce postpartum psychotic symptoms

Tests	Ruling out
Laboratory	
Complete blood count with differential	Anemia or infection
Blood urea nitrogen/creatinine	Renal insufficiency
Glucose	Hypo-/hyperglycemia
Thyroid panel	Thyroid dysfunction
Calcium	Autoimmune illness
Vitamin B12/folate	Parathyroid disease
Urinalysis and urine culture in febrile patient	Anemia
Urine drug screen	Infection
	Intoxication
Neurological imaging (for patients with history of hypertension or brain aneurism):	
Head computed tomography (with and without contrast)	Cerebral hemorrhage
Brain magnetic resonance imaging	Brain tumors

Table 4.10 Treatment of postpartum obsessive-compulsive disorder

Treatment of postpartum OCD	
Psychosocial	Pharmacological
Cognitive behavioral therapy (CBT): Empirically validated for OCD Not extensively studied in postpartum [5] Consists of: Psychoeducation Exposure to obsessions while preventing the use of maladaptive coping mechanisms Modification of distorted thinking present in obsessions	Selective serotonin reuptake inhibitors (SSRIs) (e.g., fluoxetine, sertraline, fluvoxamine) or less frequently serotonin-norepinephrine reuptake inhibitors (SNRIs) (e.g., venlafaxine, duloxetine). This is the first-line agent in the treatment of OCD. In nursing mothers, preferred medication is one least secreted into breast milk (e.g., sertraline or paroxetine) Antipsychotic augmentation (e.g., SSRI/SNRI+ quetiapine or risperidone) with severe symptomatology, including lack of insight. Risperidone is compatible with nursing

4.7.1.1 What Does Treatment of Postpartum OCD Consist of?

The treatment of OCD consists of the following aspects depicted in Table 4.10. Mild to moderate symptoms may respond to psychosocial interventions only. Moderate to severe symptoms usually require pharmacological treatment along with psychosocial interventions. Although OCD should not be confused with depression or psychosis clinically, pharmacological treatment with antidepressant medication and sometimes even antipsychotic medication may alleviate the symptoms.

4.7.1.2 What Are the Treatment Aims?

Treatment aims are:

- Reduced presence of obsessions or compulsions and/or related symptoms (i.e., secondary depression)
- Improved insight into symptoms
- Reduced degree of distress and functional impairment
- Ability to effectively cope with symptoms

An OCD Case History: Continued

While hospitalized, Vera Gold was treated with sertraline and risperidone in order to relieve her symptoms pharmacologically. At discharge, obsessive thoughts were present but not as overwhelming. Sleep and appetite stabilized. She entered an intensive outpatient program where she participated in group and individual psychotherapy and saw a psychiatrist. Her treatment consisted of cognitive behavioral therapy (CBT) combined with other psychotherapeutic modalities and medications (sertraline, risperidone). Risperidone was added due to symptom severity. After a month of treatment, obsessions were present only under stress or sleep deprivation. Individual psychotherapy became less frequent and she no longer required group psychotherapy. Obsessions no longer triggered anxiety response. Risperidone was tapered off and sertraline continued. Over a period of 10 weeks, obsessive symptoms vanished completely.

4.7.2 Postpartum Psychosis

Effective treatment of PP must target the following domains:

- Safety, i.e., psychiatric hospitalization of the mother and ensuring that the baby is cared for by family/friends
- Biological, i.e., starting immediate psychopharmacological and milieu treatment to stabilize psychosis, agitation, and mood symptoms
- Psychosocial, i.e., once the patient starts to regain insight, assisting the family and the patient in coping with the illness and promoting positive interaction with the baby

4.7.2.1 What Are Potential Preventive Measures of Postpartum Psychosis?

Potential preventive measures of PP are:

- Identifying patients at risk and referring for psychiatric preconception planning. Take special care of the patients with bipolar disorder, previous history of PP or psychotic episode(s), and first-line relatives with psychotic disorder.
- Advising patients at risk to make treatment arrangements ahead of time in case of postpartum destabilization and inability to consent.
- Educating the support system of at-risk woman: facilitating adequate sleep hygiene, recognizing first signs of illness, and obtaining immediate professional help.
- Facilitating ongoing relationship with a psychiatrist.

4.7.2.2 What Are the Steps in Treatment of Postpartum Psychosis?

The steps of the treatment process are the following: Treatment starts immediately after admission. When the patient does not consent to treatment, the decision is deferred to a judge in the mental health court. In a subset of women, long-term medication management after a PP episode is not required as symptoms are solely triggered by peripartum.

In Table 4.11 the different steps of the treatment process are depicted.

4.7.2.3 What Are the Markers of Treatment Success?

- Reduced severity of psychotic symptoms and mood stabilization
- Improvement in sleep quality and nutrition
- Presence of insight into severity of illness and necessity for treatment
- Treatment compliance
- Lifestyle adjustments in favor of stability
- Return to baseline

Psychosis Case History: Continued

While in the hospital, Malia Sapphire's baby was at home with her family. She was prescribed lithium and haloperidol and began to improve over the course of 7 days. She was discharged home where constant care was provided by her family. Symptom reduction followed and within several weeks she was tapered off haloperidol but remained on lithium. She also engaged in psychotherapy, which focused on mother-infant attachment, psychoeducation, and coping with stress of the illness and postpartum adjustment. A year following the psychotic episode, she was tapered off all of her medication and contemplated another pregnancy. She engaged in psychiatric preconception planning.

Table 4.11 Treatment of postpartum psychosis

Treatment of postpartum psychosis	
Acute management	Emergency psychiatric hospitalization Mother's separation from the newborn (the infant stays with the family or is admitted to a psychiatric mother-baby unit) Psychoeducation of the family/support system Psychotropic medication: Mood stabilizers: lithium, valproic acid, or carbamazepine Antipsychotics: first (haloperidol) and second generation (olanzapine, risperidone, quetiapine) Benzodiazepines Antidepressants should be avoided Electroconvulsive therapy (in treatment-resistant cases)
Posthospitalization management	Recommendations given: Obtain supportive psychotherapy Comply with psychotropic medication regimen and attend psychiatric visits Maintain sleep schedule (ensure that breastfeeding does not interfere with rest) Create adequate support system Reduce stress
Mother-infant bonding	Once the woman is no longer psychotic, the following recommendations are given: Obtain support with childcare tasks, and gradually increase responsibilities while taking care not to disrupt self-care Spend time with the baby to get to know her and attune to her needs and rhythms Seek psychotherapy when bonding problems persist

Note: Addiction to medication, which would lead to withdrawal symptoms upon discontinuation, is always of concern. Among medications listed above, only benzodiazepine use could have that consequence. However, due to brief administration of benzodiazepines only during the acute, psychotic state, its use does not tend to be addictive

4.8 Critical Reflection and Conclusive Remarks

Postpartum-onset OCD and PP are serious mental health disorders that can have devastating consequences when untreated.

In the absence of treatment, OCD tends to have a chronic course, is accompanied by depression and diminished insight, and exerts a significant negative influence on the mother's ability to attend to her baby.

Untreated PP carries a high risk of suicide and/or infanticide. Yet many medical professionals lack basic expertise to educate, assess, and refer women who are suffering or at risk. It is imperative that this gap in training be bridged.

Tips and Tricks

In (Suspicion of) OCD

- Be empathic.
- Ask questions such as "Many women experience troubling, repetitive thoughts, or images after having a baby. Have you been having any thoughts or images that are worrisome or concerning?" If the patient endorses symptoms, inquire about distress and degree of functional impairment to determine if symptoms warrant referral to a psychiatrist.
- Provide education about symptoms and normalize obsessions when appropriate.
- Consider administering screening tools to help detect psychiatric symptoms in the postpartum (such as Yale-Brown Obsessive-Compulsive Scale or Perinatal Obsessive-Compulsive Scale) [44].
- Refer to a perinatal psychiatrist and ensure ongoing communication (with patient's written permission).
- Educate the woman and her partner (if she consents) about treatment and recovery process to enhance motivation and compliance.

In Suspicion of Postpartum Psychosis

- Manage acute agitation (if present) via injectable antipsychotic and/or benzodiazepines.
- Obtain collateral information from family, support network, and treatment providers.
- Rule out metabolic causes and/or medical illnesses (Table 4.9).
- Refer to a psychiatric hospital if medical illness is ruled out.

Test Your Knowledge and Comprehension

Case

The patient is a married Caucasian primipara in her early 30s presenting to the mental health clinic at 3 months postpartum. She has no previous psychiatric history but identifies a strong tendency toward worry and perfectionism. She is a highly accomplished professional in her field who demonstrates strong type A personality characteristics and behavior. She has a lifelong history of insomnia, which "runs in her family." A few weeks after the birth of her daughter, the patient began to

experience thoughts of throwing the baby out the window, which led her to avoid entering the balcony and eventually to avoid holding the baby. She also reports being frightened of SIDS and repeatedly checking whether her baby is breathing. The patient reports that in the past week, these thoughts have given way to graphic images of suffocating her crying baby with a pillow. The patient is very distressed by these thoughts. Patient's mood has deteriorated and she currently reports feeling sad, overwhelmed, inadequate as a mother, and worthless. Her insomnia worsened so that she sleeps 3–4 h/night total and feels exhausted as a result. She began to avoid her newborn out of concern that she might harm her. Due to severe helplessness and hopelessness, she started experiencing passive suicidal ideation without plan or intent.

Questions 1 to 5 Refer to the Case

1. Hearing those complaints, child protective services should be called.
   (a) True
   (b) False
2. Intrusive images of harming her child are delusions.
   (a) True
   (b) False
3. Insomnia precipitates symptoms described above.
   (a) True
   (b) False
4. SSRIs are the first line of psychopharmacological agents to treat above symptoms.
   (a) True
   (b) False
5. Patient's obsessive thoughts and images are consistent with her character and values.
   (a) True
   (b) False
6. The following diagnosis can include psychotic features in the postpartum:
   (a) Major depressive disorder
   (b) PTSD
   (c) Depersonalization disorder
7. The most important risk factor for puerperal psychosis is:
   (a) Depression during pregnancy
   (b) Bipolar disorder
   (c) Having experienced a previous traumatic delivery
8. Which of the following statements about OCD is false?
   (a) By definition, OCD sufferers experience obsessions and compulsions.
   (b) Intrusive thoughts are the most common presentation in postpartum OCD.
   (c) Avoidance is one of the most common compulsions experienced by postpartum OCD sufferers.

9. What is the prevalence of postpartum psychosis?
   (a) Five women per 1000
   (b) One to two women per 1000
   (c) Ten women per 1000
10. What is most commonly used to augment the effect of SSRIs in OCD treatment?
   (a) Anxiolytics
   (b) Antipsychotics
   (c) Mood stabilizers

Answers

1. False
2. False
3. True
4. True
5. False
6. (a)
7. (b)
8. (a)
9. (b)
10. (b)

References

1. World Health Organization. International statistical classification of diseases and related health problems. 10th rev. Geneva: World Health Organization; 2011.
2. Grigoriadis S, Romans S. Postpartum psychiatric disorders: what do we know and where do we go? Curr Psychiat Rev. 2006;2(1):151–8.
3. Forray A, Focseneanu M, Pittman B, McDougle CJ, Epperson CN. Onset and exacerbation of obsessive-compulsive disorder in pregnancy and the postpartum period. J Clin Psychiatry. 2010;71(8):1061–8.
4. Brandes M, Soares CN, Cohen LS. Postpartum onset obsessive-compulsive disorder: diagnosis and management. Arch Womens Ment Health. 2004;7(2):99–110.
5. Speisman BB, Storch EA, Abramowitz JS. Postpartum obsessive-compulsive disorder. J Obstet Gynecol Neonatal Nurs. 2011;40(6):680–90.
6. Sichel DA, Cohen LS, Dimmock JA, Rosenbaum JF. Postpartum obsessive compulsive disorder: a case series. J Clin Psychiatry. 1993;54(4):156–9.
7. Zambaldi CF, Cantilino A, Montenegro AC, Paes JA, de Albuquerque TL, Sougey EB. Postpartum obsessive-compulsive disorder: prevalence and clinical characteristics. Compr Psychiatry. 2009;50(6):503–9.
8. Uguz F, Akman C, Kaya N, Cilli AS. Postpartum-onset obsessive-compulsive disorder: incidence, clinical features, and related factors. J Clin Psychiatry. 2007;68(1):132–8.
9. Fairbrother N, Woody SR. New mothers' thoughts of harm related to the newborn. Arch Womens Ment Health. 2008;11(3):221–9.
10. Russell EJ, Fawcett JM, Mazmanian D. Risk of obsessive-compulsive disorder in pregnant and postpartum women: a meta-analysis. J Clin Psychiatry. 2013;74(4):377–85.
11. Kitamura T, Yoshida K, Okano T, Kinoshita K, Hayashi M, Toyoda N, et al. Multicentre prospective study of perinatal depression in Japan: incidence and correlates of antenatal and postnatal depression. Arch Womens Ment Health. 2006;9(3):121–30.

12. Wenzel A, Haugen EN, Jackson LC, Brendle JR. Anxiety symptoms and disorders at eight weeks postpartum. J Anxiety Disord. 2005;19(3):295–311.
13. Wenzel A, Gorman LL, O'Hara MW, Stuart S. The occurrence of panic and obsessive compulsive symptoms in women with postpartum dysphoria: a prospective study. Arch Womens Ment Health. 2001;4(1):5–12.
14. Navarro P, Garcia-Esteve L, Ascaso C, Aguado J, Gelabert E, Martin-Santos R. Non-psychotic psychiatric disorders after childbirth: prevalence and comorbidity in a community sample. J Affect Disord. 2008;109(1–2):171–6.
15. Abramowitz JS, Schwartz SA, Moore KM, Luenzmann KR. Obsessive-compulsive symptoms in pregnancy and the puerperium: a review of the literature. J Anxiety Disord. 2003;17(4): 461–78.
16. Abramowitz J, Schwartz S, Moore K. Obsessional thoughts in postpartum females and their partners: content, severity, and relationship with depression. J Clin Psychol Med Settings. 2003;10(3):157–64.
17. Stewart DE, Klompenhouwer JL, Kendell RE, van Hulst AM. Prophylactic lithium in puerperal psychosis. The experience of three centres. Br J Psychiatry. 1991;158:393–7.
18. Chaudron LH, Pies RW. The relationship between postpartum psychosis and bipolar disorder: a review. J Clin Psychiatry. 2003;64(11):1284–92.
19. Jones I, Craddock N. Familiality of the puerperal trigger in bipolar disorder: results of a family study. Am J Psychiatry. 2001;158(6):913–7.
20. Brockington IF. Motherhood and mental health. Oxford: Oxford University Press; 1996.
21. Kendell RE, Chalmers JC, Platz C. Epidemiology of puerperal psychoses. Br J Psychiatry. 1987;150(5):662–73.
22. Robertson E, Jones I, Haque S, Holder R, Craddock N. Risk of puerperal and non-puerperal recurrence of illness following bipolar affective puerperal (post-partum) psychosis. Br J Psychiatry. 2005;186:258–9.
23. O'Hara MW, Wisner KL. Perinatal mental illness: definition, description and aetiology. Best Pract Res Clin Obstet Gynaecol. 2014;28(1):3–12.
24. Doucet S, Dennis CL, Letourneau N, Blackmore ER. Differentiation and clinical implications of postpartum depression and postpartum psychosis. J Obstet Gynecol Neonatal Nurs. 2009;38(3):269–79.
25. Spinelli MG. Postpartum psychosis: detection of risk and management. Am J Psychiatry. 2009;166(4):405–8.
26. Brockington IF, Cernik K, Schofield E, Downing A, Francis A, Keelan C. Puerperal psychosis: phenomena and diagnosis. Arch Gen Psychiatry. 1981;38(7):829–33.
27. Sit D, Rothschild AJ, Wisner KL. A review of postpartum psychosis. J Womens Health (Larchmt). 2006;15(4):352–68.
28. Wisner KL, Peindl K, Hanusa BH. Symptomatology of affective and psychotic illnesses related to childbearing. J Affect Disord. 1994;30(2):77–87.
29. Connell M. The postpartum psychosis defense and feminism: more or less justice for women? Case W Res L Rev. 2002;53(1):143.
30. Nau LN, McNiel DE, Binder RL. Postpartum psychosis and the courts. J Am Acad Psychiatry Law. 2012;40(3):318–25.
31. Diagnostic and statistical manual of mental disorders: DSM-5. Washington, D.C.: American Psychiatric Association; 2013.
32. Parry B. Postpartum psychiatric syndromes. In: Kaplan H, Sadock B, editors. Comprehensive textbook of psychiatry. 6th ed. Philadelphia: Lippincott Williams & Wilkins; 2000.
33. Doucet S, Jones I, Letourneau N, Dennis CL, Blackmore ER. Interventions for the prevention and treatment of postpartum psychosis: a systematic review. Arch Womens Ment Health. 2011;14(2):89–98.
34. Fairbrother N, Abramowitz JS. New parenthood as a risk factor for the development of obsessional problems. Behav Res Ther. 2007;45(9):2155–63.
35. Abramowitz JS, Khandker M, Nelson CA, Deacon BJ, Rygwall R. The role of cognitive factors in the pathogenesis of obsessive-compulsive symptoms: a prospective study. Behav Res Ther. 2006;44(9):1361–74.

36. Barr LC, Goodman WK, Price LH. The serotonin hypothesis of obsessive compulsive disorder. Int Clin Psychopharmacol. 1993;8 Suppl 2:79–82.
37. Leckman JF, Goodman WK, North WG, Chappell PB, Price LH, Pauls DL, et al. Elevated cerebrospinal fluid levels of oxytocin in obsessive-compulsive disorder. Comparison with Tourette's syndrome and healthy controls. Arch Gen Psychiatry. 1994;51(10):782–92.
38. Bergink V, Gibney SM, Drexhage HA. Autoimmunity, inflammation, and psychosis: a search for peripheral markers. Biol Psychiatry. 2014;75(4):324–31.
39. Bergink V, Lambregtse-van den Berg MP, Koorengevel KM, Kupka R, Kushner SA. First-onset psychosis occurring in the postpartum period: a prospective cohort study. J Clin Psychiatry. 2011;72(11):1531–7.
40. Sharma V, Smith A, Khan M. The relationship between duration of labour, time of delivery, and puerperal psychosis. J Affect Disord. 2004;83(2–3):215–20.
41. Sharma V. Role of sleep loss in the causation of puerperal psychosis. Med Hypotheses. 2003;61(4):477–81.
42. Sandyk R. Postpartum psychosis and the pineal gland. Int J Neurosci. 1992;62(1–2):101–5.
43. Cookson JC. Post-partum mania, dopamine, and estrogens. Lancet. 1982;18 (2 (8299)):672.
44. Lord C, Rieder A, Hall GB, Soares CN, Steiner M. Piloting the perinatal obsessive-compulsive scale (POCS): development and validation. J Anxiety Disord. 2011;25(8):1079–84.

A Woman with a Positive Prenatal Test on Trisomy 21: Counseling in Prenatal Diagnosis

5

Sibil Tschudin and Christianne Verhaak

5.1 Introduction and Aims

Trisomy 21 is the most prevalent numeric or structural chromosomal aberration. Nowadays, prenatal tests for screening and diagnosing trisomy 21, as well as some other chromosomal aberrations, exist.

The existence of prenatal tests allows, and at the same time forces, pregnant women to make decisions and choices. Ethically delicate questions arise such as the value of unborn life, the value of a life of a child with a mental handicap, and the consideration about pros and cons regarding the impact on the parents' life. Accordingly, the introduction of noninvasive prenatal testing (NIPT) into the market had a remarkable echo in society and led to concerned reactions from the side of disability organizations.

The complexity of the situation affords comprehensive information and counseling by health professionals previous to any prenatal testing, but especially when a chromosomal aberration such as trisomy 21 is suspected or diagnosed. At the same time, trisomy 21 is just one of a variety of congenital anomalies, and other congenital anomalies could have similar consequences for the couples concerned and the health professionals who take care of them. The decision whether to terminate pregnancy or not is very much dependent on the individual evaluation of the couples

S. Tschudin, MD (✉)
Department of Obstetrics and Gynecology, University Hospital Basel, Basel, Switzerland
e-mail: Sibil.tschudin@usb.ch

C. Verhaak, PhD
Department of Medical Psychology, Radboud University Medical Center, Nijmegen, The Netherlands
e-mail: Chris.verhaak@radboudumc.nl

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_5

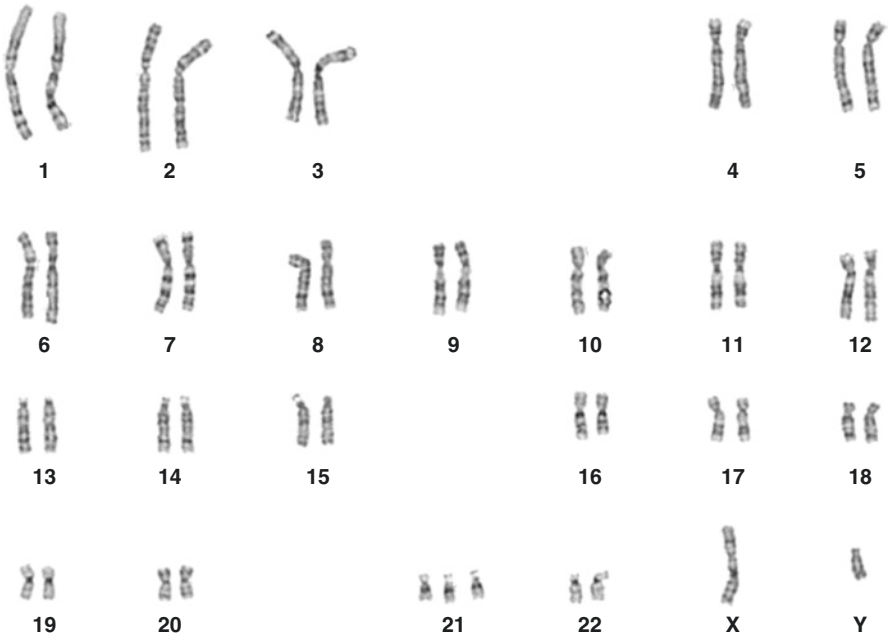


Fig. 5.1 Karyotype in case of trisomy 21/Down syndrome (Used with permission from Schweizerische Akademie der Medizinischen Wissenshchaftern (Hrsg). Abklärung von Erbkrankheiten. Genetik im Medizinischen Alltag. Ein Leitfaden für die Praxis. Eigenverlag SAMW; 2011)

concerned. A nonjudgmental and nondirective approach is of utmost importance. This is especially true during the shared decision-making process. Thereafter health professionals are confronted with the challenging task to provide support and meet the specific needs of those couples who decide to terminate and those who carry out pregnancy.

5.2 Definitions in Lay Terms

5.2.1 Trisomy 21

Trisomy 21 is a numeric chromosomal aberration (Fig. 5.1). It is a genetic disorder caused by the presence of a third copy of chromosome 21 [1]. It is also known as Down syndrome and is typically associated with physical growth delay, characteristic facial features, and mild to moderate intellectual disability [2]. It is a condition that when compared with other numeric chromosomal aberrations, such as trisomy 13 or 18, is not lethal but viable, even if associated with more or less severe handicaps and a shorter life expectancy for the person affected.

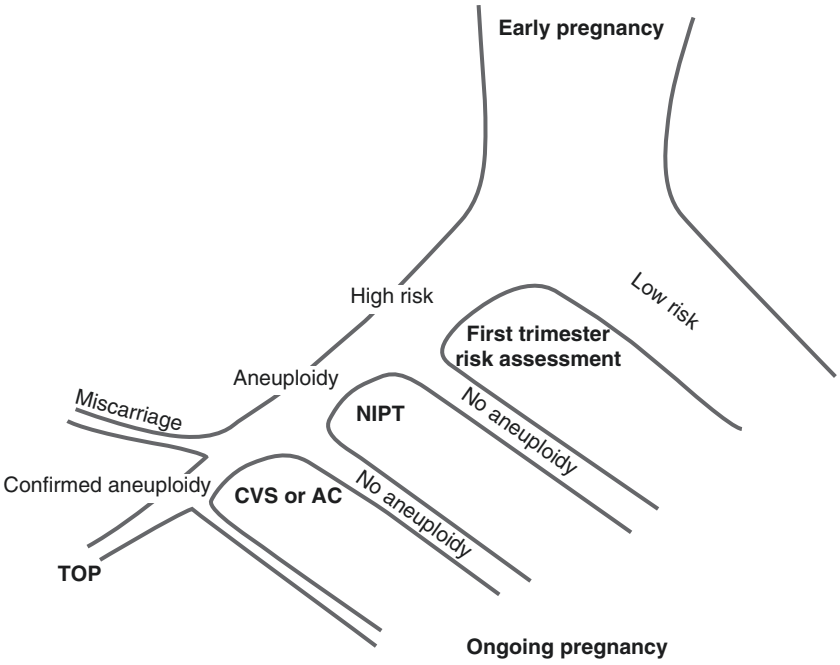


Fig. 5.2 History of prenatal tests

5.2.2 Prenatal Tests for Trisomy 21

Nowadays, prenatal tests for screening and diagnosing trisomy 21, as well as some other chromosomal aberrations, exist (Fig. 5.2). The first trimester risk assessment is the currently available option for screening. Meanwhile diagnosis is generally suspected at first by a noninvasive prenatal (blood) test (NIPT), which is followed by invasive testing with chorionic villi sampling or amniocentesis for confirmation.

5.3 Didactic Goals

After reading this chapter, you:

- Know about the frequencies of malformations in general and the most common chromosomal aberrations.
- Are familiar with the indications and limitations of the currently available noninvasive and invasive prenatal tests.
- Are familiar with the special characteristics of prenatal tests and their ethical implications.
- Are familiar with the aspects of decision-making and possible decisional conflicts.

Case History

Dymphna Lemon, a 41-year-old woman, consults her gynecologist in early pregnancy. She is a gravida 6 para 1 with a history of a traumatizing termination of pregnancy 20 years ago, four curettages for miscarriages in early pregnancy, and a cesarean section on demand 2 years ago. At her first consultation, she gets information about the available prenatal tests in general and her increased risk for chromosomal aberrations such as trisomies 13, 18, and 21 due to her advanced reproductive age. Since Dymphna does not think she would continue with a pregnancy with a trisomy 21 child, after counseling she opts for a noninvasive first trimester screening on trisomies 21, 13, and 18. At the 12th week of gestation, she has an ultrasound check including risk assessment for chromosomal aberrations. Although the nuchal translucency is within normal limits, the final risk assessment, including the biochemical parameters, pregnancy-associated plasma protein A (PAPP-A), and β(beta)-hCG, indicates an elevated risk for trisomy 21 of 1:60. Since she wants to be sure, she agrees to go on for noninvasive prenatal testing (NIPT). She receives the result after a waiting period of 2 weeks, which she experiences as a long and stressful. The NIPT shows that her fetus has trisomy 21 indeed, which is then confirmed by chorionic villi sampling.

- Are familiar with specific communicative skills and tools for supporting the decision-making.
- Are familiar with helpful strategies to support women and their partner when they are opting for termination of pregnancy.
- Are familiar with helpful strategies to support women and their partner when they are opting to continue their pregnancy.
- Have reflected your own attitudes and are able to support a woman in the given situation in a nonjudgmental way.

5.4 Facts and Figures: Definitions, Classification, and Prevalence

5.4.1 Formal Definition

5.4.1.1 Birth Defects: Trisomy 21

Congenital anomalies are defects that are not acquired during life but are already existent at an individual's birth. About half of the defects are of unknown etiology, a quarter is multifactorial, and the others are either due to teratogens, mutations, or chromosomal aberrations (Fig. 5.3) [3]. The most prevalent numeric or structural chromosomal aberration is trisomy 21.

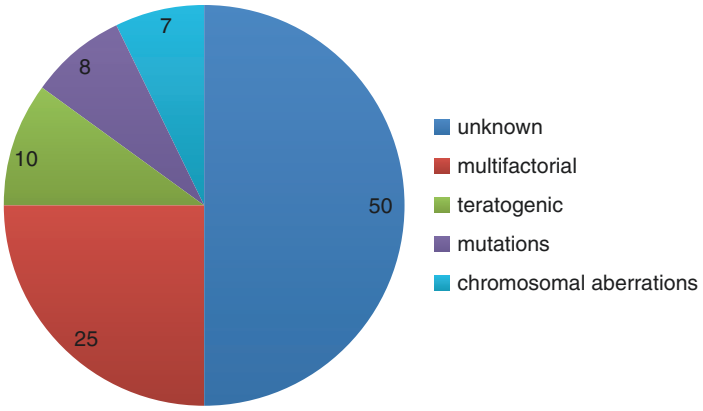


Fig. 5.3 Prevalence of congenital anomalies

Trisomy 21 is typically associated with physical growth delay, characteristic facial features, and mild to moderate intellectual disability. People with trisomy 21 may have some or all of these physical characteristics: a small chin, slanted eyes, poor muscle tone, a flat nasal bridge, a single crease of the palm, and a protruding tongue. They have an increased risk of a number of other health problems, including congenital heart disease, leukemia, and thyroid disorders.

Other less frequently occurring trisomies are trisomies 13 and 18, also known as Patau and Edwards syndrome, respectively. These trisomies, however, are lethal and result in stillbirth or the demise of a severely handicapped child during delivery or soon afterward. Besides the triplication of one chromosome, there exist also triploidies of the entire chromosome set, which generally lead to an early demise of the fetus. Another relatively frequently occurring numeric chromosomal aberration is aneuploidies of the sex chromosomes resulting in Turner syndrome (X aneuploidy), Klinefelter syndrome (XXY), and other less frequent sex aneuploidies.

5.4.1.2 Which Are the Available Tests for Risk Assessment and Diagnosis of Chromosomal Aberrations?

The development and implementation of prenatal diagnosis started in the 1960s (Fig. 5.4). At that time amniocentesis (AC) and ultrasound were introduced. In the 1980s chorionic villi sampling (CVS) followed and allowed early detection of structural chromosomal aberrations such as trisomy 21. However, the procedure was at the cost of a risk of 1–2 % of inducing a miscarriage [4, 5]. In order to reduce the number of women exposed to this risk, noninvasive screening tests were developed then. In the 1990s, the relatively imprecise alpha-fetoprotein plus test, which could only be performed in the second trimester, could soon be replaced by the first trimester risk assessment combining the nuchal translucency with the biochemical markers PAPP-A (pregnancy-associated plasma protein A) and free

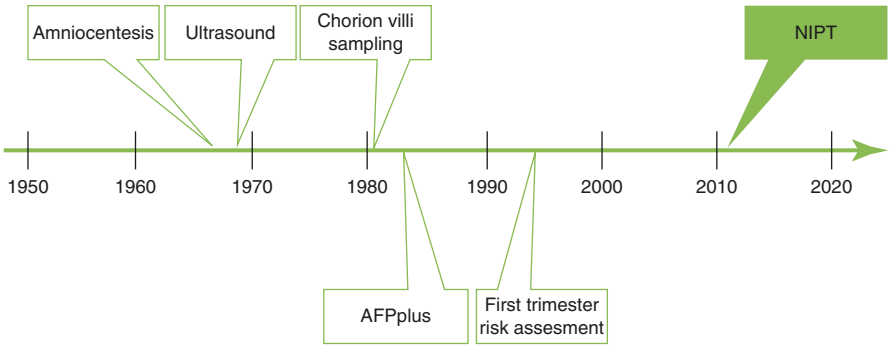


Fig. 5.4 Current algorithm for prenatal diagnosis of aneuploidy in early pregnancy. *NIPT* noninvasive prenatal test, *CVS* chorionic villi sampling, *AC* amniocentesis, *TOP* termination of pregnancy

β(beta)-hCG, as well as the age of the pregnant woman [6–8] (Table 5.1). The detection rate for trisomy 21 is about 90 %, and the test is constructed in such a way that about 5 % of the women have a positive test result. To further reduce the persisting risk of CVS-induced miscarriages for the women who screen positive, further research concentrated on noninvasive diagnostic procedures. These are now available with the so-called noninvasive prenatal test (NIPT). The underlying investigational technology is based on the fact that a pregnant mother's blood contains free fetal DNA fragments [9]. By quantifying them, aneuploidies such as trisomies 21, 18, and 13 can be detected, as well as a triploidy (tripling of all chromosomes) and anomalies of the sex chromosomes. The sensitivity for trisomy 21 of the currently available tests is 99.1 % (CI 97–100); the rate of false-positive results is 0.3 % (CI 0.2–0.7) [10]. The test is validated for women with a positive first trimester risk assessment, is applicable in singleton and recently also in twin pregnancies, and cannot detect mosaic trisomies. It can be performed from the tenth week of gestation onward. To date a positive NIPT should be confirmed by CVS or AC.

5.4.2 What Proportion of Pregnant Women Is Confronted with a Suspicious or Pathological Prenatal Test?

The prevalence of any congenital anomaly is about 4 %. About 7 % of all these anomalies are chromosomal aberrations. The most frequent chromosomal aberration is trisomy 21, occurring in about 15/10.000, followed by trisomy 18 (3/10.000), and trisomy 13 (2/10.000). Furthermore, the frequency of trisomy 21 is dependent upon the pregnant woman's age and is about 1/1000 at the age of 20 and 1/100 at the age of 40 years. The detection rate in the second trimester depends on the type of anomaly and lies between 13 % (congenital heart defects) and 77 % (cerebral defects) [11].

Table 5.1 List of available prenatal tests

	Invasive vs. noninvasive	Screening vs. diagnostic (detection rate)	Time frame	Detectable defects	Comments
Alpha-fetoprotein (AFP)	Noninvasive	Screening	14–21 weeks	ONTD	
AFP plus Alpha-fetoprotein Estriol Beta-hCG	Noninvasive	Screening (65 %)	15–21 weeks	Trisomy 21 ONTD	Rarely used nowadays as detection rate is low and test is applicable only in 2nd trimester
First trimester risk assessment Nuchal translucency Beta-hCG PAPP-A	Noninvasive	Screening (89 %)	11–14 weeks	Trisomies 21, 18, 13	
NIPT (fetal DNA)	Noninvasive	"Diagnostic" (affords confirmation by AC or CVS) (99.1 %)	≥10 weeks	Trisomies 21, 18, 13 X, XXX, XXY, XYY	
Amniocentesis	Invasive	Diagnostic	>15 weeks	All major chromosome problems	Risk of miscarriage: 0.5 %
Chorionic villi sampling	Invasive	Diagnostic	>11 weeks	All major chromosome problems	Risk of miscarriage: 0.5 %

ONTD open neural tube defect, *AFP* alpha-fetoprotein, *NIPT* noninvasive prenatal test, *AC* amniocentesis, *CVS* chorionic villi sampling

5.4.3 Classification

5.4.3.1 Medical Perspective

Congenital anomalies can be classified as minor or major birth defects. Furthermore, they can be subdivided in (at least partly) treatable malformations and untreatable chromosomal aberrations. This is an important aspect when couples that are confronted with an affected fetus have to be guided and supported in making the decision whether to continue or terminate pregnancy.

5.4.3.2 Legal Perspective

The legal framework concerning termination of pregnancy (i.e., abortion) differs from one country to the other. This has an impact on the choices that can be made in the case of fetal anomalies and chromosomal aberrations, such as trisomy 21. In general, the diagnosis of an anomaly is not made until the first 12 weeks of gestations, and the common limits of legal abortion on the woman's demand have passed. Thus other regulations are in duty then. In many countries abortions are induced no later than the beginning of the stadium of prematurity, i.e., 24 weeks of gestation. After this time point, feticide has to be performed before labor induction, in order to prevent delivering a viable neonate. In some countries this practice is allowed; meanwhile, in others this is not an option, as feticide is not allowed beyond 24 weeks of gestation.

5.4.3.3 Ethical Perspective

In general, health professionals are educated to save lives, to cure, and to care. In the context of prenatal diagnosis, they are sometimes confronted with the conflicting situation that the diagnostic procedure they perform does not contribute to treatment of a condition but only leads to elimination of the unborn individual (fetus) that suffers from it. When considering the principles of biomedical ethics that are autonomy, beneficence, non-maleficence, and justice, at least the second and the third of these four principles are not considered from the perspective of the fetus [12]. Depending on their personal attitudes and beliefs, physicians may experience ethical and moral conflicts when they are confronted with a request for termination of pregnancy. The conflict might be minor in case of severe anomalies and major when the condition in question is compatible with life, such as trisomy 21.

5.4.3.4 Psychological Perspective

Being confronted with a positive prenatal screening test or the prenatal diagnosis of a fetal chromosomal aberration is a very challenging situation for the pregnant women/couples concerned. It causes a high level of distress. As a consequence the capacity to make a decision is impaired, even though a decision with an impact on the future life of the couple has to be made within a short time period and thus under considerable pressure. The confrontation with a positive test result can never

Case History (Continued)
It is the sixth pregnancy of Dymphna Lemon, a practicing lawyer, who is together with her partner for 20 years. Due to the intense engagement in her profession, it was only in her late 30s that she started thinking about having children. After several miscarriages she consulted a specialist in reproductive medicine and was very happy when she got pregnant spontaneously and gave birth to a healthy boy 2 years ago. Wishing to have a second child and sibling for her son, she was very happy when she got pregnant again spontaneously. Dymphna is very sad about the fact that a trisomy 21 was detected. It took a long time to get pregnant again and now she is confronted with this chromosomal abnormality of her baby. She feels unable to take care of a handicapped child, as she has a demanding job and wants to be present for her son. She is also concerned that she might not be patient enough due to her advanced age. At the same time, she would never have imagined having an abortion due to her religious faith and sees herself confronted with reactions of incomprehension from the side of some family members and friends. One of her relatives even blamed her for killing a baby and suggested she have at least a tubal ligation in the aftermath of the abortion.

be anticipated entirely and will always be a psychological shock, but pretest counseling might nevertheless set the framework for the decision-making and reduce excessive stress. Our case demonstrates this exemplarily.

5.5 Etiology and Pathogenesis

5.5.1 Risk Factors for Congenital Anomalies

Even if approximately 50 % of all congenital anomalies cannot be linked to a specific cause, there are some known causes or risk factors. Congenital anomalies are more frequent among resource-constrained families and countries, in case of consanguinity, maternal infections such as syphilis, cytomegalovirus, and rubella. They also depend on maternal nutritional status—with higher risks in case of iodine deficiency, folate insufficiency, obesity, or diabetes—and on environmental factors, for example, exposure to pesticides, certain medications, alcohol, tobacco, other psychoactive substances, and high doses of radiation [13]. With regard to trisomy 21, however, the only relevant risk factor is in general increasing maternal age. In only 2–4 % of the cases of trisomy 21, the tripling of chromosome 21 is due to a Robertsonian translocation in one of the parents. This results in a 15 % chance of having a child with Down syndrome when the mother is affected and a less than 5 % risk if the father is affected.

5.5.2 Unfortunate Pregnancy

Pregnant women and couples who are confronted with the suspicion or diagnosis of a fetal trisomy 21 or any other fetal anomaly experience a so-called unfortunate pregnancy. They are confronted and have to cope with the fact that they have to give up their dream of the perfect and ideal child, sometimes even of (further) parenthood at all. The waiting time that is often linked to the diagnostic procedures might be experienced as very burdensome. Furthermore, the information about severity and prognosis of a certain anomaly often remains vague. Depending on the familiar background and support, the stability of the partnership, and the individual coping resources, such an experience might bring pregnant women and couples at or beyond the limits of tolerance and induce crisis. This has to be considered when one counsels and cares for such couples.

5.5.3 Working Model

Counseling in the context of prenatal diagnosis has to take into account that it might be difficult to impart what a certain risk means, as risk and probability are something abstract on the one hand and very much depending on an individual's perception and estimation of what this risk means to him and her on the other. That is, actual and perceived risk may be something totally different. Furthermore, the willingness to take or accept a risk differs from one person to another.

In medicine, decisions that have to be made can be subdivided into two groups, i.e., preference-sensitive decisions and evidence-based decisions. This division depends on the existing knowledge and evidence but also on the character of a given condition or disease. The decision to start an insulin therapy for gestational diabetes follows evidence-based criteria, and for most pregnant women concerned, the benefit clearly outweighs the burden of the treatment. In the case of prenatal diagnosis, however, the decisions that have to be made are mainly preference sensitive, as they mostly depend on individual estimation and attitudes of pregnant women and couples concerned. Often little is known about the extent and the consequences of a given malformation, and to give parents an estimation about the expected quality of life of the unborn child in an evidence-based manner is very difficult. Even if percentages can be given, parents have to weigh this information against their own moral and ethical balances.

Parents have to make decisions about additional diagnostic procedures and about continuation or discontinuation of pregnancy. They have to do this in a short time frame, at the same time as they have to adjust to the bad news of the positive screening result of their unborn child. This combination of short time frame and situations with high emotional impact makes well-informed decision-making difficult. Cognitive capacity to make choices could be diminished. Counseling has to take these very sensitive aspects of the situation into account. Our case is an example therefore.

Case History (Continued)
Dymphna Lemon is weeping and feels incapable of coping with the situation. At the same time, she feels certain in her decision to have a termination of pregnancy as soon as possible. Nevertheless, she is very concerned and anxious about the upcoming induction of labor, as she previously had a very bad experience with heavy bleeding and unbearable pain after misoprostol for an abortive pregnancy some years ago. Only repeated comprehensive and reassuring information about the abortion procedure and the existing options to reduce pain could reduce her concerns and allow her to separate her decision about termination of pregnancy from her fears with regard to the process she has to go through.

5.6 Counseling and Care

Couples with a positive prenatal test for trisomy 21 need supportive counseling that enables them to make their decision to either proceed with the pregnancy or not. According to a study by Götzmann et al., about every third pregnant woman was not aware of the problem of the decisional conflict that might arise when she was confronted with a positive result of prenatal testing and the resulting question about termination of pregnancy [14]. This makes evident how important it is to provide thorough information and to counsel properly already previously to any testing. Health professionals are confronted with an ethically complex situation, as the child whose existence is in question cannot be directly involved in decision-making. Therefore, they have the difficult task to give whenever possible consideration to both the pregnant woman and the fetus. At the same time, they also have to respect the pregnant woman's right of ignorance, of "not knowing."

Once the diagnosis is given, health professionals should approach the couple concerned in a nonjudgmental and nondirective manner. They should beware of giving any recommendations, but at the same time cautiously confront with the possible consequences of the envisaged choice.

5.6.1 Problem and Patient Orientation

Progress in prenatal diagnosis offers excellent possibilities to detect a number of diseases prenatally; to initiate further investigations, if necessary; to consider treatment options, if available; or to terminate pregnancy. On the other hand, the couples that are involved are urged to make difficult choices and might experience considerable decisional conflict. Furthermore, the fast increase in knowledge and available options in the field is not the only challenge for gynecologists; it also requires a high competence in communication skills in order to offer a comprehensive counseling

Table 5.2 Risk communication

Give numbers to illustrate verbal and multi-interpretable indications of risk, such as often and seldom
Bring numbers into a context of daily life experiences (e.g., the risk for death by car accident is low with 1:10 000; meanwhile, the average risk for trisomy 21 is moderate with 30:10 000)
Use natural frequencies, absolute risks, and a common nominator (e.g., on average trisomy 21 occurs in one of 300 pregnancies; the risk is 3:1000; for a woman in her 20s, the risk is 1:1000)
Omit change of the nominator (e.g., 1:1000 and 5:1000 instead of 1:1000 and 1:200)
Show positive and negative outcomes (e.g., if your risk is 1:190, one child would be affected and 189 children would not be affected by trisomy 21)
Visualize probabilities (e.g., 1000 persons chart)

that includes ethical and psychological issues. And in some situations, it might confront health professionals with their own ethical and moral limits.

5.6.2 Information Phase

5.6.2.1 Which Information and Counseling Has to Be Provided Previous to Performing Prenatal Tests?

Information has to be provided with respect to several perspectives, i.e., the factual, the emotional, and the relational one:

- *Factual*—In the context of prenatal diagnosis, factual information is given by diagnosis or numbers, which lay people can often not associate with a very concrete notion.
- *Emotional*—From the emotional perspective, information about the child often evokes intense feelings. In case of good information, this is joy and pride; in case of information on pathological results, however, this is anxiety, uncertainty, and doubt.
- *Relational*—Providing information on the unborn child impacts on the doctor-patient relationship. As a matter of fact, gynecologists might be considered as placing themselves in-between the mother and the child and introducing the medical perspective.

5.6.2.2 How Can the Perception and Estimation of One's Individual Risk Be Facilitated Best?

From all three perspectives, communication and interaction might be complicated:

- *Factual*—With regard to the factual perspective, understanding and perception of risk can be facilitated when the aspects listed in Table 5.2 are considered. In order to increase the probability that patients understand the information provided and that their needs are met, communication should be based on common rules (Table 5.3), and information giving should follow the principle of "elicit, provide, elicit" developed by Miller and Rollnick (Table 5.4) [15]. Oral information can be complemented by written material and illustrated by graphs (Fig. 5.5).

Table 5.3 Common rules of information exchange

Give structure
Provide small units of information
Announce important messages
Summarize
Allow checking back

Table 5.4 Information exchange: basic principles

Elicit	Patient's preexisting knowledge and questions
Provide	Information in small units and short sentences
Elicit	Patient's understanding and evaluation of the information "What does this information mean to you?"

Data from Miller and Rollnick [15]

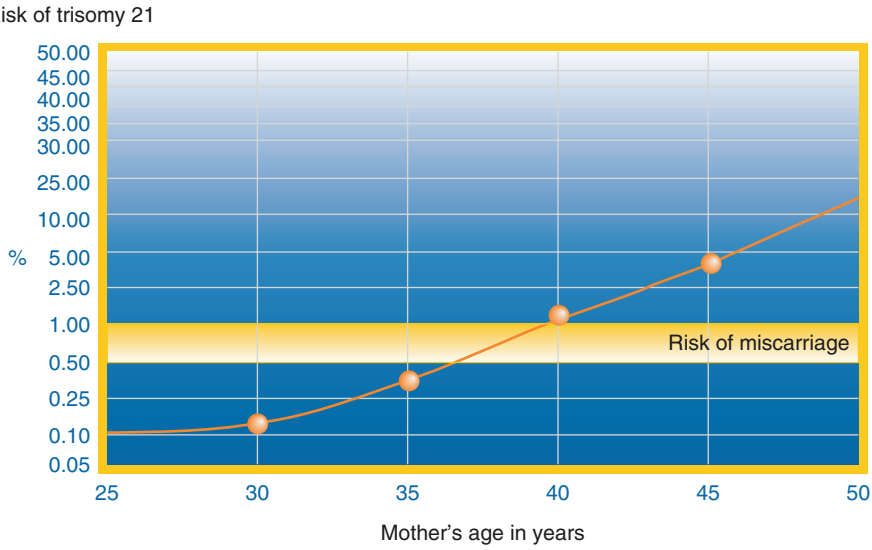


Fig. 5.5 Risk of trisomy 21 in relation to risk of miscarriage due to invasive diagnostics (Used with permission from Hölzle R, Zimmermann R, Pòk Lundquist J, Braga S, Tschudin S, Bitzer J, Holzgreve W, Tercanli S. Kurzfassung—Leitfaden für vorgeburtliche Untersuchungen. Schweizerische Gesellschaft für Gynäkologie und Geburtshilfe, Bern; 2006)

- *Emotional*—Concerning the emotional reactions and the resulting task of the counseling physician, there are mainly three distressing clinical situations, such as:
  1. The high risk according to the first trimester risk assessment
  2. A complication (mainly a miscarriage) due to an invasive procedure (CVS or AC)
  3. The diagnosis of a chromosomal aberration, most frequently trisomy 21

Table 5.5 Emotions and physician's tasks in case of distressing situation

Situation	Emotions	Physician's tasks
1	Uncertainty Anxiety Distrust Transiently disturbed relationship with the unborn Distress due to the waiting time	The emotions should be perceived, respected, and addressed. It might be helpful when patients are asked actively "What distresses you most?" "How can we help?" "How could you help yourself in this moment?" "What would be helpful to reduce uncertainty in terms of written information, the offer of subsequent appointments, and further opportunities to ask questions?"
2	Despair Feelings of guilt Aggression against oneself or the physician Partnership distress	In order to reduce the feelings of guilt, patients should be encouraged To express their negative feelings and thoughts To recapitulate their decision-making It is important to inform about grief and mourning and indicate the according time frame
3	Paralysis Disbelief Despair Revolt against fate Envy against others Deep grief Ev. depression	Permit emotions Bear negative feelings No quick comfort Recapitulate the previously made decisions and steps

Table 5.6 Patient-centered approach: principles of reflective listening

More listening than talking
Responding to what is personal rather than to what is impersonal, distant, or abstract
Restating and clarifying what the other has said, not asking questions or telling what the listener feels, believes, or wants
Trying to understand the feelings contained in what the other is saying, not just the facts or ideas
Working to develop the best possible sense of the other's frame of reference while avoiding the temptation to respond from the listener's frame of reference
Responding with acceptance and empathy, not with indifference, pure objectivity, or fake concern

Data from Rogers and Farson [16]

The different kinds of emotions and physician's tasks are listed in Table 5.5.

- *Relational*—With regard to the doctor-patient relationship, a nondirective communication style is decisive. This is best provided by applying the patient-centered approach based on the principles of reflective listening (Table 5.6) [16].

To better guarantee that information is not only comprehensive but also adapted to the patients' needs and current emotional condition, it is recommended to follow, or at least orientate on, checklists (Table 5.7).

Under high levels of distress, information provided is difficult to process and difficult to remember. It is therefore important to give patients the opportunity to make additional appointments in case of questions and to give information also in

Table 5.7 Information checklists

(a) *Information previous to prenatal testing*
Clarify the expectations of the pregnant woman/couple concerned
Check the preexisting knowledge/level of information concerning prenatal tests
Assess the personal attitudes of the pregnant woman/couple with regard to prenatal tests
Assess psychological aspects: Fears? Previous experiences?
Inform about first trimester risk assessment including the fact that it delivers uniquely a case-related probability
Discuss the personal risk perception
Inform about the consequences of the test results
Point to the decisional conflict that might arise in case of a positive result
Point to the ethical dilemma that might arise and ask which options the pregnant woman/couple considers in case of a positive result
Point out that 95 % of the tests performed will be negative (i.e., normal)
Point out that the test screens for chromosomal aberrations and other anomalies will not be detected with it
(b) *Information on suspicious or pathological test results*
Inform about the suspicion without contributing to unnecessary anxiety and panic
Explain the limits of knowledge and the existing uncertainties
Provide help and support
(c) *Information about the diagnosis of an untreatable fetal condition*; "*breaking bad news*" (*documents prepared*, *time*, *privacy*)
Ask about current mental state/announce
Provide the diagnosis in simple and clear words
Wait for individual reactions, arising emotions, and questions. Address emotions
Structure, support, offer help
Do not provide quick and cheap comfort, but try to sustain negative emotions and to endure them

written form, so that patients are able to read things over in their own environment. It also provides the opportunity to share the information with important others.

5.6.3 Decision-Making Phase

5.6.3.1 What Is the Difference Between Effective and Preference-Sensitive Decision?

The decision, in the context of prenatal tests and in case of a prenatally diagnosed anomaly in general and a trisomy 21 in particular, is typically preference sensitive. In other terms, the cost/benefit relation is very much dependent on the individual evaluation of the woman/couple concerned.

Decision-making should be participative (shared decision-making). This implies a mutual exchange between the physician and the patient and her partner. The expert presents options and their advantages and disadvantages. The patient can question them and bring in her measures of value. A cycle of information exchange and a transparent search for a suitable solution is installed. Therefore the physician's evaluation has to be declared, and the patient must understand the different options and have the opportunity to anticipate the various scenarios. This form of

decision-making might be compromised under certain circumstances: e.g., when we are confronted with language and cultural barriers. Due to the more paternalistic structures in their country of origin, some immigrants might not feel comfortable with participative decision-making. According to the research of one of the coauthors of this chapter, there is some evidence that these patients wish that with regard to prenatal tests, "standard care" is performed, if they do not explicitly express particular reservations or requests [17, 18]. Furthermore, they may be prone to delegate the decision to the doctor or to the head of the family.

5.6.3.2 Which Topics Have to Be Broached When a Pregnant Woman/Couple Is Confronted with the Diagnosis of Trisomy 21 and Has to Make the Decision for or Against?

When pregnant women/couples have to decide whether to carry out pregnancy or to have an abortion, they generally need support as follows:

- In a first step, the measures of value have to be made aware: "What is the significance of disability?"
- Then the options and scenarios should be considered together, each for carrying out and terminating pregnancy: "Which are the consequences (emotionally, behaviorally, from further perspectives)?" "Which are the strains and which are the resources (crisis of life)?"
- A particularly challenging situation occurs when the partners have different perspectives regarding the decision. The attitudes and opinions of both of them have to be considered, even though the woman who carries the pregnancy finally has to make the decision.

5.6.4 Informed Consent Phase

Informed consent is required previous to every intervention, and in many countries it is even a legal obligation when genetic tests are performed or abortions are induced. Especially in the case of termination of pregnancy, the patient has to be explicitly informed that she can withdraw from her decision until the abortion induction is started and that her will is decisive.

5.6.5 Pregnancy

5.6.5.1 How Do Couples Cope with Carrying Out a Pregnancy and Giving Birth in the Case of Trisomy 21?

The Patient Decides for Termination of Pregnancy

The particular strain in this situation is:

- Loss of the hope for a healthy child
- Having to say goodbye to the child

- Feelings of guilt because the woman/couple actively contributes to terminate pregnancy
- Fears with regard to the intervention

For many women/parents, the experienced ambivalence is particularly burdensome. On the one hand, they had wanted the investigations and the intervention with the aim to avoid the burden of a handicapped child; on the other hand, they will lose a child and actively contribute to this loss. They frequently have to make a decision in which no good solution exists. The sadness for a lost dream is paired with the wish to liberate oneself from the current strain. This ambivalence may compromise the mourning process. Furthermore, couples concerned might be confronted with the expectation that they are relieved and would immediately concentrate on a new child. Therefore it is especially important to invite them to express their feelings and to encourage them to allow themselves to mourn. At the same time, one has to be aware that what facilitates the mourning process considerably varies from one person to the other. For some patients it is important and helpful to say goodbye to the child by taking him/her in the arms. For others this might be traumatizing [19]. This has to be discussed in every individual case and whenever possible previous to abortion induction.

The Patient Decides to Carry Out Pregnancy
The particular strain in this situation is:

- Preparation for a life with a handicapped child
- Reorientations with regard to one's life projects
- Overcoming the envy toward others and the anger against oneself and the child
- General reactions of exhaustion and incapability

In this situation it is important that the counselor understands and supports the patient's coping strategies and, if necessary, seeks together with her for additional options to better cope with this burden. This might be complementary information, self-help groups, etc. A particular challenge is the communication between the partners, as well as with family and friends. The patients and couples often need advice in how to explain themselves and how to protect themselves from additional strain caused by helpless reactions from the environment (exaggerated pity, curiosity, quick judgments, cheap comfort).

5.6.6 Delivery

Having a termination of pregnancy and delivering a dead or dying child is a very painful event in every perspective. The actively experienced delivery and confrontation with the dead child with or without any externally visible stigmata, however, at the same time offer a concrete object, and thus separation might be easier than from a lost child that only exists in one's dreams and imagination. Couples should be

encouraged to express their individual wishes with regard to burial and concomitant rituals, which then should be considered as far as possible. The needs and ideas may vary considerably according to a couple's personal beliefs and their sociocultural and religious background. The mourning process may be sometimes compromised when couples experience self-guilt. They may keep secret the true reason for their loss of pregnancy and feel very isolated in their mourning [20].

The situation that a couple decides to proceed with a pregnancy when a trisomy 21 is diagnosed in the second trimester is far less frequently occurring. Delivery confronts the parents with the real presence of the condition and is experienced differently from couple to couple. As the decision to go on with pregnancy is generally a much reflected one, the couples concerned are usually well prepared. Health professionals engaged in the postpartum care, however, have to be attentive with regard to emotional reactions and special needs of these couples, who might want a somehow normal and at the same time particular approach.

Case History (Continued)
Dymphna Lemon is finally admitted at the hospital for termination of pregnancy at the 18th week of gestation. As she has a history of C-section 2 years ago, abortion is induced by a regimen adapted to the given condition (uterine scar). Nevertheless, the procedure is complicated by a severe hemorrhage due to a uterine rupture and results in a laparotomy and prolonged recovery.

Even if this is a rare complication of abortion induction, it highlights that it can have not only psychological, but even physical sequelae.

5.6.7 Follow-Up Care

5.6.7.1 How Do Couples Cope with the Experience of Abortion and What Should Be Considered When Following Them?

After a termination of pregnancy (e.g., for trisomy 21), at least one visit at the institution where the termination of pregnancy was performed should be offered to the patient/couple concerned. The following checks should be made:

- How did the couple experience the delivery/abortion?
- How did they feel supported by the caring team?
- How is their current mental condition?
- Are they able to cope with the current situation?
- Is there enough support or does something additional need to be initiated?

Usually, information about normal grief reactions may help couples to understand their emotional reactions. It helps them to gain more control over what happens to them. It might also contribute to early identification of pathological grief reactions and depression.

Even if a next pregnancy is highly desired in many cases, women and their partners experience high levels of stress and concern—at least at the beginning of a next pregnancy and until the anomaly, diagnosed during the last pregnancy, could be ruled out. More frequent controls should be offered at the beginning, but antenatal care should also aim at normalizing the perception of this pregnancy, and strategies to reduce anxiety should be introduced.

5.7 Critical Reflection and Conclusive Remarks

Even if women and couples get all the information in advance, they will never be prepared when they are confronted with a positive result of a prenatal test. In such situations pregnant women have to make irreversible decisions with a high impact on their life, as well as on the life of their partner and of the future child.

Physicians have to counsel women and their partners as well as possible by providing them with information, not only once but also repeatedly. They have to be able to talk about these delicate ethical issues, which implies that they have to be aware of their own attitudes and how those could interfere with the decision-making process of the couple.

Tips and Tricks

- To better guarantee that information is not only given in a comprehensive way but also adapted to the patients' needs and current emotional condition, it is recommended to follow or at least orientate on checklists (Table 5.7).
- Under high levels of distress, information provided is difficult to process and difficult to remember. It is, therefore, important to give patients the opportunity to make additional appointments in case of questions and also to give information in written form.
- Decision-making should be participative (shared decision-making): This implies a mutual exchange between the physician and the patient and her partner. The expert presents options and their advantages and disadvantages. The patient can question them and bring in her measures of value.
- When pregnant women/couples have to decide whether to carry out pregnancy or to have an abortion, they generally need support as follows:
  - In a first step, the measures of value have to be made aware: "What is the significance of disability?"
  - Then the options and scenarios should be considered together, each for carrying out and terminating pregnancy: "Which are the consequences (emotionally, behaviorally, from further perspectives)?" "Which are the strains and which are the resources (crisis of life)?"
- After a termination of pregnancy (e.g., for trisomy 21), at least one visit at the institution where the termination of pregnancy was performed should be offered to the patient/couple concerned.

- Information about normal grief reactions may help couples to understand their emotional reactions. It helps them to gain more control over what happens to them. It might also contribute to early identification of pathological grief reactions and depression.
- Note that during the following pregnancy, women and their partners experience high levels of stress and concern. More frequent controls should be offered at the beginning, but antenatal care should also aim at normalizing the perception of this pregnancy, and strategies to reduce anxiety should be introduced.

Test Your Knowledge and Comprehension

1. Nowadays the noninvasive prenatal (blood) test (NIPT) replaces chorionic villi sampling or amniocentesis for diagnosis of trisomy 21.
   (a) True
   (b) False
2. Trisomy 21 is the most prevalent numeric or structural chromosomal aberration.
   (a) True
   (b) False
3. If the nuchal translucency is within normal limits, an elevated risk for trisomy 21 is excluded.
   (a) True
   (b) False
4. To provide thorough information and to counsel properly previously to any prenatal testing are questionable, as only a small percentage of couples are confronted with a positive result and, thus, all other couples might be alarmed and distressed vainly.
   (a) True
   (b) False
5. For a good mourning process after a second trimester termination of pregnancy, it is absolutely necessary that parents say goodbye to the child by taking him/her in the arms.
   (a) True
   (b) False
6. The first trimester risk assessment combining the nuchal translucency with the biochemical markers PAPP-A and free β(beta)-hCG as well as the age of the pregnant woman is constructed to be positive in about —— % of cases.
   (a) 0.5 %
   (b) 5 %
   (c) 15 %
   (d) 40 %
7. In many countries abortions are induced no longer than until …… weeks of gestation.
   (a) 18
   (b) 34
   (c) 24
   (d) 28

8. About —— % of all congenital anomalies are of unknown etiology.
   (a) 20 %
   (b) 90 %
   (c) 70 %
   (d) 50 %
9. In the case of prenatal diagnosis, the decisions that have to be made mostly depend on individual estimation and attitudes of pregnant women and couples concerned; thus, they can be characterized as ——————
   (a) Well informed
   (b) Preference sensitive
   (c) Evidence based
   (d) Case sensitive
10. The risk of inducing a miscarriage when performing an amniocentesis or chorionic villi sampling is —— %.
   (a) 5–8 %
   (b) 0.1–0.2 %
   (c) 0.3–1.0 %
   (d) 10–15 %

Answers

1. False
2. True
3. False
4. False
5. False
6. b
7. c
8. d
9. b
10. c

References

1. Patterson D. Molecular genetic analysis of down syndrome. Hum Genet. 2009;126(1): 195–214.
2. Weijerman ME, de Winter JP. Clinical practice. The care of children with down syndrome. Eur J Pediatr. 2010;169(12):1445–52.
3. Lammens M, ten Donkelaar HJ, van Vugt J, van Noort G, Willemsen M, Hamel B. Causes of congenital malformations. Clinical neuroembryology. Berlin/Heidelberg: Springer; 2006. p. 97–143.
4. Alfirevic Z, Sundberg K, Brigham S. Amniocentesis and chorionic villus sampling for prenatal diagnosis. Cochrane Database Syst Rev. [Review]. 2003;3:CD003252.
5. Scott F, Peters H, Boogert T, Robertson R, Anderson J, McLennan A, et al. The loss rates for invasive prenatal testing in a specialised obstetric ultrasound practice. Aust N Z J Obstet Gynaecol. [Comparative Study]. 2002;42(1):55–8.
6. Gasiorek-Wiens A, Tercanli S, Kozlowski P, Kossakiewicz A, Minderer S, Meyberg H, et al. Screening for trisomy 21 by fetal nuchal translucency and maternal age: a multicenter project in Germany, Austria and Switzerland. Ultrasound Obstet Gynecol. 2001;18(6):645–8.

7. Kagan KO, Wright D, Baker A, Sahota D, Nicolaides KH. Screening for trisomy 21 by maternal age, fetal nuchal translucency thickness, free beta-human chorionic gonadotropin and pregnancy-associated plasma protein-A. Ultrasound Obstet Gynecol. 2008;31(6):618–24.
8. Tercanli S, Holzgreve W, Batukan C, Gerber A, Ermis H, Miny P. Screening for aneuploidy by first trimester nuchal translucency measurement: results from a prospective trial including 1980 cases in a single center in Switzerland. Ultraschall Med. 2002;23(1):22–6.
9. Wong BC, Lo YM. Cell-free DNA and RNA in plasma as new tools for molecular diagnostics. Expert Rev Mol Diagn. [Research Support, Non-U.S. Gov't Review]. 2003;3(6):785–97.
10. Benn P, Cuckle H, Pergament E. Non-invasive prenatal diagnosis for down syndrome: the paradigm will shift, but slowly. Ultrasound Obstet Gynecol. 2012;39(2):127–30.
11. Chitty LS. Ultrasound screening for fetal abnormalities. Prenat Diagn. 1995;15(13):1241–57.
12. Beauchamp TL, Childress JF. Principles biomedical ethics. 5th ed. Oxford: Oxford University Press; 2001.
13. WHO. Congenital anomalies. 2014; Available from: http://www.who.int/mediacentre/factsheets/fs370/en/.
14. Gotzmann L, Romann C, Schonholzer SM, Klaghofer R, Zimmermann R, Buddeberg C. Communication competence in ultrasound examination in pregnancy. Gynakol Geburtshilfliche Rundsch. 2001;41(4):215–22.
15. Miller WR, Rollnick S. Motivational interviewing: preparing people for change. New York: Guilford Press; 2002.
16. Rogers C, Farson R. Active listening. In: Kolb D, Rubin I, MacIntyre J, editors. Organizational psychology. 3rd ed. Englewood: Prentice Hall; 1979.
17. Tschudin S, Holzgreve W, Conde N, Alder J, Bitzer J, Tercanli S. Pregnant women's assessment and level of knowledge of prenatal counseling. Ultraschall Med. 2009;30(2):157–62.
18. Tschudin S, Huang D, Mor-Gultekin H, Alder J, Bitzer J, Tercanli S. Prenatal counseling–implications of the cultural background of pregnant women on information processing, emotional response and acceptance. Ultraschall Med. [Comparative Study]. 2011;32(Suppl 2):E100–107.
19. Hughes P, Riches S. Psychological aspects of perinatal loss. Curr Opin Obstet Gynecol. 2003; 15(2):107–11.
20. Kersting A, Wagner B. Complicated grief after perinatal loss. Dialogues Clin Neurosci. 2012; 14(2):187–94.

Parents Who Lost Their Baby: Guiding the Mourning Process in Stillbirths and Pregnancy Terminations

6

Denise Defey

6.1 Introduction and Aims

"Perinatal loss" refers to the psychosocial consequences of a pregnancy or birth ending in the death of the fetus or newborn. This loss is a devastating experience for parents, families, and, often, healthcare staff as well. The aim of this chapter is to provide both information and guidelines for clinical management of the psychosocial issues involved.

6.2 Definition in Lay Terms

Perinatal loss is a term used to bridge the gap between the biomedical aspects of the subject, on the one hand and, on the other, the psychosocial issues involved when pregnancy or birth ends with the death of the fetus/newborn. This event is always a devastating experience.

6.3 Didactic Goals

After reading this chapter you are expected to be able to:

1. Acknowledge the risks involved in unresolved grief after perinatal loss
2. Become sensitive to parents' emotional needs as it concerns healthcare
3. Distinguish between normal and abnormal psychosocial consequences of perinatal loss

D. Defey
Department of Obstetrics, University of Uruguay, Maternity Hospital Uruguay, Montevideo, Uruguay
e-mail: denisedefey@vera.com.uy

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_6

4. Know how long normal mourning lasts
5. Manage and use relevant information concerning the clinical features expected in this type of mourning process
6. Have a clear concept of the underlying foundation for the guidelines for clinical management presented
7. Manage clinical obstetric interventions during pregnancy, labor, delivery, and postpartum, taking into account and handling adequately the psychosocial issues involved
8. Recognize in yourself and other colleagues the emotional aftermath involved in clinical management of perinatal loss, developing protective measures for yourself and others

Case History

Maria Maroon, 32 years old, is a nurse, happily married, and mother of two preschool female children. Pregnant for the third time and highly expectant of a baby boy, she stops feeling fetal movements at week 22. Though her family insists that she consults the emergency department, she stays at home for several long days, absent-minded and singing nursery rhymes while she caresses and speaks to her unreactive fetus. Finally taken to the hospital after several days, she is delivered from the stillborn. The delivery is complicated by severe postpartum hemorrhage, losing 4 l of blood. Therefore, she is admitted to the intensive care ward, remains hospitalized in a severe physical condition for several days, and finally recovers. Later on, she recalls her experience of being unable to accept reality and the need to deny the loss of this child, so highly wished for and expected, even at the cost of her own health. For weeks, she remains distant from her children's care, and it is only after what she recalls as "endless hours" of conversation with her husband that she manages to overcome the loss. An essential component in their adaptation process is the acknowledgment of the baby boy as a lost "child," as valuable and precious as their other two children. This recognition of her lost son as a true person is in sheer contrast to the reactions of the hospital staff. They spoke about her son as a "product" to be expelled from her body and gave her medication to suppress her grief. Even some family members and colleagues tried to distract her from her sorrow by disregarding the lost fetus as a person, as her son. A couple of years later, she volunteered to help women undergoing stillbirth and, finally, gave birth to a healthy child.

6.4 Facts and Figures: Definitions, Classification, and Prevalence

6.4.1 Definitions

Perinatal loss is the term used to refer to the emotional and psychosocial consequences for the mother, her family, and relations of the loss of a child in the second or third trimester of pregnancy or in the first week after birth. These have been

termed as "perinatal bereavement" and generate multiple risks for the woman's mental health as well as for that of her subsequent child(ren).

Perinatal mortality is defined by the World Health Organization (WHO) as "the number of stillbirths and deaths in the first week of life" [1]. Although other definitions also are used, WHO defines the perinatal period as commencing at 22 completed weeks of gestation (154 days) and after seven completed days after birth.

Due to the varying definitions and the extreme variations among countries (and even within them, according to financial and socio-sanitary status), the WHO has not produced an estimated prevalence figure, though perinatal mortality is considered a key criterion to assess healthcare status and, furthermore, the degree of global development of a given country.

6.4.2 Historic Overview

Clinical management of perinatal loss has changed in the last decades in most Western countries, especially in those with adequate healthcare standards and in those where psychosocial issues are normally included in standard perinatal care. From the 1980s onwards, more and more attention was paid to the deleterious effects of perinatal loss, especially when followed by inadequate healthcare management [2–7]. Appleby, for instance, showed an increase of 600 % in suicide rates after perinatal loss [8], and Condon pointed out a significant increase in psychiatric hospitalization and consequences for children born after the loss [9]. At that time, in many countries, standard care involved cesarean section with general anesthesia and lack of any information about the dead child (including gender, weight, physical conditions, or estimated/assessed cause of death).

Furthermore, normal grief reactions were treated as pathological side effects; clinicians tended to provide antidepressants and sedatives to suppress desperation, pain, and mourning, also "prescribing" an immediate substitute pregnancy and a recommendation to forget this "unimportant event." Fathers were obviously not expected to undergo significant mourning for an unborn or very small child. Parents were advised to give the next child the same name as they had chosen for the lost child [10]. "Deny and forget what happened, look at the future" was the motto that added insult to injury. The iatrogenic effect of this motto manifested itself not only to the parents but also to the children yet to come, as shows in terms as the "replacement child syndrome" [3, 5] or the "vulnerable child syndrome" [4], which often appeared after neonatal death or when only one of a twin survived [11]. Other authors referred to the psychological consequences in terms of "black hole" or a "conspiracy of silence" [12], a "nonevent" [13], and "an overlooked catastrophe" [2].

What all these pioneering papers had in common was their alarming function, which caused a major change in the way hospital staff managed perinatal deaths. Both in the Northern Hemisphere as in Latin America, organizations such as the WHO or World Association of Infant Mental Health (WAIMH) produced the first guidelines for clinical management of perinatal death [14, 15].

At present, most hospital and community services use this kind of guidelines, which are also in line with state-of-the-art theoretical, clinical, and empirical developments on the importance of early attachment between parents and infant on the one hand and the need to emphasize prevention in mental healthcare, such as favoring normal grief processes, on the other.

It has even been stated that it is no longer ethical to do research on clinical management, which is so obviously in line with overwhelming evidence about the relevance of attachment and healthy grief processes by having, for example, parents randomly assigned to viewing their dead infant or not viewing it [15]. This lack of randomized clinical trials (a measure taken to protect parents) has, on the other hand, unfortunately led clinicians and researchers to revise management or develop guidelines based upon inconclusive evidence, such as Hughes et al.'s 2002 paper [16], which provided statistically nonsignificant data about posttraumatic stress disorder (PTSD) after viewing the dead child, an aftermath that was also disconfirmed in a later paper by the same research group [17].

In recent years, some clinical developments, such as the concept of "complicated grief," initially put forward by Boelen and van den Bout in 2008 [18], have been applied to perinatal loss [19], thus giving more sound ground to clinical observations about the unique character of the mourning process after perinatal death. This is especially important in order to prevent confusion with a concept that became quite popular in that decennium: the posttraumatic stress syndrome (PTSS), and therefore avoid clinical management which, upon inaccurate assessment of PTSD, may hinder the development of this very special type of mourning process.

Attention has been also called on the risk of what has been termed as "absence of mourning," especially after the loss of an "absent child," as it happens in stillbirth [15].

6.5 Etiology and Pathogenesis

In order to manage the consequences of perinatal loss, one has to understand the basic psychological principles of mourning. Mourning is a normal psychological reaction to the death of a beloved one, which always involves to some extent being deprived of something personal, which is carried away by whomever is lost. This process—which is the equivalent of a mental level of digestion—implies working through the loss, i.e.:

1. Accepting the reality of the loss, admitting that something terrible has happened, which is irreversible, on a cognitive level
2. Experiencing the pain of the loss on an emotional level
3. Adapting to the new situation and (slowly) returning to daily life on a behavioral level

If done successfully, some fundamental aspects of the loss become part of the person's inner world or strengthen the self by integrating parts of what is lost. The

person recognizes thoughts and feelings about the lost person as normal and valuable but is no longer overwhelmed by them. This process takes time (estimated at 6–12 months in normal conditions) and is characterized by reactions that may take place one after the other or overlap at different moments of the process. This pathway leads, finally, to acceptance and reorganization. However, it is essential to understand that, unlike depression, the whole process means not only pain and sorrow but also a struggle: against reality of the loss, against guilty feelings, against collapsing into depression, and "dying" alongside the lost person.

Mourning itself is often preceded by shock, which may last minutes, hours, or, sometimes, even days. The person is not able to react in any way and a sort of "blackout" appears, where no voluntary actions (let alone decisions) may be undertaken. In many countries, informed consent or even signed documents under such a state are not considered legally valid. In medical practice, this reaction may mislead attending personnel either into thinking that the person is mentally disabled or, the opposite, that he/she has overcome totally and wisely the traumatic situation in a few minutes. Asking parents to make decisions under such conditions about themselves (e.g., sterilization) or their infant (e.g., autopsy), even if legally valid, is neither wise nor sensible, as parents may regret for years decisions that often cannot be reversed later.

After shock has been overcome, the human mind still needs time to come to terms with painful facts, and therefore denial and dissociation delay real, deep perception of the loss. Denial implies not fully accepting the reality of the loss, even if it may seem to be so, since there is a cognitive acknowledgment of reality. This lack of emotional reactions may induce staff to believe either that the parents do not care about their child or that the loss has been readily accepted and overcome.

Dissociation, though normal under extreme circumstances, leads the person to pragmatic reactions totally devoid of affection, which may induce observers to think of emotional detachment and lack of involvement in the loss or, alternatively, that the traumatic situation has generated an abnormal reaction, equaled to psychiatric pathology.

In normal mourning, both denial and dissociation fade away progressively, giving way to full perception of the loss. This induces parents, their relatives, and staff to believe that, as time passes, the process becomes worse, since increasing awareness leads to increasing pain and depressive ideas and feelings, with the phantom of suicide always hovering over the scene.

Since mourning is also a struggle to survive the loss and its saga, hostile reactions often appear, which is especially relevant in this case, since it may lead to legal action against medical staff. This reaction is midway between denial ("I will win the struggle with death if I win the trial"), on the one hand, and depression, with its saga of guilty feelings, on the other ("He is to blame, not me"). The more guilty the person feels, the stronger the need to blame others.

Finally, reality wins; the loss no longer can be denied, and adaptation finally comes after this long period (months), in which the person "travels" to an inner world filled with memories and an inner presence that helps forget the absence of the loved one in the real world. Anniversaries and meaningful dates provide not only

memories but also the risk of relapse into the early signs of mourning, with the added risk of solitude and misunderstanding, since people around may not remember dates. This brings along increased risk of suicide, biological fragility, and, last but not least, the start of unnecessary psychiatric follow-up (in the wrong belief that time passes and things go not for the better but for the worse, often confusing complicated grief processes with PTSD).

6.5.1 Mourning After Perinatal Loss

All the aforesaid becomes especially intense, dramatic—and dangerous—when the loss involved is that of an infant, furthermore a newborn, furthermore an unborn child. This gradient of drama and risk is due to the fact that the early loss of a child stirs symbiotic feelings. The lack of a personal "social" history of the child makes it hard for parents to build his/her identity and memories upon this [20–23].

Mourning becomes extremely difficult when there is no clear distinction between the person who suffers the loss and the one who dies, be it due to symbiotic feelings or biological features. In stillbirth, both factors coincide. Normal psychological processes preparing for bonding and attachment during pregnancy make the mother feel all at one with her fetus who, at the same time, is still a part of its mother's body [24, 25].

Besides, the postpartum period is a time of extreme sensitivity in order to prepare the mother to protect and fully attach to the newborn child, conforming to what Winnicott described as primary maternal preoccupation [26]. This inevitably leads to extreme vulnerability, and, when the infant dies, the mother remains at extreme risk of psychological collapse, which may in turn lead to a psychiatric breakdown or even suicide, which has been proved to increase after the loss of a child [9, 27–30]. In the author's experience, religion may play an important role here in the prevention of suicide. Because in many religions suicide is punished with hell, all hope of reunion with the lost child in heaven is lost, so many parents feel obliged to carry on despite their enormous burden.

6.5.2 Complicated Grief

Perinatal loss often brings along complicated mourning. Not only the real person—the unborn or very young child—is mourned; many other losses are involved: the imaginary child created by the parent's minds [31], the child-to-be in parents' plans and dreams for the future, pregnancy itself as a state, and the mother's self-esteem, especially in stillbirth, where her body has been the scenario of her infant's death [14].

Therefore, the expected time of 6–12 months is too short, and the evolution of mourning gets entangled with biosocial conditions of the puerperium. The first month, which overlaps with primary maternal preoccupation, is marked by intolerable feelings of perplexity, bodily loss (similar to those felt in mutilation), and

emptiness. In a time meant to be devoted to nesting, caring, and sharing, mothers feel disoriented, while they often also carry the burden of their body producing blood and milk and frequently also wounded by scars of surgery or episiotomy. The urging need to hold and care for a child may lead parents to try to get pregnant again shortly after the loss or promptly adopt another child, be it legally or illegally.

The following months may be filled with nostalgia, rage, impotence, and loss of meaning. Meaningful dates (such as the expected due date or Christmas) arouse the same maddening sensation of the first days, accompanied by solitude, lack of understanding, and even pressure and criticism from the surrounding others, who underestimate the dimension of the loss and the magnitude of pain and desperation. If we do not take into account that perinatal loss, with its enormous emotional and psychosocial consequences for all involved, is a major life event that requires perinatal bereavement, we can wrongly define any disturbance of this adaptive process as pathological. The fact that an unborn, a newborn, or a very young infant is the object of mourning makes this adaptation process especially intense, dramatic, and thereby extremely vulnerable for "pathological" disturbances. This fits well with the description of complicated grief, which is characterized by searching and yearning, preoccupation with thoughts about the deceased, crying, disbelief about the loss, being stunned by the death, lack of acceptance of the loss, and impairment of global functioning, mood, sleep, and self-esteem [19, 32].

The following pregnancy is a time of heightened anxiety and medical risks as well as demand for support from attending staff [33–38]. Though research shows that parents do not wish to be given advice (just information) about the adequate time for the next pregnancy [39], clinically it is clear that some time is needed for parents to go through the loss before undergoing a new pregnancy, which should never be "prescribed" to calm down anxiety, replace the lost child, or subdue emotional involvement with the loss.

Some psychosocial risk factors have been identified for complicated grief after perinatal loss: lack of social support, preexisting relationship difficulties, the absence of surviving children, ambivalent attitudes, or heightened perception of the reality of pregnancy [19]. Some medical conditions have been shown to lead to a high prevalence of both complicated grief and psychiatric symptoms, such as pregnancy termination due to fetal malformation, intense ambivalence or attempted abortion, and previous psychopathology in the mother [19, 40–43].

Consequences of perinatal loss on the following child have been extensively researched [10, 44]. Risk factors for replacement child syndrome in the child born after the loss are specially relevant in the situations in which parents (especially the mother) do not get to view and give a name to their stillborn or dead newborn child and getting pregnant before a minimum time of 6 months after the loss [3, 5]. Having lost a twin sibling or being born after the previous child underwent severe pathology, often with neonatal intensive care unit (NICU) hospitalization, makes the following child prone to undergo what has been termed the vulnerable child syndrome [4], which often induces parents to perform excessive medical consultations, in which medical staff may take wrong clinical decisions following parents' distorted report of the child's condition.

Mothers and fathers do not take the same time to mourn or follow the same path, which brings added fear of loss by separation, as fathers often lack empathy for the time mothers need to mourn their multiple losses or misunderstand the way they mourn, often considering it masochistic or risky for their mental health. Unequal or incongruent grief between father and mother has been shown to increase both the risk of complicated grief as that of couple separation [19, 45]. On the other hand, deleterious consequences for other members of the family have been described especially after unresolved perinatal bereavement [46].

A father's mourning is often suffocated initially due to external (and internal) pressure to protect his wife, while he may flee into overwork in order to forget/avoid depressive feelings, which tend to appear later when the wife is able to offer some support [14, 45]. According to the author's clinical experience in the field, sexual life is often affected, both from depressive feelings in the mother and genitalia being associated with the painful situation surrounding birth instead of pleasure and enjoyment.

6.5.3 Grief in Perinatal Loss of One (or More) Twins

An issue of special concern is the perinatal loss of a twin [47]. This is often what today could be called "an overlooked catastrophe," since staff working in neonatal intensive care units often forget the lost child and only care for the surviving (and often at-risk) child. Besides that, relatives and friends tend to underestimate parents' feelings, believing that if one child is alive this will suffice to compensate the loss. In fact, parents face almost impossible simultaneous tasks: attaching and detaching, welcoming and letting go, and receiving congratulations and condolences. Frequently, parents split these processes and one attaches to the living child, while the other mourns the lost one. Hopefully, they will take turns in each role; otherwise, pathological grief may take over [11].

Assisted reproductive techniques have increased dramatically the amount of losses in multiple pregnancies, being the misnamed "embryo reduction" (feticide, in fact), a practice that is usually not addressed by researchers and clinicians as to its devastating consequences for parents. Though literature on the subject is scant, it describes panic attacks, and it is clinically sound to believe it has deleterious effects for the surviving children as well [48].

6.5.4 Grief in Late Pregnancy Termination

In perinatal loss due to late pregnancy termination, complicated grief or the development of psychiatric symptoms is more frequent than in perinatal loss due to natural death of the child [19, 42]. Guilty feelings involved may become intolerable, and research [49] has shown that decisions taken without proper reflection and agreement between the parents, as well as lack of pity for the unborn child (which may be considered as a nuisance in parents' lives), are the main risk factors for

complicated grief, couple discord, and breakup, as well as psychiatric pathology in parents, especially mothers.

6.6 Specific Diagnostic Aspects

6.6.1 Assessment of Stillbirth

Stillbirth is usually assessed by ultrasound scanning. This may be during a routine scan or after a period in which lack of fetal movements has been experienced by the pregnant woman.

It is advisable to scan another time, leaving some hours or a day between one and the other scanning. This may give time for the woman and her partner to go back home, talk to her other children and/or relatives and friends, set home and childcare issues, pick up adequate clothing for herself, etc. All these issues are relevant not only on practical grounds but help to diminish the feeling of chaos (and therefore risk of dissociation) generated by this unexpected and generally abrupt ending of pregnancy. Furthermore, this double scanning gives her subjective time to minimally "come to terms" with the news, leaving room to normal shock and denial/dissociation mechanisms after traumatic events and, therefore, helping adaptive mechanisms to emerge and be put into action during the intense days to come during labor, delivery, and the puerperal period. Furthermore, this time allows for other members of the family and/or the child's father to be present at the second confirmatory ultrasound session and support the mother through delivery and the subsequent days, providing also practical help for hospitalization.

6.6.2 Neonatal Death

In neonatal death, there are often difficulties stemming from a combination of parents' vulnerability and healthcare staff difficulties in handling emotional issues involved. This sometimes leads staff to stimulate what has been called "anticipatory grief" asserting that the infant will die. This may have devastating effects. If the child in fact dies, it may complicate mourning when parents feel guilty later for having given up caring for the child while it was still alive, something which parents often do in order to avoid intolerable sorrow. If the child finally survives, it has been found [50] that having undergone this anticipatory grief affects the quality of attachment with the infant. Furthermore, the fact that parents may give up participating in its care and providing it with emotional support may, in fact, increase the risk of death for that given newborn.

Delivering information to parents concerning either stillbirth or the severe condition and later death of their newborn child is a difficult process whose traumatic effect will be remembered for years by parents and has been shown to increase health risks for medical staff [13, 14]. Adequate care involves providing information in a private setting, giving parents adequate sitting time, and providing time and

privacy for primary reactions both in the interview as well as after the news has been delivered. Showing respect for the dying or dead child as a person, however ill, malformed, or premature it may have been, is considered paramount by parents.

6.6.3 Extreme Prematurity

A special reference should be made to newborns who die due to their extreme prematurity. Parents are often asked for informed consent on the decision of whether to provide invasive care or not in the worst moment: immediately after birth, if the decision is urgent. This may lead to one parent answering, either because the mother may not be in a physical condition to do so or simply because one of them is more introverted or needs a longer time to make these hard decisions. Depending on later events (e.g., a severely disabled child or its death), this may put at stake the stability of the family in the years to come, which may be filled with discord and reproaches over the quick decision. Parents must be given time to make a joint decision privately, whenever possible, before the birth of an extremely premature infant. Even a short period of time to discuss this may protect the couple and family's continuity over time.

6.6.4 Prenatal Detection of Malformations

In the case of prenatal detection of malformations that may or will eventually lead to pregnancy termination, providing repeated consultation (which may happen at different moments of the same day in families living far from healthcare centers) is essential to provide parents time to discuss termination between them and with other members of the family or close friends, as well as with professionals they trust. The fact that it is a consensus decision is paramount to the parents' relationship in the years to come. Therefore, healthcare staff should be careful about the way the clinical interview is conducted, giving clear messages that the opinion of both parents is essential. This should be expressed both in verbal and in nonverbal communication. Healthcare professionals need to pay attention to nonverbal details, such as putting the right number of chairs in the meeting room (also a chair for the partner) or which partner is addressed at by gestures during delivery of information concerning the assessment of malformation and decisions to be made.

6.7 Specific Therapeutic Aspects

In stillbirth, clinical management must fulfill the essential aim of granting the foundations for normal grief. This means that the parents must be provided with perceptual evidence of the child's separation from the mother's body and the fact that it is no longer alive. Therefore, the preferable way of delivery is a vaginal delivery instead of a cesarean section. Some studies based upon small samples and providing

inconclusive evidence have questioned the long-term beneficial effects of viewing the stillborn child [16]. However, clinical experience in the author's maternity hospital for more than 30 years with several thousands of mothers as well as the conclusions of experts (e.g., Zeanah [15] and Klaus and Kennel [6]) makes it clear to us that delivery of a stillborn must be treated naturally and without interfering with the mother's (and father's) spontaneous reaction to see (or not see) their dead infant. We believe that the mere fact of asking introduces a distortion, subtly suggesting that there might be something that they should better not see. On the other hand, evidence seems to become conclusive regarding holding the dead infant, which has been significantly associated with PTSD and marital discord [51].

Some neonatal deaths occur immediately after delivery, which makes it unclear for parents whether the child was stillborn or died during or very shortly after delivery. In our experience, the staff will often tell them that their child was stillborn. This may be done out of goodwill and following the belief that this will relieve parents' sorrow. The staff should be very careful not to do that. On the one hand, it does not alleviate psychological pain, since mothers usually feel more guilty when their child dies inside their bodies. On the other, this may increase risk for future pregnancies, since it may deviate research into other causes of the death, which was wrongly described as a stillbirth.

Be it by stillbirth or early neonatal death, when parents lose a child, some clinical management issues that may seem irrelevant for the staff may be essential for parents: keeping a memento (such as a picture of the baby, hand- and footprints, a picture of an ultrasound scan, etc.), giving the child a name, performing religious rituals, etc., may soothe desperation and emptiness. When the child dies after birth, sharing the last moments, being able to hold the child, and have contact with it both before and after death not only provide memories but also the chance to offer the child some of the affection and care that was in waiting. In all cases, perceiving a respectful and warm attitude from the staff toward the child—no matter how small, no matter how severely malformed—is repeatedly pointed out by parents as what could be called "essential spiritual care" [52, 53].

In all cases, providing at least approximate or estimate information about likely causes of death may relieve the mother from believing that it has been merely her fault. In this respect, wording such as "neonatal depression" or "fetal distress" are to be carefully avoided, since they increase mothers' feelings of guilt and the intolerable sensation that their child was not able to enjoy life even prenatally.

6.7.1 Funeral Rituals and Burial

The issue of funeral rituals and burial is controversial. Although they undoubtedly constitute part of parents' rights, they may turn out to be overwhelming, and many mothers have reported feeling awkward in crowded funerals with their breasts full of milk and pain they cannot speak about. Other mothers have described leaving their longed-for child in a cemetery far from their living place in a cold, impersonal burial place as almost equally traumatic as the loss. Lately, many parents

choose to keep their child's ashes at home, which provide some consolation for their wish to provide warmth and care as they had dreamed of. It is important that parents get the possibility to choose the rituals that suit best with their background and needs.

6.7.2 Information to the Parents

6.7.2.1 How Long Does Mourning Last? Is Formal Psychotherapy Needed for All Cases of Perinatal Loss?

An essential task for staff is informing mothers, fathers, and other relatives about the expected time for the mourning processes to evolve, as well as reactions expected in anniversaries or other special dates. It is essential to include a clear reference to the different features, paces, and length of mothers' versus fathers' mourning processes.

6.7.3 Information to Siblings

It is also necessary to confirm that older children have been informed about the death, since it has been repeatedly informed that risk for their mental health does not lie so much in the loss of a sibling they have had no relation with but in the total lack of information about the death. They may be filled with fear at children "vanishing" in the family, confused (and often guilty) at their parents' sorrow and tears, and burdened by fantasies that fill them with anguish, such as suffering the same disease that caused their sibling's death.

In some countries, older siblings are allowed in NICUs. In this way, they might have met their sibling already before it had died, supporting the reaction after the death. Also grandparents may be offered to meet their newborn grandchild.

Only in cases of complicated mourning or lack of evidence of normal grief processes, as in the case of parents with previous psychopathology, formal psychotherapy should be prescribed. Both research and clinical practice [54] show that normal grief first of all needs company, not treatment. Mostly, in parents undergoing losses, support in some special times, such as around expected date of birth and anniversaries, is sufficient [55]. Psychotropic medication should be used in a generous way to protect sleep, especially in the first weeks and, eventually, for some special anxiety-ridden moments but not to hinder normal sorrow and anxiety.

6.8 Critical Reflection and Conclusive Remarks

After first being detected as an "overlooked catastrophe," perinatal loss today has received proper, empathic care in most healthcare settings. Its relevance has been well stated, research has been conclusive and clear, and therefore, guidelines protect

both parents and staff from the strain of one of the most—if not the most—stressing outcomes in perinatology.

What remains to be highlighted and studied further are some still overlooked dramas, such as the aftermath of termination due to fetal anomaly, second and third trimester voluntary termination of pregnancy, and the loss of one or more twins (especially due to feticide).

Tips and Tricks

Guidelines for Clinical Management of Perinatal Loss

Concerning medical management:

1. Repeat confirmatory scanning of stillbirth.
2. Do not manage stillbirth as an urgency; give parents time to settle private/family affairs, and put some order in their lives before delivery.
3. Before birth of an extremely premature infant, give parents time and privacy to discuss and take decisions together as to management of their child's health situation.
4. In stillbirth, avoid unnecessary cesarean section or sterilization, while using all necessary analgesia to protect mother from unnecessary labor pain.
5. In neonatal death occurring immediately after birth, do not register it in clinical records or report it to parents as stillbirth, to avoid misleading research into causes of death.
6. Consider that all informed consent immediately after disclosure/death may not reflect parents' real needs or rights, since they will be under shock and unable to make decisions.
7. Stimulate parents to have an autopsy performed.
8. Provide psychotropic medication, even without being asked for it, to protect sleep, especially in first days.
9. Manage hospitalization of mother in order both to protect privacy and not disqualify her identity as a mother (e.g., placing her in another area of the hospital).
10. In stillbirth, discuss with parents the length of stay of the mother in the hospital after delivery.
11. Avoid suppressing normal grief by not providing antidepressants; prescribe, if necessary, tranquilizers only to be used in moments of extreme anguish.
12. Make sure routine puerperium medical follow-up of the mother is performed (preferably in a setting different from that of her child's death).
13. Make sure parents are offered the opportunity to take over the proceedings of burial and other death rites, but remember this may be extra stressful for them. Do ensure the child's body is respectfully dealt with and parents know its burial place. For parents living in distant places, favor a burial place they can visit often.
14. If parents wish to keep the ashes at home, do not consider this complicated or pathological grief but a consequence of their mental preparation to take care of their child.

Concerning mourning:

1. Favor and control evolution of normal mourning processes by follow-up at key moments: first week, first month, third month, and special dates (expected date of birth, anniversaries, etc.).
2. Pay special attention to the timing of parents' reactions according to time elapsed since death.
3. In high-risk pregnancies and neonatal death, avoid stimulating anticipated mourning, even in extremely severe cases, by mentioning likelihood, not certainty, of a fatal outcome.
4. Pay special attention to subdued mourning reactions, especially in fathers.
5. Validate normal aspects of grief, such as guilty feelings, as proofs of concern about the child and not something they should not feel.
6. Make sure older children have been informed about their sibling's loss.

Concerning parents' subjective experience of the loss:

1. Pay special attention to respecting parents' (or mother's) wish to view their dead infant, even if not openly expressed, by dealing with it respectfully and naturally (in neonatal death, also while it is alive).
2. If parents or other relatives have been unable to see the dead child, build mental representations of it by providing information that is both realistic and soothing.
3. In order to make a decision as whether or not to recommend parents to view a malformed stillborn child, remember that some medical conditions (such as cardiopathy, kidney agenesia, hydrops fetalis, macrosomia, PEG, or some conjoined twins) are not visually traumatic to parents, while less severe conditions (such as cleft palate or gastroschisis) may shock them.
4. In severely malformed newborn infants who are likely to die, consider possibility of parents viewing them in a protected way (e.g., covering exposed organs in gastroschisis).
5. Favor giving the dead child a name to avoid replacement child syndrome.
6. If possible, offer religious assistance for death rites.
7. Shortly after disclosure and/or death, provide general information as to likeliness of medical cause of death to avoid mothers' blaming themselves.
8. Discuss with parents and other relatives their beliefs about cause of death, emphasizing the lack of reliability of most circulating information about maternal stress affecting fetal welfare.
9. Prevent complicated grief and disavowal of the child's existence/death by providing perceptual confirmation of the reality of the infant and its death (viewing, photographs, mementos, etc.).
10. Avoid terms such as "fetal stress" or "neonatal depression" that induce guilt and confusion in parents.

11. In cases of perinatal loss of a twin, do not disqualify parent's complicated feelings, and provide evidence of memory and respect for the lost child, granting mental health control for the surviving child(ren).
12. In so-called embryo reduction, do not disregard risk for mental health for parents and surviving child(ren); if all fetuses/infants die, consider it a mental healthcare priority.

Concerning subsequent pregnancy/infant:

1. Discourage immediate next pregnancy, to avoid increased obstetrical risk and replacement child syndrome (6 months' time being a reasonable minimum).
2. After stillbirth, emphasize differences between this pregnancy and the previous one.
3. After second or third trimester stillbirth, be careful about mother generating conditions for a premature birth (e.g., not complying with bed-rest) in the belief she will avoid repetition of stillbirth, especially taking into account that many persons believe the eighth month to be of greater risk than the seventh.
4. After neonatal death (especially of a twin), make sure this information is included in the next/twin child's clinical information, and stimulate the parents to have one family pediatrician to prevent vulnerable child syndrome.
5. Specially avoid fetal sex assessment (or emphasize its lack of accuracy), since errors may induce another mourning process (for the imaginary child, in this case) and reactivate the previous mourning, putting at stake both mother's mental health and bonding processes.

Test Your Knowledge and Comprehension

1. Initial reaction to perinatal loss is sadness produced by the immediate full perception of the loss and its relevance.
   (a) True
   (b) False
2. Posttraumatic stress disorder is the most frequent pathological consequence of perinatal loss.
   (a) True
   (b) False
3. Viewing the dead infant as well as keeping mementos of its existence helps to set the foundations for normal grief, making both the infant and the loss more real, as well as contributing to help the mother realize it is no longer part of her.
   (a) True
   (b) False
4. Parents should be advised to be pregnant again as soon as possible after perinatal loss.
   (a) True
   (b) False

5. Mourning over perinatal loss should be processed as in any other loss, since there is no reason to expect a high rate of so-called complicated grief.
   (a) True
   (b) False
6. How long can mourning over perinatal loss last within the limits of a normal reaction?
   (a) 3 months
   (b) 6 months
   (c) 1 year
   (d) 1 year, with some elements still expanding into the second year
7. In stillbirth, delivery should be considered as
   (a) An emergency to be performed promptly after assessment of intrauterine death
   (b) A medical act devoid of all consideration for psychosocial issues involved, which are to be dealt with later by mental health staff
   (c) A capital moment in the lives of the parents and the family as a whole, which requires that also medical staff take emotional issues into account both in making decisions and to the clinical management
   (d) A traumatic event, which is very likely to result in posttraumatic stress syndrome, therefore a cesarean section is indicated
8. The use of psychotropic medication after perinatal loss should take into account the following issues:
   (a) Antidepressants should be provided routinely in order to avoid grief and mourning.
   (b) Sleep should be protected, especially in the first days after the loss, and some kind of sedatives can be used at given moments.
   (c) No medication at all should be prescribed in all cases, since mourning is a healthy process.
   (d) Sedatives should be prescribed to all mothers in the 6 months after the loss.
9. Which are aspects that are important in viewing and touching the dead infant?
   (a) Parents should be advised not to do any of these actions since evidence is conclusive about its harmful effect.
   (b) Parents should not be allowed to touch or see their dead infant.
   (c) Delivery should be handled so that the dead infant is treated with respect and parents may feel free to act about it as they naturally feel.
   (d) Parents must be shown the dead infant, whether they want or not to view it, since this is essential for normal mourning.
10. Which mourning reactions can be expected after perinatal loss?
   (a) Parents may be in shock after confirmation of their child's death, so they should not be asked to make any kind of decision at that moment.
   (b) Parents who do not react immediately to the news of death may have cognitive problems or psychiatric pathology.
   (c) Parents may act in an unemotional way after confirmation of death, which is proof of their lack of interest in the child or its loss.
   (d) If parents wish to have another child immediately after the loss, this means they have overcome this loss.

Answers

1. False
2. False
3. True
4. False
5. False
6. d
7. c
8. b
9. c
10. a

References

1. World Health Organization. http://www.who.int/maternal_child_adolescent/topics/maternal/maternal_perinatal/en/.
2. Lewis E, Page A. Failure to mourn a stillbirth: an overlooked catastrophe. Br J Med Psychol. 1978;51(3):237–41.
3. Cain AC, Cain BS. On replacing a child. J Am Acad Child Psychiatry. 1964;5:445–56.
4. Green M, Solnit AJ. Reactions to the threatened loss of a child: a vulnerable child syndrome pediatric management of the dying child, Part III. Pediatrics. 1964;34(1):58–66.
5. Posnaski EO. The "replacement child": a saga of parental unresolved grief. J Pediatr. 1972;81:1160–5.
6. Klaus M, Kennel J. Parent-infant bonding. St Louis: C. V. Mosby; 1982.
7. Bourne S, Lewis E. Psychological aspects of stillbirth and neonatal death. An annotated bibliography. London: Tavistock Clinic; 1992.
8. Appleby L. Suicide during pregnancy and in the first postnatal year. BMJ. 1991;302(6769):137–40.
9. Condon J. Women's mental health: a "wish-list" for the DSM V. Arch Womens Ment Health. 2010;13(1):5–10.
10. Defey D. El nacimiento de un hijo luego de una perdida perinatal. In: Defey D, editor. Mujer y Maternidad. vol IV. Montevideo: Roca Viva; 1996.
11. Defey D. The psychosocial aftermath of the perinatal loss of a twin. In: Osofsky J, Fitzgerald H, editors. WAIMH handbook of infant mental health. New York: Wiley; 2000. p. 348–59.
12. Lewis E. Stillbirth: consequences and strategies of management. Adv Perinatal Med. 1983;3(6):205–24.
13. Bourne S. The psychological effects of stillbirths on women and their doctors. J R Coll Gen Pract. 1968;16(2):103.
14. Defey D, Diaz Rossello JL, Friedler R, Nuñez M, Terra C. Duelo por un niño que muere antes de nacer. Latin American Center of Perinatology (CLAP PAHO/WHO); 1985.
15. Zeanah CH. Adaptation following perinatal loss: a critical review. J Am Acad Child Adolesc Psychiatry. 1989;28(4):467–80.
16. Hughes P, Turton P, Hopper E, Evans CDH. Assessment of guidelines for good practice in psychosocial care of mothers after stillbirth: a cohort study. Lancet. 2002;360(9327):114–8.
17. Turton P, Evans C, Hughes P. Long-term psychosocial sequelae of stillbirth: phase II of a nested case-control cohort study. Arch Womens Ment Health. 2009;12(1):35–41.
18. Boelen PA, van den Bout J. Complicated grief and uncomplicated grief are distinguishable constructs. Psychiatry Res. 2008;157(1):311–4.
19. Kresting A, Wagner B. Complicated grief after perinatal loss. Dialogues Clin Neurosci. 2012;14(2):187–94.

20. Theut SK, Zaslow MJ, Rabinovich BA, Bartko JJ, Morihisa JM. Resolution of parental bereavement after a perinatal loss. J Am Acad Child Adolesc Psychiatry. 1990;29(4):521–5.
21. Hughes P, Riches S. Psychological aspects of perinatal loss. Curr Opin Obstet Gynecol. 2003;15(2):107–11.
22. Bennett SM, Litz BT, Lee BS, Maguen S. The scope and impact of perinatal loss: current status and future directions. Prof Psychol Res Pr. 2005;36(2):180.
23. Badenhorst W, Hughes P. Psychological aspects of perinatal loss. Best Pract Res Clin Obstet Gynaecol. 2007;21(2):249–59.
24. Lovell A. Some questions of identity: late miscarriage, stillbirth and perinatal loss. Soc Sci Med. 1983;17(11):755–61.
25. Blin D, Soubieux M. Perte perinatale. Dueil, depression ou movement nostalgique. Neuropsychiatr Enfance Adolesc. 1999;47(1–2):22–6.
26. Winnicott DW. The theory of the parent-infant relationship. Int J Psychoanal. 1960;41(6):585–95.
27. Bunch J, Barraclough B, Nelson B, Sainsbury P. Suicide following bereavement of parents. Soc Psychiatr. 1971;6(4):193–9.
28. Li J, Laursen TM, Precht DH, Olsen J, Mortensen PB. Hospitalization for mental illness among parents after the death of a child. N Engl J Med. 2005;352(12):1190–11.
29. Harper M, O'Connor R, Dickson A, O'Carroll R. Mothers continuing bonds and ambivalence to personal mortality after the death of their child–an interpretative phenomenological analysis. Psychol Health Med. 2011;16(2):203–14.
30. Blackmore ER, Côté-Arsenault D, Tang W, Glover V, Evans J, Golding J, O'Connor TG. Previous prenatal loss as a predictor of perinatal depression and anxiety. Br J Psychiatry. 2011;198(5):373–8.
31. Lebovic S, Weil-Harpern F. Psychopathologie du bébé. Paris: Presses Universitaires de France-PUF; 1989.
32. Prigerson HG, Frank E, Kasl SV, Reynolds CF, Anderson B, Zubenko GS, Kupfer DJ. Complicated grief and bereavement-related depression as distinct disorders: preliminary empirical validation in elderly bereaved spouses. Am J Psychiatry. 1995;152(1):22–30.
33. Bourne S, Lewis E. Pregnancy after stillbirth or neonatal death: psychological risks and management. Lancet. 1984;324(8393):31–3.
34. Armstrong D, Hutti M. Pregnancy after perinatal loss: the relationship between anxiety and prenatal attachment. J Obstet Gynecol Neonatal Nurs. 1998;27(2):183–9.
35. Cŏté-Arsenault D, Mahlangu N. Impact of perinatal loss on the subsequent pregnancy and self: women's experiences. J Obstet Gynecol Neonatal Nurs. 1999;28(3):274–82.
36. Hughes PM, Turton P, Evans CD. Stillbirth as risk factor for depression and anxiety in the subsequent pregnancy: cohort study. Brit Med J. 1999;318(7200):1721–4.
37. Franche RL, Mikail SF. The impact of perinatal loss on adjustment to subsequent pregnancy. Soc Sci Med. 1999;48(11):1613–23.
38. Gaudet C, Séjourné N, Camborieux L, Rogers R, Chabrol H. Pregnancy after perinatal loss: association of grief, anxiety and attachment. J Reprod Infant Psyc. 2010;28(3):240–51.
39. Davis DL, Stewart M, Harmon RJ. Postponing pregnancy after perinatal death: perspectives on doctor advice. J Am Acad Child Psy. 1989;28(4):481–7.
40. Condon JT. Management of established pathological grief reaction after stillbirth. Am J Psychiatry. 1986;143(8):987–92.
41. Zeanah CH, Harmon RJ. Perinatal loss and infant mental health: an introduction. Inf Mental Health J. 1995;16(2):76–9.
42. Salvesen KÅ, Øyen L, Schmidt N, Malt UF, Eik-Nes SH. Comparison of long-term psychological responses of women after pregnancy termination due to fetal anomalies and after perinatal loss. Ultrasound Obstet Gynecol. 1997;9(2):80–5.
43. Turton P, Hughes P, Evans CD, Fainman D. Incidence, correlates and predictors of post-traumatic stress disorder in the pregnancy after stillbirth. Br J Psychiatry. 2001;178:556–60.
44. Heller SS, Zeanah CH. Attachment disturbances in infants born subsequent to perinatal loss: a pilot study. Inf Mental Health J. 1999;20(2):188–99.

45. Zeanah CH, Danis B, Hirshberg L, Dietz L. Initial adaptation in mothers and fathers following perinatal loss. Inf Mental Health J. 1995;16(2):80–93.
46. Callister LC. Perinatal loss: a family perspective. J Perinat Neonatal Nurs. 2006;20(3): 227–34.
47. Lewis E, Bryan EM. Management of perinatal loss of a twin. BMJ. 1988;297(6659):1321–3.
48. Nantermoz F, Molenat F, Boulot P, Hedon B, Roy J, Visier J. Implications psychologiques de la reduction embryonnaire sur grossesse multiple: reflexions preliminaires. Neuropsychiatr Enfance Adolesc. 1991;39(11–12):594–7.
49. Quadrelli A, Mechoso B, Laufer M, Jaumandreu C, Vaglio A. Parental decisions to abort or continue a pregnancy following prenatal diagnosis of chromosomal abnormalities in a setting where termination of pregnancy is not legally available. Prenat Diagn. 2007;27(3):228–32.
50. Shah PE, Clements M, Poehlmann J. Maternal resolution of grief after preterm birth: implications for infant attachment security. Pediatrics. 2011;127(2):284–92.
51. Rådestad I, Surkan PJ, Steineck G, Cnattingius S, Onelöv E, Dickman PW. Long-term outcomes for mothers who have or have not held their stillborn baby. Midwifery. 2009;25(4):422–9.
52. Hutti MH. Social and professional support needs of families after perinatal loss. J Obstet Gynecol Neonatal Nurs. 2005;34(5):630–8.
53. van de Wiel H. Counselling following stillbirth. In: Facchinetti F, Dekker G, Baronciani D, Saade G, editors. Stillbirth: understanding and management. Boca Raton: CRC Press; 2010. p. 105–8.
54. Allumbaugh DL, Hoyt WT. Effectiveness of grief therapy: a meta-analysis. J Couns Psychol. 1999;46(3):370.
55. Forrest GC, Standish E, Baum JD. Support after perinatal death: a study of support and counselling after perinatal bereavement. Brit Med J. 1982;285(6353):1475–9.

A Pregnant Woman Who Could Not Stop Drinking: Management of Alcohol Abuse in Pregnancy

7

Devinalini Misir and K. Marieke Paarlberg

7.1 Introduction and Aims

Alcohol abuse during pregnancy has been found to be harmful for pregnancy outcome and the health of the unborn child [1]. In addition to this, alcoholism in a pregnant mother also harms her social environment, her transition to motherhood, and her relationships with her partner, relatives, friends, and also healthcare providers [1, 2].

Drinking too much alcohol means "binge drinking." In the English literature, this is defined as drinking four or more alcoholic drinks for women and five or more for men in a 2-h period. In these situations, the blood alcohol [3] concentration rises about 0.08 g/dl or more [3, 4]. If the same amount is spread over days or hours, it is not considered binge drinking according to this definition [5]. It is important to state that in the literature, there are many definitions available for alcohol use, as alcohol use is a cultural norm in various parts of the world. We will avoid mentioning all these different definitions, as it is beyond the scope of this chapter to get into the details of the different definitions and into the cultural and international connotations associated with alcohol use.

Whereas alcohol abuse in everyday life already may lead to serious problems, drinking alcohol during pregnancy may result in fetal alcohol spectrum disorder (FASD), of which fetal alcohol syndrome (FAS) is the most severe diagnosis at the end of the spectrum. These conditions are a preventable cause of mental retardation

D. Misir, MD (✉)
Department of Psychiatry, University of Buffalo, Erie County Medical Center, Buffalo, NY, USA
e-mail: Devi_nalini@hotmail.com

K.M. Paarlberg, MD, PhD
Department of Obstetrics and Gynecology, Gelre Hospitals, Apeldoorn Location, Apeldoorn, The Netherlands
e-mail: km.paarlberg@xs4all.nl

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_7

in the offspring. The statistics from the US Centers for Disease Control and Prevention (CDC) [6] estimate the rate of FAS in the United States is 0.5–2 cases for every 1000 live births, with enormous costs in terms of quality of life and money. Therefore, it is important that obstetrical caregivers know how to recognize the use of alcohol in pregnant women and know how to counsel these women in order to reduce their alcohol use as much as possible.

7.2 Definition in Lay Terms

Alcohol abuse means that someone drinks too much alcohol in a short time period. In the English literature, this is defined as drinking four or more alcoholic drinks for women and five or more for men in a 2-h period.

7.3 Didactic Goals

After reading this chapter, you will know

- What is the prevalence of alcohol use in pregnancy
- The definition of binge drinking
- That there are international differences in what is considered a "standard drink" in terms of grams of alcohol
- The difference in the metabolism of alcohol in pregnant women versus nonpregnant women
- The teratogenic effects of alcohol and the associated neurobehavioral effects on the growing infant
- The factors that influence alcohol use during pregnancy
- How to identify/recognize pregnant women with alcohol use disorder
- The role of biomarkers of alcohol use in pregnancy
- How to manage pregnant women with alcohol abuse
- Medications available for alcohol abuse that are safe during pregnancy
- The main barriers to treatment and some ways to overcome them
- Guidelines regarding alcohol use in different countries across the world
- Possible public health measures that might dissuade pregnant women from using alcohol

Case History

Elaine Cobalt is a 30-year-old primigravid woman visiting her gynecologist Matthew Lilac for the first time. Elaine tells Matthew that she is pregnant by her boyfriend with whom she just had broken up after an intense quarrel. During the physical examination and ultrasonography, Matthew finds out that she is already 16 weeks pregnant. Elaine herself tells him that she was initially

very shocked, but after discussing the issue openly with her mother and her closest friends, she decided to continue the pregnancy. After the examination, she mentions herself that it maybe wasn't the right time to get pregnant, having just broken up with her boyfriend, but she "really would like to become a mother."

After listening to her story, Matthew replies in a neutral tone of voice that the whole situation must be quite demanding for her. She confirms his reaction by telling him that it will be a dramatic change in her life because she used to be quite a "party animal." So much in fact that she, not for the first time, forgot to take her contraception pills—until now without repercussions.

"A party animal, what does that mean for you?" Matthew asks.

Elaine turns her face away a bit and blushes, "Well, just going to parties and pubs, but only on the weekends, because during the week I work in a fashion shop."

Matthew asks her, "Until when have you been partying?"

She admits that this was until 2 weeks ago. And then reacts brusquely, "Everybody around me does this, we're just having fun!"

He realizes that she apparently somewhere felt offended by his questions, arising from his worries about possible binge drinking during the first trimester of pregnancy. Because there is no use in crying over spilled milk, and he doesn't want to jeopardize a good doctor-patient relationship because she's probably going to need all his support in the future in order to cope with her transition into parenthood, he tries to act in a friendly neutral way. He therefore also consciously chooses for a generalization in his formulation of the point he wants to make, "Most of my patients who are 'party animals' don't drink water all night. Does that also apply to you?"

Elaine hesitates as she answers, "Yeah, you may say so… and now I am very anxious that I have done harm to my baby…"

Matthew shows respect for her feelings and praises her for taking responsibility by showing concern. At the same time, he avoids adding insult into injury, "Good of you to come and discuss these things here with me. I see you're worried about your baby, and I can imagine that you feel some regrets. However, on the other hand, you didn't know that you were pregnant…"

She nods and when she continues to tell her story, Matthew notices how immature she acts despite her 30 years of age. "My ex-boyfriend and I used to drink whiskey during the weekends. He drank most of it!"

In order to open her up and to tell the truth as much as possible about her drinking behavior, Matthew avoids the authority trap, "I'm not your father and you're a fully grown woman. So it's not up to me to have any moral judgment about you or your boyfriend. That's completely up to you. The only concern I have is that people who were party animals yesterday don't change into the Virgin Mary overnight, not even when they know they're pregnant. So I think

it would be wise for you to think about how to deal with this during your pregnancy and how I can be of any support to you when doing so. But only if you want me to."

Elaine seems surprised about his offer to support her instead of scolding her. "Would you really want to help me cope with this?" She sounds a bit scared but mostly surprised.

"Of course, that's my job," he reacts confirming in neutral way but preparing to make the switch. "However, in order to do my job, we have to be open with each other, which may mean that I have to ask you some difficult or even painful questions about your way of life. Not about your past way of life but present way of life, the coming months. So maybe it's wise to take some time to think this over. Shall we end this conversation right now and make an appointment within a few days?"

Elaine looks at Matthew with, for the first time, a smile on her face and replies rather self-confidently, "That's fine, but I've already made up my mind. I think I need all the help I can get. So if you have any questions right now, let's move on to it."

7.4 Facts and Figures: Definitions, Classification, and Prevalence

7.4.1 What Is the Prevalence of Alcohol Use in Pregnant Women?

The Centers for Disease Control (CDC) in the United States analyzed the surveys conducted by Behavioral Risk Factor Surveillance System (BRFSS). As can be seen in Table 7.1, the CDC found that from 2001 through 2005, the following percentages of women reported to continue to drink alcohol during their pregnancy [3].

Women with an unplanned pregnancy had a higher proportion of binge drinking during the preconception period (16 % versus 12 %) in comparison to women with a planned pregnancy. The Canadian Maternity Experiences Survey (2009) indicated that 62.4 % of women acknowledged drinking alcohol 3 months prior to pregnancy. However, only 10.5 % of these surveyed women reported that they continued drinking alcohol while they were pregnant, of which 0.7 % drank two drinks on the day they drank, and 9.7 % drank less than once per week [7].

In 2010, in the United Kingdom, 80 % of the women drank alcohol prior to pregnancy; however, it dropped to 40 %, when they became pregnant. Among women who drank before pregnancy, about 49 % stopped drinking during pregnancy, whereas 46 % cut down on the amount of alcohol. Two percent of women did not change their drinking habits after they knew that they were pregnant [8].

In France, 23–52 % of pregnant women reported they continued drinking during pregnancy, of which 3.4–7.3 % reported at least one binge drinking episode [9].

Table 7.1 Estimated percentage of women aged 18–44 years who reported any alcohol use or binge drinking, by pregnancy status and selected characteristics

	Pregnant	Pregnant	Nonpregnant	Nonpregnant
Characteristic	Any use %	Binge drinking %	Any use %	Binge drinking %
Total	11.2	1.8	54.6	12.6
Age group in years				
18–24	8.6	2.5	55.5	19.6
25–34	11.2	1.4	55.1	12.2
35–44	17.7	1.8	53.6	8.9
Education				
High school diploma or less	8.5	1.8	43.1	11.6
Some college	11.2	2.0	57.2	14.4
College degree or more	14.4	1.8	66.3	12.0
Employed				
Yes	13.7	2.3	59.1	13.5
No	8.3	1.3	46.1	10.9
Married				
Yes	10.2	1.1	52.6	8.4
No	13.4	3.6	56.9	17.6
Race/ethnicity				
White/non-Hispanic	11.6	1.8	60.9	14.9
Black/non-Hispanic	10.3	2.1	43.3	6.8
Hispanic (any race)	10.2	1.7	41.1	8.9
Other race (non-Hispanic)	12.1	2.5	46.0	9.7

Source: the Behavioral Risk Factor Surveillance System (BRFSS) Surveys. The United States, 2001–2005. Washington, DC; the United States Department of Health and Human Services; and the Centers for Disease Control

Percentage weighted to represent the US population

Defined as five or more drinks on at least one occasion

Beginning in 2006, the US definition of binge drinking in women changed to four drinks on at least one occasion. Because of this change, data collected after 2006 are not included

Thirty percent of pregnant women reported regular alcohol use during pregnancy, of which 9 % reported drinking more than five drinks more than once a month, and 1 % reported drinking more than five drinks at least once a week [10].

Women drinking alcohol early in pregnancy are more likely to be from Caucasian race, have higher education, better socioeconomic status, and single as compared with women who do not drink alcohol early in pregnancy [8, 11]. Women who continue drinking alcohol during pregnancy are more likely to be from African-American origin and use other recreational drugs.

7.4.2 What Is Internationally Meant by a "Standard Drink"?

Different types of alcoholic beverages, such as beer, wine, malt, whiskey, etc., contain different alcohol percentages. For healthcare givers and patients, it is essential to know what a standard drink constitutes so that one might be able to understand

the impact of alcohol in their national system. The definition of a "standard drink" differs over various countries.

To date, there is no standard convention across countries to define what a "standard drink" is. Most countries do not use standard definitions for drinks, and they are measured by serving sizes, which depend on the local culture and customs. This factor should be taken into account when comparing alcohol use across countries as there is a wide range of alcohol content (8–14 g) in a "standard drink."

7.4.3 What Is the Definition of Binge Drinking?

Next to the difference in definition of a "standard drink," the definition of binge drinking also varies from country to country:

- In the United Kingdom, binge drinking is defined as drinking more than twice the daily recommended unit of alcohol in one session, which is more than six units of alcohol (48 g of alcohol) for women and eight units of alcohol (64 g of alcohol) for men [12].
- In other European countries, binge drinking is defined as "a single drinking session," which includes at least 40 g of alcohol for women and 60 g of alcohol for men within a 2-h period [5].
- In the United States, the National Institute of Alcohol Abuse and Alcoholism (NIAAA) defines binge drinking as a pattern of drinking alcohol that brings the blood alcohol concentration (BAC) to more than 0.08 g/l or above, which corresponds to 56 g or more for females and 70 g or more for males in a 2-h period [4].

7.4.4 What Is the Difference Between Men and Women Drinking Alcohol?

When a woman and a man drink the same amount of alcohol, of the same type of drink, the alcohol concentration in a woman is higher compared to a man at that given time, because women have less body water and more fat compared to men of the same body weight [13]. Moreover, women have lower activity of alcohol dehydrogenase, the enzyme that breaks down alcohol, resulting in higher alcohol percentages in women compared to men.

7.4.5 Why Are People Drinking Alcoholic Beverages?

In most cultures, drinking alcohol is a socially accepted norm, as the expected immediate effect of alcohol is reduction in social anxiety, becoming more sociable, and developing a positive mood, with a sense of euphoria [14]. However, people who go through some form of psychological distress, which could be secondary to physical, sexual, or emotional trauma, may more easily become dependent on

Table 7.2 International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10) definition of harmful use of alcohol

ICD-10 definition of harmful use of alcohol	
	Clear evidence that alcohol use contributed to physical or psychological harm, which may lead to disability or adverse consequences The nature of harm should be clearly identifiable The pattern of use has persisted for at least 1 month or has occurred repeatedly within a 12-month period Symptoms do not meet criteria for any other mental or behavioral disorder related to alcohol in the same time period (except for acute intoxication)
Criteria for alcohol dependence: *three or more of the clustering criteria, occurring together for at least 1 month or if less than a month, occurring together repeatedly within a 12-month period*	
1	Need for significantly increased amounts of alcohol to achieve intoxication or desired effect or markedly diminished effect with continued use of the same amount of alcohol, also defined as tolerance
2	Physiological symptoms characteristic of the withdrawal syndrome for alcohol or use of alcohol to (or closely related substances) to relieve or avoid withdrawal symptoms
3	Difficulties in controlling drinking in terms of onset, termination, or levels of use: drinking in larger amounts or over a longer period than intended or a persistent desire or unsuccessful efforts to reduce or control drinking
4	Important alternative pleasures or interests given up or reduced because of drinking
5	Great deal of time spent in activities necessary to obtain, to use, or to recover from the effects of drinking
6	Persisting with drinking despite clear evidence and knowledge of harmful physical or psychological consequences
7	A strong desire or sense of compulsion to drink
Duration criterion	
Three or more of dependence criteria occurring for at least 1 month or if less than 1 month, occurring together repeatedly within a 12-month period	

Data from World Health Organization (WHO) [15]

alcohol. Alcohol will numb their feelings so that they do not have to face the psychological distress, which may create a vicious cycle. Both the *International Statistical Classification of Diseases and Related Health Problems*, *Tenth Revision* (*ICD-10*) [15], and the *Diagnostic and Statistical Manual of Mental Disorders*, *Fifth Edition* (*DSM-5*) [16], have defined criteria for harmful use of alcohol. In Table 7.2, the criteria of ICD-10 are depicted.

7.5 Etiology and Pathogenesis

7.5.1 How Is Alcohol Metabolized and Transferred to the Fetus?

Alcohol is metabolized to acetaldehyde by the alcohol dehydrogenase, which is then oxidized to acetic acid by acetaldehyde dehydrogenase. Alcohol and acetaldehyde freely enters the fetal circulation through the placenta. Since the fetal alcohol

dehydrogenase is less active compared to the maternal alcohol dehydrogenase, alcohol stays in the fetal circulation for a longer period of time compared to the length of stay in maternal circulation [1].

7.5.2 What Are the Teratogenic Effects of Alcohol Use in Pregnancy?

Alcohol and its primary metabolite acetaldehyde are teratogenic. Although it is universally accepted that alcohol is a teratogen, there is a general lack of consensus regarding the safe level of alcohol consumption during pregnancy, which is reflected by varying policies on safe amount of alcohol consumption while pregnant throughout the world.

Fetal development is a multistage, sequential process. Exposure at any given time will affect the organ or system that is developing at that time. The effect on each developing system or function is related to the dose of exposure [11]. The teratogenic effect of prenatal alcohol use depends on the nutritional status of the pregnant women, on how much and how often the alcohol intake was spread out over a period of time, the role of binge drinking, and the gestational period during which alcohol was consumed. Alcohol exposure early in pregnancy causes major morphological defects and growth restriction with alcohol exposure to the latter part of pregnancy. Neurodevelopmental deficits occur with alcohol exposure throughout pregnancy. Therefore the deficits might not be the same for a newborn being exposed to alcohol throughout pregnancy compared to a newborn exposed to alcohol during specific periods of gestation.

A prospective study from the United Kingdom found a statistically significant ($p<0.05$) increased risk of preterm, low birth weight, and lower birth percentile babies in pregnant women who had taken less than two units of alcohol during their first trimester. Third trimester exposure to alcohol is associated with reduced brain weight to body weight ratio, also called microcephaly [17].

7.5.2.1 Fetal Alcohol Spectrum Disorder (FASD) and Fetal Alcohol Syndrome (FAS)

Children who were exposed to alcohol prenatally, throughout the whole gestational period [14], may develop fetal alcohol spectrum disorder (FASD). In FASD, a varying degree of neurobehavioral disturbances may be seen with deficits in verbal learning, spatial memory and reasoning, reaction time, balancing, and other motor skills. These children are found to have issues with mental health later in their life, as they have varying degree of social awkwardness. The most severe end of this disorder is called fetal alcohol syndrome (FAS). Children with FAS usually are small for their age, with characteristic facial anomalies and central nervous system deficits. The Birth Defects Monitoring Program reports a prevalence of 5.2 children with FAS for every 10,000 live births [18]. These children are characterized by growth deficiency (height or weight $\leq$10th percentile),

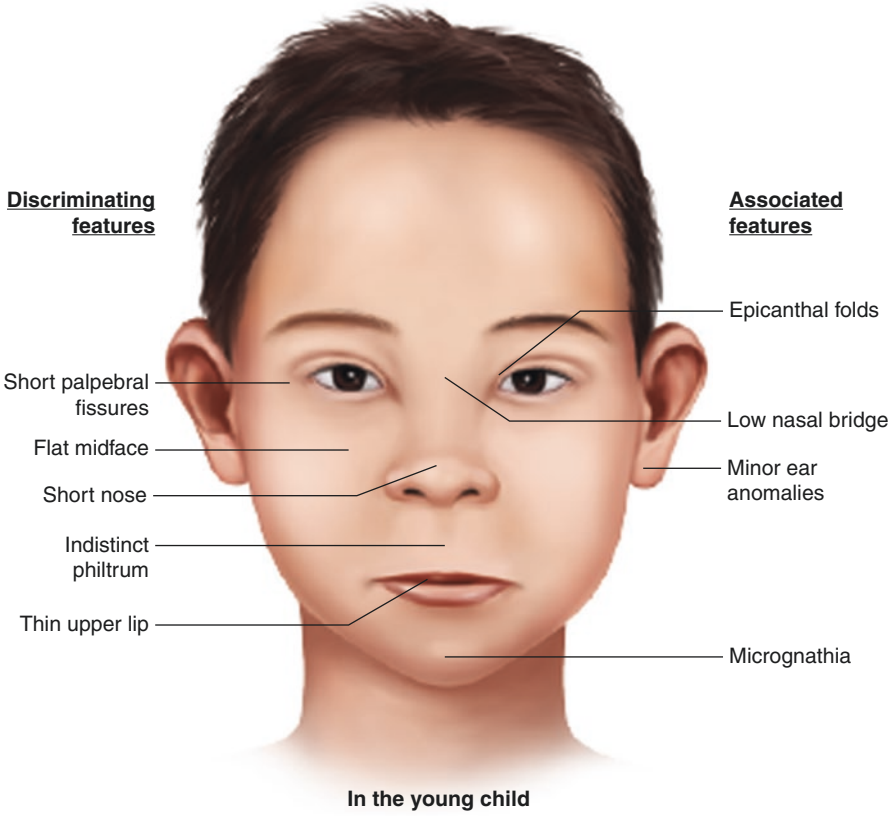


Fig. 7.1 Characteristics of fetal alcohol syndrome in young child (based on, with permission, Streissguth and Bonthius [19])

unique facial anomalies, such as short palpebral fissure, short mid face, etc. (Fig. 7.1) [19], and severe central nervous system deficits including mental retardation [11].

7.5.3 Why Is It Important to Identify Women Drinking Alcoholic Beverages During Pregnancy?

As there is an increased association between prenatal alcohol exposure and the risk of developing neurobehavioral teratogenicity in the fetus, it is of utmost importance to identify these women on various levels. Early intervention in these pregnant women might reduce or stop further alcohol use while they are pregnant. This in turn reduces the possible exposure of the fetus to alcohol, thereby minimizing the damage to the growing brain of the fetus. Identifying alcohol use later in pregnancy or even after the baby is born helps with identifying high-risk infants, who can be

closely monitored for alcohol-related neuroteratogenic issues, providing them with increased support at school and stable living arrangement with or without special services as deemed appropriate.

7.6 Specific Diagnostic Aspects

7.6.1 How Can Pregnant Women Drinking Alcoholic Beverages Be Identified?

7.6.1.1 History Taking

Every pregnant woman should routinely be asked about drinking alcoholic beverages. Health caregivers should express an open attitude toward all answers they may get. When there is no problematic drinking, most people answer quite frankly and openly to these questions. This might be different in women with problematic drinking. The following questions may be asked to find out about problematic drinking:

- How frequently do you drink alcoholic beverages?
- When you drink, how many alcoholic drinks do you take on average?
- How often do you drink four glasses or more?
- How often in the previous year you have noticed that you couldn't stop drinking after you began drinking?
- How often in the previous year did you leave issues that you actually would like to have done due to drinking alcohol?
- How often in the previous year did you feel guilty due to alcohol use?
- How often in the previous year couldn't you remember things due to alcohol use?
- Were you or somebody else ever injured due to alcohol use?
- Has there been a family member, friend, or your general practitioner who mentioned that he/she was worried about your alcohol use?

7.6.1.2 Self-Report Questionnaires

Maternal self-report has been used as one of the modalities for identifying prenatal alcohol exposure. This is of limited value, as it is associated with recall bias and fear of stigmatization or repercussion associated with disclosure [20]. Administering a screening questionnaire each time a pregnant mother meets with a healthcare worker is also associated with similar limitations. To overcome this barrier, screening every woman of child-bearing age for alcohol use, irrespective of their pregnancy status, helps a pregnant alcohol-using patient be more forthcoming about her use and not perceive that she is going to be judged based on her disclosure. Making a note of the same in the charts might give us an idea if that woman was using alcohol prior to her becoming pregnant, as the most reliable predictor of alcohol use during pregnancy is alcohol use prior to pregnancy. However, a positive screen does not necessarily mean that the woman is using alcohol during her current pregnancy, but it will allow the healthcare provider to start a dialogue regarding alcohol use in pregnancy.

7.6.1.3 Biological Tests

Biological samples such as blood, urine, and hair from the mother and the newborn and meconium from the newborn are used to identify prenatal alcohol use. However, maternal and neonatal blood and urine can identify only recent alcohol use. Maternal or neonatal hair, if available, may indicate prenatal alcohol use. Since meconium starts to accumulate as early as the thirteenth week of pregnancy, meconium might be a fertile matrix to assess parental alcohol use, but it is available only for the first 2–3 days after the birth of the newborn.

Researchers have been looking for biomarkers for prenatal alcohol use, to identify these patients. Indirect biomarkers—such as carbohydrate-deficient transferrin (CDT) [21], gamma-glutamyl transferase (GGT) [21], ratio of aspartate amino transferase and alanine amino transferase (AST/ALT) [21], increased mean corpuscular volume (MCV) [21], hemoglobin-acetaldehyde adducts [21], which is formed by the binding of hemoglobin to acetaldehyde, a breakdown product of alcohol—are all associated with at-risk drinking. However, these biomarkers are not specific and sensitive enough for diagnosing prenatal alcohol exposure. Fatty acids and alcohol interact together to form fatty acid ethyl ester (FAEE), and they have been detected in cord blood, meconium, and hair of infants and in adults. Bearer et al. [22] found strong association between FAEE in meconium and self-reported alcohol use in pregnant mothers. More research is needed to replicate these findings and to understand if there are any confounders to this biomarker.

7.6.2 How Do Health Caregivers Have to Take Anamnesis Concerning Alcohol Use During Pregnancy?

Though drinking alcohol is an accepted norm in most cultures, there is a stigma associated with the word "addiction," and pregnant women might feel that they are being judged if and when they disclose that they have been drinking while they are pregnant. Women, especially from the Western countries, fear that they might lose custody of the child, will be incarcerated, or mandated to quit using alcohol if they disclose to healthcare providers that they have been drinking alcohol while pregnant [20].

Comorbid psychiatric issues and/or trauma make it harder for these women to reach out for help. Partners of pregnant women with active addiction to alcohol may not be conducive for these women to access treatment for addiction. Possible treatment might also be hampered by lack of access to child care or transportation. Fear of losing custody of their child might also prevent women from accessing help.

Therefore, it is important to create an atmosphere that is nonjudgmental, welcoming, and supportive, with an individualized treatment plan that goes a long way in helping these women.

7.7 Specific Therapeutic Aspects

7.7.1 What Should Be the First Things to Address When a Caregiver Is Confronted with Alcohol Use During Pregnancy?

The patient's basic survival needs, such as housing, food, and access to healthcare, should be initially addressed. Involving any and all sober support as possible, including support groups such as Alcoholics Anonymous (AA), should be the goal. Having an individualized case manager, who can follow up with the patient with a phone call to see if the patient did keep her appointment with the chemical dependency unit, is prudent. If the patient did keep the appointment, she should be praised for her behavior. If the patient missed her appointment for any reason, finding out why she missed the appointment and discussing with rescheduling the appointment are essential. Negotiating a behavioral contract regarding the number of visits she will make to the chemical dependency unit before she decides to quit also should be considered.

7.7.2 Are There Medicinal Options in Treating Pregnant Women Who Drink Alcohol?

In the first trimester of pregnancy, it is prudent to avoid any medications, if possible, as this is the period of organogenesis. None of the available medications for alcohol dependence—such as naltrexone, acamprosate, disulfiram, or nalmefene—are recommended for use in pregnant women, especially during the first trimester.

7.7.3 What Are the Recommendations in Different Countries Concerning Alcohol Use in Pregnancy?

Most countries have recommendations regarding alcohol use in pregnancy, and it does differ from region to region. See Table 7.3 for the overview [23].

7.7.4 How Are Health Care Policies in Different Countries Carried Out?

Knowing all the resources that are available in the community for pregnant women with alcohol use and referring them appropriately is prudent. Health caregivers usually focus on education on an individual and/or family level. In this level, the woman could be motivated to start with a 12-step program to establish a sober support system that is helpful as well [24].

Alcoholics Anonymous (AA) is a fellowship for men and women with drinking problems. The only requirement necessary to join this fellowship is the desire to

Table 7.3 Alcohol use in pregnancy: guidelines by country

Country	Standard drink	Drinking guidelines
Australia	10 g	The National Health and Medical Research Council recommends: For women who are pregnant or planning to become pregnant, not drinking is the safest option
Canada	13.6 g	The Canadian Centre on Substance Abuse recommends: If you are pregnant or planning to become pregnant, the safest choice is to drink no alcohol at all
Denmark	12 g	The Danish National Board of Heath recommends: No exact limit is known for how little a pregnant woman can drink without harming her unborn baby; the recommendation is therefore for pregnant women not to drink alcohol at all, and, if planning to become pregnant, you should not drink alcohol
France	10 g	The French Ministry of Social Affairs, Health, and Women's Rights recommends zero alcohol during pregnancy
Ireland	10 g	The Health Promotion Unit's Health Files recommend: Those who are trying for a baby should cut down or stop alcohol intake; during pregnancy, stopping drinking is the safest advice. More than three drinks a day increases the risk of miscarriage; more than 12 drinks a week increases the risk of premature birth; avoid binge drinking, as sudden high levels of alcohol can damage the developing brain. Children exposed to alcohol show poor attention and hyperactivity
The Netherlands	10 g	The Health Council of the Netherlands' Scientific Report on Revisions to Guidelines for Healthy Eating recommends: If you are pregnant, breast feeding, or trying to become pregnant, it is recommended not to drink
New Zealand	10 g	The NZ Ministry of Health recommends: Women who are pregnant or planning to become pregnant should avoid drinking alcohol
Spain	10 g	The Spanish Ministry of Health, Social Services, and Equality recommends: Women planning to conceive and pregnant women should abstain from alcohol
Switzerland	10 g	The Federal Commission on Alcohol-Related Problems recommends: Those planning to become pregnant and pregnant women should give up alcohol
The United Kingdom	8 g	The Department of Health, UK Chief Medical Officers' Alcohol Guidelines Review: If you are pregnant or planning a pregnancy, the safest approach is not to drink alcohol at all
The United States	14 g	The US Surgeon General's Advisory on Alcohol Use in Pregnancy recommends: Women who are or may be pregnant should not drink alcohol; women who are considering becoming pregnant should abstain from alcohol

From http://www.iard.org/policy-tables/drinking-guidelines-pregnancy-breastfeeding/. Copyright by and reproduced by permission of International Alliance for Responsible Drinking

stop drinking. AA has a 12-step program, which helps patients navigate toward recovery and sobriety (Table 7.4) [24].

A community strategy may involve school alcohol education. This is a strategy to target teenage women, informing them about the harmful effects of binge

Table 7.4 Twelve-step program of Alcoholics Anonymous (AA)

AA 12-step program	
1	We admitted we were powerless over alcohol—that our lives have become unmanageable
2	Came to believe that a power greater than ourselves could restore us to sanity
3	Made a decision to turn our will and our lives to the care of God as we understood Him
4	Made a searching and fearless moral inventory of ourselves
5	Admitted to God, to ourselves, and to another human being the exact nature of our wrongs
6	Were entirely ready to have God remove these defects of character
7	Humbly ask him to remove our shortcomings
8	Made a list of all persons we had harmed and became willing to make amends to them all
9	Made direct amends to such people where ever possible, except when to do so would injure them or others
10	Continued to take personal inventory and when we were wrong promptly admitted it
11	Sought through prayer and meditation to improve our conscious contact with God, as we understood Him, praying only for knowledge of his will for us and the power to carry that out
12	Having had a spiritual awakening as the result of these steps, we tried to carry these message to alcoholics and to practice these principles in all our affairs

From http://www.aa.org/. The Twelve Steps are reprinted with permission of Alcoholics Anonymous World Services Inc. (AAWS). Permission to reprint the Twelve Steps does not mean that AAWS has reviewed or approved the contents of this publication or that AA necessarily agrees with the views expressed herein. AA is a program of recovery from alcoholism only; use of the Twelve Steps in connection with programs and activities which are patterned after AA but which address other problems or in any other non-AA does not imply otherwise

drinking and advocating the need to use contraceptives to prevent unwanted pregnancies.

Another community intervention is influencing alcohol advertisements, since they affect attitudes of teens concerning use of alcohol. As an example, in the United States, there is a policy regarding alcohol use in pregnancy: It is mandatory to have the US Surgeon General's warning on the labels of beverage containers that women should not drink alcohol, while they are pregnant as they are more likely to have babies with birth defects. In the United States, positive health-related statements associated with alcohol are prohibited on labels or in advertisements [25].

Case History (Continued)

During one of the consultations, Elaine raises the question whether Matthew Lilac can predict whether her baby will suffer from FAS, given her serious drinking during the first trimester of her pregnancy. He answers her that he cannot make predictions right now and asks her if she worries a lot about this issue. She confirms sometimes lying awake at night, worrying about the future.

He accepts the hint and reacts in a neutral tone, "It must be difficult at those moments, worrying, lying awake at night all by yourself and not being able to have a drink? How do you cope with that? Can you?"

Elaine reflects her internal struggle. First she looks sad then proud, "It's hard but until now I haven't been drinking a sip of alcohol, not even a cherry bonbon."

Matthew thinks that maybe some and preferably more specific support is needed in order to avoid a relapse. "Okay, until now we have been successful but now things are becoming really rough and tough. I'm just a simple gynecologist, would it be a good idea to draw in some additional and maybe more specialized forces?"

She agrees to talk with the social worker of his team. During the next time he sees her, she tells him that she's grateful for the help, since the social worker helps her with housing and her financial problems after the breakup. Her mother and a few friends are very supportive and will help her with the preparations for the new baby. The social worker accompanies her to the pediatrician, connected to Matthew Lilac's hospital, who is specialized in FAS. She will counsel her and after the baby is born, it will be followed up at her outpatient department.

7.8 Critical Reflection and Conclusive Remarks

Harmful effects of alcohol in pregnancy, such as FASD and FAS, are preventable. However, given the resiliency of (bad) habits, it may require quite a lot of effort to decrease if not preclude these effects. Government agencies, public organizations, educational institutions, healthcare workers, families, and friends should join hands to prevent this major public health hazard.

The individual healthcare worker should be able to address and acknowledge (problematic) drinking of alcoholic beverages during pregnancy in order to prevent FASD and FAS in infants on the one hand and providing a safe and welcoming family for the newborn on the other.

Tips and Tricks

1. Since pregnant women have difficulty disclosing their alcohol use, it is important to express an open and welcoming attitude. Women should feel supported and trust their caregivers. Therefore, women need to be counseled in a nonjudgmental way, where it is important to build a firm doctor/midwife relationship. Such a good relationship gives the best opportunity for women to be motivated to stop drinking alcohol on the one hand and feel supported in their upcoming motherhood on the other.
2. Ob/Gyns and midwives working with pregnant women should collaborate closely with social workers, pediatricians, and professionals in alcohol treatment programs. Working in interdisciplinary teams may alleviate the pressure on the different professionals and allows optimal treatment.

3. Frequently, it is difficult to refer women to specialists in substance abuse, such as professionals who run alcohol treatment programs. Therefore, it might be helpful to state, "I am an Ob/Gyn/midwife, and I do not have much knowledge on alcohol use during pregnancy. Therefore I need you to see a specialist in this area in order to help me treat you as well as I can." This takes away the pressure on the woman but allows her to help you in providing the best possible care.

Test Your Knowledge and Comprehension

1. Almost all women stop drinking alcohol as soon as they realize that they are pregnant.
   (a) True
   (b) False
2. Fetal alcohol syndrome (FAS) is a preventable cause of mental retardation.
   (a) True
   (b) False
3. Guidelines on using alcohol while pregnant are consistent throughout the world.
   (a) True
   (b) False
4. The ethanol content of a standard drink is consistent throughout the world.
   (a) True
   (b) False
5. There are reliable alcohol biomarkers available to detect the amount of alcohol consumed throughout pregnancy.
   (a) True
   (b) False
6. What is the incidence of pregnant women who continue to drink alcohol after they realize that they are pregnant?
   (a) Under 24 % of the women
   (b) Between 25 % and 34 %
   (c) Above 35 %
   (d) Women always stop drinking as soon as they realize that they are pregnant
7. In which country is the ethanol content of a so-called standard drink the highest?
   (a) The United Kingdom
   (b) Australia
   (c) The United States
   (d) The Netherlands
8. During pregnancy, which medications are recommended for treating alcohol use?
   (a) Acamprosate
   (b) Naltrexone
   (c) Disulfiram
   (d) None of the above

9. What is a requirement to join Alcoholics Anonymous?
   (a) Belief in God
   (b) Desire to stop drinking alcohol
   (c) Higher socioeconomic background
   (d) To be a Caucasian male
10. What is a risk factor for continuing drinking alcohol during pregnancy?
   (a) Being from Caucasian race
   (b) Being from African-American race
   (c) Having a higher socioeconomic status
   (d) None of the above

Answers

1. False
2. True
3. False
4. False
5. False
6. c
7. c
8. d
9. b
10. b

References

1. Bhuvaneshwar C, Chang G, Epstein LA, Stern TA. Alcohol use during pregnancy: prevalence and impact. Prim Care Companion J Clin Psychiatry. 2007;9(6):455–60.
2. Hannigan JH, Armant DR. Alcohol in pregnancy and neonatal outcome. Semin Neonatol. 2000;5(3):243–54.
3. Centers for Disease Control and Prevention (CDC). Alcohol use among pregnant and nonpregnant women of childbearing age – United States, 1991–2005. 2009. http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5819a4.htm.
4. National Institute on Alcohol Abuse and Alcoholism (NIAA). Drinking levels defined. http://www.niaaa.nih.gov/alcohol-health/overview-alcohol-consumption/moderate-binge-drinking.
5. Institute of Alcohol Studies. Deutsche Hauptstelle für Suchtfragen e.V. (DHS). Binge Drinking and Europe. Hamm: DHS; 2008. http://www.dhs.de/fileadmin/user_upload/pdf/Pathways_for_Health-Project/binge_drinking_and_europe_report.pdf.
6. Centers for Disease Control and Prevention (CDC). Alcohol screening and counseling: an effective but underused health service. CDC Vital Signs. 2014. http://www.cdc.gov/vitalsigns/alcohol-screening-counseling/index.html.
7. Public Health Agency of Canada. What mothers say: the Canadian Maternity Experiences Survey. Ottawa: Public Health Agency of Canada; 2009. http://www.violapolomeno.com/survey-eng.pdf.
8. The Health and Social Care Information Centre (HSCIC) Dietary supplements, smoking and drinking during pregnancy. 2012. http://www.hscic.gov.uk/catalogue/PUB08694/ifs-uk-2010-chap11-diet-supp-smok-drink.pdf.

9. de Chazeron I, Llorca PM, Ughetto S, Vendittelli F, Boussiron D, Sapin V, et al. Is pregnancy the time to change alcohol consumption habits in France? Alcohol Clin Exp Res. 2008;32(5):868–73.
10. Göransson M, Magnusson A, Bergman H, Rydberg U, Heilig M. Fetus at risk: prevalence of alcohol consumption during pregnancy estimated with a simple screening method in Swedish antenatal clinics. Addiction. 2003;98(11):1513–20.
11. Larkby C, Day N. The effects of prenatal alcohol exposure. Alcohol Health Res World. 1997;21(3):192–8.
12. National Health Service (NHS). Binge drinking. 2014. http://www.nhs.uk/Livewell/alcohol/Pages/Bingedrinking.aspx.
13. Swift R. Direct measurement of alcohol and its metabolites. Addiction. 2003;98 Suppl 2:73–80.
14. Grønkjær M, Curtis T, De Crespigny C, Delmar C. Acceptance and expectance: cultural norms for alcohol use in Denmark. Int J Qual Stud Health Well-being. 2011;6:8461. DOI: 10.3402/qhw.v6i4.8461.
15. World Health Organization (WHO). The ICD-10 classification of mental and behavioural disorder: diagnostic criteria for research. 1993. http://www.who.int/classifications/icd/en/GRNBOOK.pdf.
16. American Psychiatric Association. Diagnostic and statistical manual of mental disorders, 5E (DSM-5). 2014. http://www.dsm5.org/Pages/Default.aspx.
17. West JR. Alcohol and brain development. In: West JR, editor. Prenatal alcohol exposure and neuronal damage. New York: Oxford University Press; 1986. p. 120–57.
18. Coerdero JF, Floyd RL, Martin ML, Davis M, Hymbaugh K. Tracking the prevalence of FAS. Alcohol Health Res World. 1994;18(1):82–5.
19. Streissguth AP, Bonthius DJ. Alcohol and pregnancy and the fetal alcohol syndrome. Wiley Online Library. 2006. eLS.
20. The American Congress of Obstetricians and Gynecologists (ACOG). Committee on health care for underserved women. Committee opinion. Substance abuse reporting and pregnancy: the role of the obstetrician-gynecologist. 2011 http://www.acog.org/Resources-And-Publications/Committee-Opinions/Committee-on-Health-Care-for-Underserved-Women/Substance-Abuse-Reporting-and-Pregnancy-The-Role-of-the-Obstetrician-Gynecologist.
21. Bearer CF, Stoler JM, Cook JD, Carpenter SJ. Biomarkers of alcohol use in pregnancy. National Institute on Alcohol Abuse and Alcoholism (NIAAA). 2004/2005. http://pubs.niaaa.nih.gov/publications/arh28-1/38-43.pdf.
22. Bearer CF, Jacobson JL, Jacobson SW, Barr D, Croxford J, Molteno CD, et al. Validation of a new biomarker of fetal exposure to alchol. J Pediatr. 2003;143(4):463–9.
23. International Center for Alcohol Policies (ICAP). International guidelines on drinking and pregnancy. 2009. http://www.icap.org/table/InternationalDrinkingGuidelines.html.
24. Alcoholics Anonymous (AA). http://www.aa.org/.
25. ALLGOV. Alcohol and Tobacco Tax and Trade Bureau. 2015. http://www.allgov.com/departments/department-of-the-treasury/alcohol-and-tobacco-tax-and-trade-bureau?agencyid=7258.

A Young Woman Asking for Labia Reduction Surgery: A Plea for "Vulvar Literacy"

8

K. Marieke Paarlberg and Harry B.M. van de Wiel

8.1 Introduction and Aims

In the last decades, the demand for genital cosmetic surgery and, more specifically, labia reduction surgery has increased. Labia reduction surgery means that parts of the labia minora are surgically removed. Several reasons for this increased demand for labia reduction surgery have been suggested, such as the trend to shave pubic hair resulting in more visible genitals, an increased exposure in public media of digitally altered images of the female genital suggesting an "ideal female genital," and the advertising of labia reduction surgery by aesthetic surgeons and clinics as a way to rejuvenate and to regain (sexual) attractivity [1, 2]. An explanation we would like to add here is that there is a growing intolerance toward any kind of (physical) imperfection—for instance, like children's teeth—which could be seen as a side effect of medical technological progress. Interestingly, in several African countries, it is common to elongate the labia minora by teaching adolescent girls to stretch them manually, suggesting that this would increase male and female sexual pleasure [3, 4].

Many gynecologists and plastic surgeons regularly encounter a patient requesting labia reduction surgery whose physical appearance may vary between clear pathology and the objective absence of that.

K.M. Paarlberg, MD, PhD (✉)
Department of Obstetrics and Gynecology, Gelre Hospitals, Apeldoorn Location, Apeldoorn, The Netherlands
e-mail: km.paarlberg@xs4all.nl

H.B.M. van de Wiel, PhD
Wenckebach Institute, University of Groningen, University Medical Centre Groningen, Groningen, The Netherlands
e-mail: h.wiel@umcg.nl

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_8

8.2 Definition in Lay Terms

Labia reduction surgery means that parts of the inner labia are surgically removed.

8.3 Didactic Goals

After reading this chapter you will know:

- What are the normal morphological ranges of external female genitalia
- What is labia reduction surgery
- Which cultural aspects and background factors should be considered
- Which complaints are most common in women requesting labia reduction surgery
- How to examine a woman who requests labia reduction surgery
- How to balance different treatment options as a professional
- Which aspects to address in counseling a request for labia reduction surgery
- Which contraindications can be defined for labia reduction surgery

Case History
Julia Carmine, a 19-year-old young woman, enters the office of gynecologist Audrey Rose together with her mother. She tells Audrey that she already suffers from large inner labia for 6 years and is considering labia reduction surgery. She does not dare to take a shower with her sports teammates. In addition to this, she does not dare have sex with a boy, because she is so ashamed of how she looks down there. She also experiences unpleasant friction wearing tight jeans. Until recently, she did not tell anyone. Recently she told her mother and showed her labia to her mother. Her mother told her that her own inner labia are much smaller and those of her sister as well. Also, on the Internet Julia saw labia much smaller than hers, and she found sites from aesthetic surgery practices that showed "before and after" pictures.

When Audrey asks her to summarize her complaints, she answers: "I feel like a freak down there and I want you to operate on me so I look normal."

8.4 Facts and Figures: Definitions, Classification, and Prevalence

8.4.1 What Is the Normal Morphological Range and Size of the Different Parts of the External Female Genitalia?

Lloyd et al. [5] have described the variations in genital dimensions of 50 normal women, aged between 18 and 50. There is a large variation in appearance and size

Table 8.1 Examination of the labia minora in relation to other vulvar structures

	Aspect	Range	Mean (SD)
Dimensions [5]	Clitoral length (mm)	5–35	19.1 (8.7)
	Clitoral glans (mm)	3–10	5.5 (1.7)
	Clitoris to urethra (mm)	16–45	28.5 (7.1)
	Labia majora length (mm)	7.0–12.0	9.3 (1.3)
	Labia minora length (mm)	20–100	60.6 (17.2)
	Labia minora width (mm)	7–50	21.8 (9.4)
	Perineum length (mm)	20–100	31.3 (8.5)
	Vaginal length (cm)	6.5–12.5	9.6 (1.5)
Aspect of the skin [5]	Tanner stage pubic hair	IV	
		V	
	Color of genital area compared with surrounding skin	Same	
		Darker	
Consistence [5]	Rugosity of labia minora	Smooth	
		Moderate	
		Marked	
Protrusion	Level of protrusion of labia minora as compared with labia majora	Lying beneath the level of labia majora	
		Lying at same level of labia majora	
		Protruding outside labia majora	
Symmetry	Level of asymmetry of labia minora	Both labia minora have the same size	
		Width of one labium minus is larger than the other	
		Length of one labium minus is larger than the other	
		One labium minus is thicker than the other	
Proportional aspects	Labia majora aspect	Labia majora are flat due to little subcutaneous tissue	
		Labia majora are filled with subcutaneous tissue	
	Clitoral hood	Clitoral hood lies below the level of the clitoral tip	
		Clitoral hood lies at the level of the clitoral tip	
		Clitoral hood covers the clitoral tip	

Used with permission of John Wiley and Sons from Lloyd et al. [5]

of the different vulvar structures. Table 8.1 describes which morphological dimensions can be addressed when examining the vulva in regard to the request for labia reduction surgery [5]:

- Position: labia minora lie between the labia majora. Posteriorly, they merge together. They separate into two folds and anteriorly they form the clitoral hood.

- Color: the color of the aspect of the skin may vary from woman to woman depending on her skin color and blood flow intensity.
- Texture: the texture, especially the rugosity of the labia minora, varies between women.
- Consistence: labia minora consist of skin and fibroelastic stroma rich in neural and vascular elements.
- Protrusion: in adolescence and in most women, labia minora start to protrude outside the labia majora.
- Symmetry: marked asymmetry is occasionally present in the growth and development of labia minora during adolescence.
- Proportionality: although each part may look normal, the "picture as a whole" may look out of shape or proportion, for instance, when, as in the case in this chapter, normal but a little flat labia majora emphasize the protrusion of the normal labia minora. This is often the case in slender women without much subcutaneous fat tissue. In this respect, the size of the labia minora also should be viewed in relation to the size of the clitoral hood, which may have different dimensions as well. When considering labia reduction surgery, one must take into account these proportional aspects and the aspect of the remaining tissue after surgery.
- Short- and long-term changeability: sexual arousal may cause temporary swelling of the labia minora and changes coloring, etc. If women are not aware of this, it could lead to misperceptions. During a lifespan, the appearance of the labia majora and minora may change due to hormonal influences and other factors, such as birth trauma, vulvar edema, and vulvar diseases, i.e., lichen sclerosus.

8.4.2 How Frequently Do Women Request Labia Reduction Surgery?

In recent years, the number of labia reduction surgeries has increased fivefold (from 400 in 2001 to more than 2000 in 2010) in the National Health Service of the United Kingdom [6]. A comparable increase has been observed in the figures for Australia (from slightly more than 600 in 2001 to almost 1600 in 2011) [7]. The total number of operations will be (much) higher, since the figures of private clinics are not published.

8.4.3 Which Complaints Are Most Common in Women Requesting Labia Reduction Surgery?

The kinds of complaints women present at consultation are physical complaints on the one hand and psychological complaints on the other. Table 8.2 describes the different kinds of complaints that may be presented. In one patient several complaints may coexist [1, 6, 8–10].

Table 8.2 Common complaints of women requesting labia reduction surgery

Physical complaints	Psychological complaints
Pain in vulvar region	Appearance of the external genitalia, including asymmetry of labia minora
Discomfort in clothing, such as in tight trousers and underwear	Anxiety, embarrassment, or distress about the external genitalia
Discomfort in exercise, such as running, bike riding, and horseback riding	Relationship difficulties
Entry dyspareunia by rubbing of the labia and/or labia slipping in the vagina during sexual intercourse	

8.4.4 What Are the Expectations of Women Seeking Surgery?

It has been found that the majority of women seeking labia reduction surgery would like to improve the "appearance" of their labia minora [6]. In addition, they would like to remove discomfort in clothing and during athletic activity and improve their experience of sexual intercourse. Some hope to improve their confidence in themselves and in their relationships. A minority of the women believe that the operation makes them cleaner in their genital region. Women might be disgusted by the idea of not appearing normal. Disgust has been related to body dysmorphic disorder symptoms [11]. Body dysmorphic disorder is a common disorder that is characterized by repetitive behaviors or mental acts in response to preoccupations with perceived defects or flaws in physical appearance [12]. Although disgust is one of the strongest emotions, health-care professionals rarely ask about it.

8.5 Etiology and Pathogenesis

8.5.1 Which Developmental (Embryological) Factors or Later Physical Traumata May Lead to Dysmorphic Labia?

Significant labia minora hypertrophy has been described in cases of chronic lymphedema [13] and chronic irritation due to rubbing in, for instance, chronic diaper dermatitis in incontinent women [14]. Marked asymmetry between the labia minora incidentally occurs, comparable to asymmetry in breast development or due to lymphedema in one labium, which may be disappreciated by the woman. In some women, labia minora may be very small [5].

8.5.2 Which Sociocultural Factors May Be Addressed Influencing the Request for Labia Reduction Surgery?

In the Western world, during the last two decades, female genitals have become more apparent in the public domain than ever before. In magazines, Internet sites, and television programs, female genitals are more explicitly shown than before, and

size and function are openly discussed. In addition, the visibility of female genitals has been enhanced in general due to the trend of shaving pubic hair. But here, perhaps, also a side effect of modern medicine may become visible. The more we technically can achieve, the less tolerant we become toward imperfection. In evolution, however, variability within the species prevails above individual standardization so there will always be "anomalies," even without clear functional status. In a world dominated by and obsessed with "youthful appearance," all aspects of the female body, except for the breasts, should be "small."

In daily language, vulvas are usually called "vaginas," which might suggest that female genitalia consist mainly of the "inner genitalia" (vagina, uterus, ovaries, etc.), while women, just like men, clearly have visible external genitalia (labia majora, labia minora, clitoral hood, and clitoral tissue).

In erotic and soft-porn magazines and Internet sites, it is common to digitally remove protruding labia minora. Although there is a wide variety of vulvar appearances, numerous aesthetic clinics market labiaplasty procedures by falsely suggesting that "normal" labia minora should be smaller than and lying beneath the level of the labia majora. While protruding labia minora are very common, these suggestions and advertisements give it a negative meaning, possibly influencing women negatively with regard to their genital body image [2]. Women considering labia reduction surgery are mostly influenced by television programs and secondly by magazines [8]. Furthermore, personal predisposition of the physician and gender may influence the way women seeking labiaplasty are counseled. A Dutch study revealed that plastic surgeons are more inclined to perform a labia reduction procedure as compared to gynecologists. And male physicians are more open to this procedure than female physicians [15]. Because surgical intervention is invasive and irreversible and health-care resources are scarce, the request for labia surgery addresses more than just "a matter of taste" or cultural norms. It forces us to make a deliberate choice in which different types of reasoning may be followed.

8.5.3 What Are Characteristics of Women Seeking Labia Reduction Surgery?

In comparison to controls, women seeking labiaplasty do not seem to be more anxious or depressed, neither did they experience more adverse childhood events. However, the latter express reduced sexual satisfaction and less satisfaction with genital appearance and more distress about their genital appearance than control women [10]. In a study comparing women seeking labiaplasty with healthy controls, the former more frequently reported that they received negative comments concerning the appearance of their labia minora, resulting in less satisfaction with the appearance of their own genitalia [16]. The size of the labia does not seem to be associated with satisfaction with the genital appearance. In some publications, it is reported that women mainly choose labiaplasty for their own personal reasons rather than for reasons determined by others [10, 16]. This is an interesting observation that reflects the Western vision on personal (here female) autonomy. This

is in contrast to more family-oriented cultures or to the evolutionary psychological perspective, in which man is an ultra-social species, for whom social reputation means everything [17]. Therefore, probably more interesting is the finding that in most women seeking labiaplasty, the size of the labia minora is within normal limits [6].

8.6 Specific Diagnostic Aspects

8.6.1 Which Medical-Ethical Considerations Should Be Made?

As discussed earlier (see *Facts and Figures* section), when a health-care professional is confronted with a request for labia reduction surgery, it is key to take into consideration that many interests may be relevant, which may support and/or contradict each other. These interests can be categorized, using the four medical-ethical principles: autonomy, non-maleficence, beneficence, and justice. This categorization is important in order to create insight into the professional's perspective, the patient's perspective, and the interaction between professional and patient and in order to tailor the counseling and decision-making process for the individual patient.

Each domain will be briefly discussed here, i.e., autonomy, non-maleficence, beneficence, and justice:

1. The first concept of *autonomy* requests that an adult patient without mental impairment has the final decision with regard to any medical procedure. Therefore, before consenting to the request, the physician should be convinced that there is no underlying disorder, such as body dysmorphic disorder, which not only may cause the current request but also question surgery as a solution. Furthermore, the decision of the patient should be her own and not be coerced by others. This autonomy is based on informed consent and/or health literacy. The patient needs to be completely informed and aware of not only possible risks and adverse outcomes but also her own and other women's vulvar anatomy.
2. Because surgery is always invasive and irreversible, secondly, *non-maleficence* is binding and obligatory. This concept allows the physician to refuse to perform the intervention requested if he or she feels that the operation might harm the patient. This means that autonomy of the patient is restricted by the physician's views.
3. Thirdly, *beneficence* means that if a physician decides to perform the operation, he or she needs to be skilled and have sufficient experience with the technique in order to obtain the optimal results. While this is frequently only interpreted from a technical viewpoint, beneficence also requires a chronological or developmental perspective: Will the patient still be happy in 5 or 10 years?
4. Fourthly, the concept of *justice* concerns the consideration of the manner in which societal resources are used. On the one hand, necessary treatments should be available and accessible for everyone; on the other hand, excess should be prevented. Labia reduction surgery might be seen as "luxury medicine," which

may weigh too much on scarce health-care funds. In contrast, if there are circumstances in which it is accepted practice for some patients, one has to have strong arguments to be able to refuse it for others. It is also important to be aware of the fact that new medical possibilities create new norms and thereby also a new market. Orthodontia, in the beginning of its usage, was a solution for children with pathological dental growth. Now it has become the (social) norm. Especially when clear pathology is lacking, the concept of justice becomes very complex, i.e., requires the deliberation of many nonmedical values.

It is important to notice that, within each domain, pros and cons may interact. Surgery may be positive for the feeling of autonomy at the moment, but negative from a feminist perspective (a debate comparable to the issue of wearing head scarves). Also, conflicts between the different domains may rise. For instance, surgery may contribute to autonomy, but may be detrimental to justice. In order to make a *balanced* decision as a physician, one has to be sure that "all elements are present in the equation." This requires a thorough history taking.

8.6.2 Which Issues Should Be Addressed in History Taking?

In women with vulvar complaints and/or request for labia reduction surgery, a thorough history should be taken [18]. It is important to examine which possible factors might be the reasons behind the request. A biopsychosocial approach should be used to examine the full scope of the underlying complaint. In addition to history taking, the physician can make use of validated questionnaires (Genital Appearance Scale (GAS) and Cosmetic Procedure Screening-Labia (COPS-L)) to obtain better insight into genital satisfaction and to screen for body dysmorphic disorder [10]. It is essential to have an open attitude in order to invite the patient to express herself about the complaint and its consequences for her. Ask the patient what she expects that the operation will bring her. Be aware of previous traumatic experience, such as childhood abuse and adverse sexual experiences that might affect satisfaction with the genital appearance and/or the decision-making process. If thinking about the current appearance of or about vulvas at all is unbearable for the patient, if things cannot be put into words, how do you come to a well-balanced decision?

It depends on the reaction of the patient how the conversation and the examination will develop. In Fig. 8.1 some examples are depicted depending on how the conversation might develop.

After the examination, it may be helpful to show the patient various pictures of the normal range of labia. This intervention is under research, since in an experimental condition, it was found that women not seeking labia reduction surgery who were confronted with a series of normal vulvas developed a more positive genital self-esteem as compared with control women who were confronted with neutral objects [19].

One should especially be aware of paradoxical communication: women who confirm that there is indeed no abnormality, but still…. Often our explorations stop

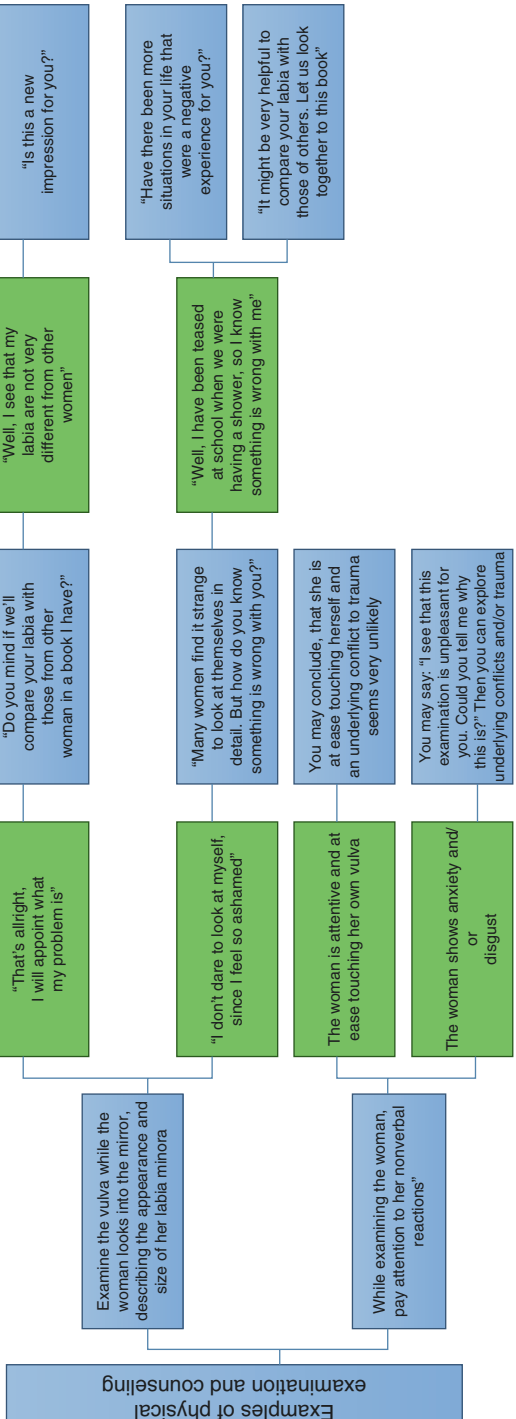


Fig. 8.1 Examples of physical examination and counseling. In the *blue* boxes the actions and verbal expressions of the health-care professional are depicted and in the *green* boxes the verbal and nonverbal reactions of the patient

here. Sometimes, because of too much empathy, we forget to ask them: "But still…?" and then listen carefully. Often, then deeper yet more painful conflicts become visible. In such a case, it often also becomes understandable that apparently realistic young women have this "remarkable" request. Normal genitalia but still opting for an operation! If this happens, a new situation is created which sometimes solves the problem and ends the request, but more often makes referral necessary to a psychologist or sexologist.

8.6.3 Which Physical Examinations Should Be Carried Out?

The gynecological examination should be carried out in close collaboration with the patient, who receives a hand mirror in order to observe as well. Some women have never examined their genitals in detail. This may also be a sign of paradoxical communication because how do they know that their genitals are abnormal then? The woman is seated in the gynecological chair.

After spreading the labia minora with as little traction as possible, the horizontal distance between the basis (i.e., the remains of the hymen or carunculae hymenales) and the lateral widest part of the labium is measured in millimeters. The measurement is carried out by using a disposable measuring tape. It is important to note that inter- and intra-observer variability is high. It is also advisable to examine the labia from the perspective of the patient by examining the labia through the mirror standing next to her. During the examination, the physician gets the opportunity to explain anatomy and function of the different aspects of the external genitalia, but also explains the phenomenon of "the artist perspective." If you look downward, e.g., toward your legs, they look completely different than when you look from a 90° angle. If possible, show the patient pictures of various women afterward and see how the patient reacts. Sometimes there is an aversion to *the* vulva and not to *her* vulva. Take notice of possible vulvar skin diseases, such as lichen sclerosus, which may be the source of complaints [18].

Case History (Continued)

After having explained the procedure, Julia Carmine agrees to a gynecological examination. Audrey Rose examines her and asks her, with the help of a hand mirror, to point out which part of her labia make her look like a "freak." She notices that Julia has quite flat labia majora, which she frequently observes in slender adolescent girls, and that her labia minora protrude between her labia majora. Loosely measured from the hymen to side, the labia each measure 3.5 cm. Audrey explains to her that these measures are within the normal range of labia minora but that, due to her rather flat labia majora, the normal labia minora may look and feel prominent. When Julia is dressed again, Audrey summarizes her findings and indicates to Julia that the current prominence of her inner labia is not only within normal range but also may change

over time. For Julia it is difficult to believe that her labia are normal, and she asks what she should do about her complaints.

Such patient reactions make clear that only explaining is not sufficient. It is necessary to ask questions. In this way the patient allows us to relativize the complaint and/or explains to us the real conflict. "Yes, but I may/can/dare not to…." This allows us to ask her "Could you please explain why an operation is the solution for this problem?"

8.7 Specific Therapeutic Aspects

8.7.1 How Is Labia Reduction Surgery Performed?

There are different methods to perform labia reduction surgery [18]. In Fig. 8.2a–g [20], the different methods are depicted. The most common method is peripheral resection of the labia (Fig. 8.2a, g). The risk of complications with this technique is small, but the appearance of the outer labia does not resemble normal labia minora any longer. Some authors warn of contractions of the straight scar and of painful neuromas, both of which can occur at the edge of the labium. The W-technique (also called "zigzag technique," Fig. 8.2g) is a modification, which might prevent these scar complaints.

A second technique is the combined peripheral and central resection (Fig. 8.2b–d). With this technique a V-formed wedge is removed from the most protruding part of the labium. Subsequently, the remaining parts are stitched together. This technique is recommended for cosmetic reasons because the pigmentation of the free edge of the labium is better preserved than in the peripheral resection techniques.

A third technique is the central resection or de-epithelialization technique (Fig. 8.2e, f). This technique excises or just de-epithelializes a central surface of the labium corresponding with the size of the planned reduction. After excision the wound edges are approximated. After de-epithelialization, the de-epithelialized part is folded in itself and buried by stitching of the wound edges being formed. The latter technique saves the neurovascular supply of the free edge of the labium.

The procedure may be carried out under local, regional, or general anesthesia, depending on the setting, experience of the surgeon, and preference of the patient. In the techniques a part of the labia is resected, which is irreversible.

8.7.2 Which Contraindications Can Be Identified?

The procedure should not be carried out in women under 18 years of age, since their external genitalia are usually still developing during adolescence. Furthermore, operating on external genitalia may disturb their psychosexual development.

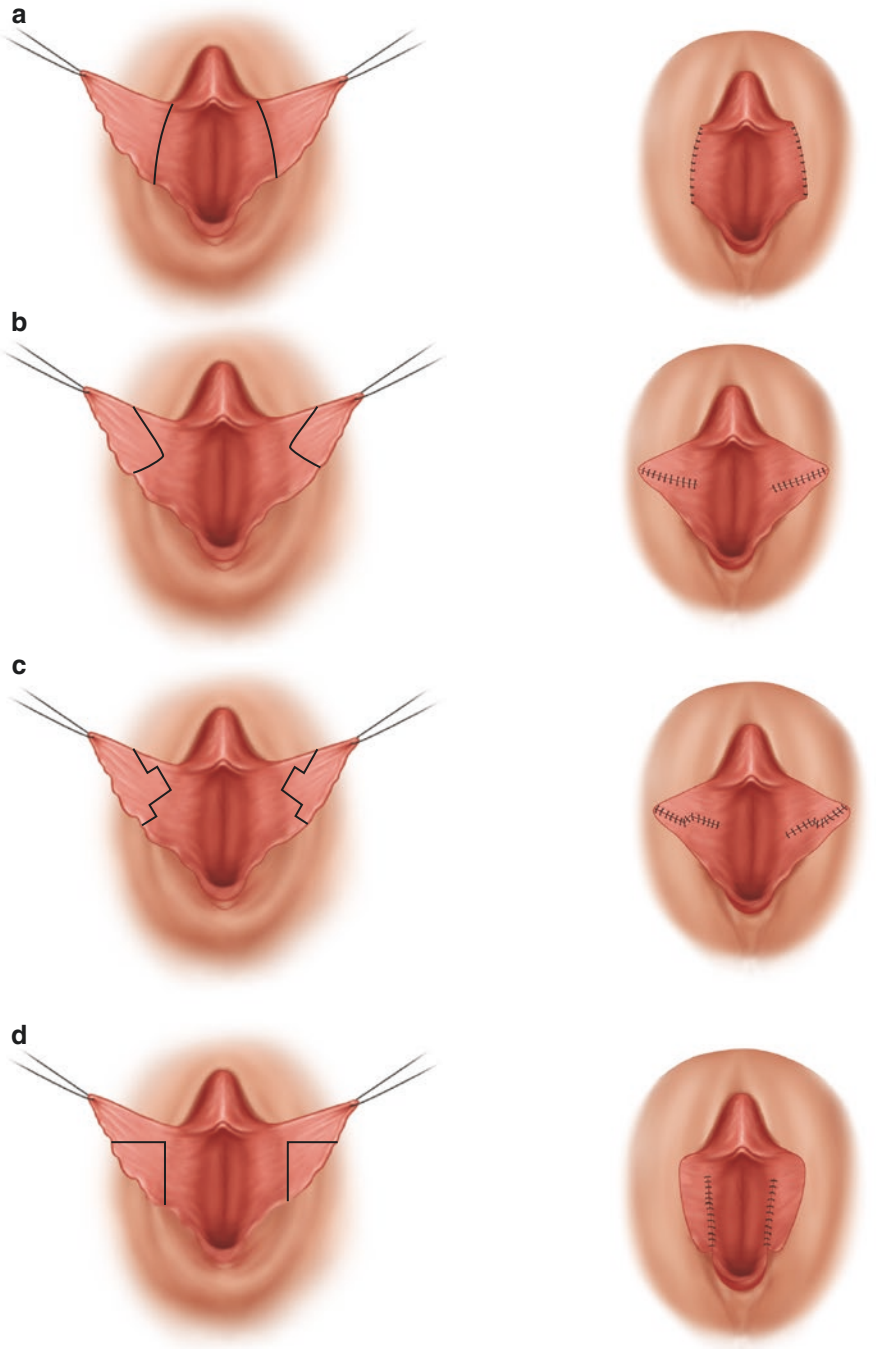


Fig. 8.2 (**a**–**g**) Different methods of labia reduction surgery (Following, with permission, Hage and Maas [20])

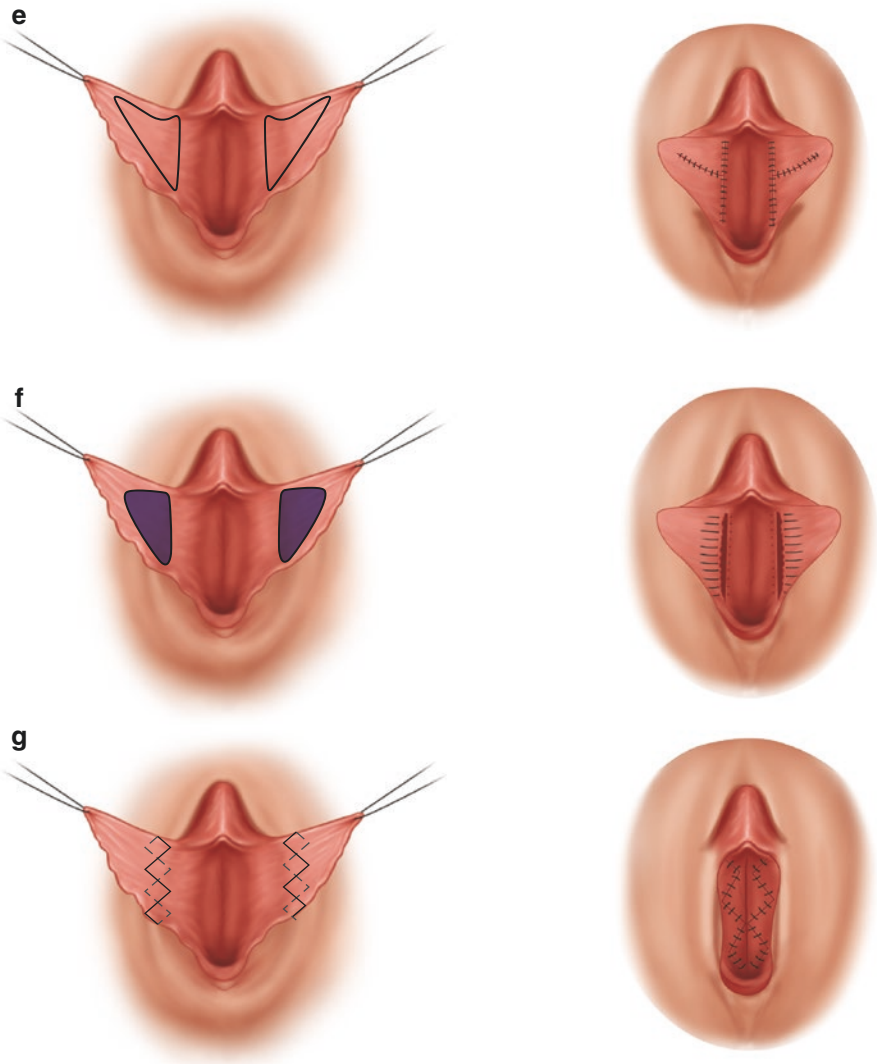


Fig. 8.2 (continued)

It is advisable to counsel these girls together with a (pediatric) psychologist or a (female) sexologist in order to check for body dysmorphic disorder and underlying psychological causes of the request.

One should also refrain from operating in the following situations: when labia are within the physiological range [5], when there is a discrepancy between the complaints and the appearance of the labia, when the patient has unreal expectations of the results of the surgery, when there are clear signs of body dysmorphic disorder, or when there is a chronic vulvar pain problem [18].

8.7.3 What Are the Results of Labia Reduction Surgery?

There are relatively few data on the outcomes of labia reduction surgery. Most articles published on this subject are anecdotal and report on retrospective studies. They usually describe the indications, the different techniques, and the kinds of complications [21]. Long-term outcomes have not been described. This has to be reported to the patient, including the absence of knowledge on the effects on giving birth.

In a case-comparison study, the majority (96 %) of the women who underwent labiaplasty showed an improvement in genital appearance satisfaction and sexual function, which remained at 91 % until 42 months after surgery [22].

The most important complications of the procedure described are wound dehiscence (7.6–13.3 %), hematomas (4.7–40.0 %), and superficial dyspareunia (23 %) [21]. In addition, Veale et al. [22] also reported problems with urination (sometimes spraying); aesthetic concerns, such as noticeable scarring; and reduced sexual arousal. Proportionality is a factor that may give rise to aesthetic problems postoperatively when this is not adequately addressed beforehand. For instance, when the clitoral hood is covering the clitoral tip and reduction of the labia minora has taken place without reduction of the clitoral hood, the clitoral hood can look larger than before, and patients may complain of prominence of the clitoral hood and ask for a surgical correction of this imbalance [23].

It is not yet known what the effects of having labiaplasty at a young age might be in postmenopausal women.

8.8 Critical Reflection and Conclusive Remarks

Dissatisfaction with genital appearance in women has become more apparent in the Western world in the last decades, resulting in an increased demand for labia reduction surgery. Both the societal influence and the availability of the procedure in both community hospitals as well as in private clinics have contributed to this increase.

The individual physician might encounter difficulties when a woman with apparently normal external genitalia requests labia reduction surgery. Given the fact that relatively few women have labia outside the normal range, it is advisable to have a structured approach in which the emphasis lies on the “why” of the request, as has been described previously. It is important to address the concerns of the patient more than superficially. Do try to find out what the cause of her complaint is and what the best solution is in her specific situation. This may or may not be an operation; frequently just listening, educating, and providing emotional support are sufficient. Sometimes, however, more is needed. The patient might need psychological counseling for decreased self-esteem or previous traumatic history.

However, some women may benefit from an operation. In that case, it is important to realize that no long-term results (none beyond 42 months) have been published yet. Currently, intervention studies are carried out to investigate whether satisfaction with genital appearance and functioning might be increased without labiaplasty.

Tips and Tricks

1. Try to find out why the woman thinks she needs a labiaplasty in order to counsel her optimally. What is the problem and why is an operation the solution?
2. Give information about normal anatomy and physiology of the external female genitalia [5].
3. Summarize the consequences of her complaint(s) from a biopsychosocial perspective.
4. Possible helpful methods:
   - Regarding discomfort in clothing: suggest less tight-fitting clothes and cotton underwear. Propose a 6-week "pilot study" and then evaluate her experiences. If this suggestion is refuted as not practical, note that a surgical intervention is also "not practical."
   - Regarding discomfort with cycling: suggest another type of bicycle seat. There are bicycle seats with openings at the front. Also, special biking shorts may be helpful. Consider a "pilot study" as noted above.
   - In case of entry dyspareunia, while there is no anatomical pathology, there is nearly always a lack of sexual arousal preventing the labia minora from swelling, spreading apart, and especially getting lubricated.
   - If, despite enduring sexual arousal, entrance remains difficult, the labia can be spread by the woman herself. Many women do not touch their own genitalia or there may be cultural barriers regarding this advice. If this is the case, it should be discussed how surgery could be a "preferred" solution.
5. Show pictures of normal genitalia. The book *Femalia* by Joani Blank might be useful [24] as is the website: The Great Wall of Vagina (http://www.greatwallofvagina.co.uk/home).
6. If possible, view these pictures as well as the patient's own genitalia together with the patient and see how she reacts. Describe emotional reactions in an open and empathetic way.
7. Extract clear statements about the desired results of the operation and make clear statements about what results can be realistically expected.
8. Collaborate closely with a psychologist or sexologist.
9. Describe the operation with the different techniques in detail, including the complication risks and the unknown long-term effects. Safety and effectiveness are not well documented scientifically.
10. Check for contraindications.

Case Description (Continued)
When Julia Carmine asks Audrey Rose what she is going to do about her complaints, Audrey realizes herself that explanation and reassurance are not enough. Because Audrey still feels that an operation is not the solution and in fact will do more harm than good, she changes to a psychotherapeutic approach. Instead of giving her suggestions, she starts to challenge Julia, in this case by "expanding" some of the patient's cognitions.

"OK, Julia, so you agree with me that your vulva looks absolutely normal and yet you still want an operation. I see that your face and hands look all right so we might operate those as well?"

This breaks the ice and Julia starts laughing. "Yes, that's strange, however… if I'm wearing tight jeans and I enter the classroom, I have the idea that everybody is staring at my crotch and can see those hideous things."

Audrey reacts in an empathic, however, also challenging way, "If you think everybody is staring at your crotch, I can imagine that you feel embarrassed, with or without your kind of labia. But tell me: are you so special that when you enter the classroom everybody is looking at you? And do you always wait until everybody is seated before you enter the class?"

Julia starts laughing again and tells Audrey that this is not really happening. She admits that these are her "ideas" about how things might go. Audrey immediately confirms that these kinds of thoughts are normal, especially for a woman of her age. At the same time, she emphasizes that there is a difference between reality and thoughts. When Julia nods, Audrey asks her, "So if you still want an operation, and given the fact that these ideas are in your head, should we best ask for a brain surgeon?"

This pattern of question and answering and thereby challenging problematic cognitions reveals that Julia finds it very difficult to be different in all respects. When Audrey questions what makes her unique, what makes her Julia and not her sister or any of her friends, she loosens up a bit. She admits that the problems are not her (vulvar) looks, but her thoughts about her appearance.

After a while Audrey brings up the idea of discussing these feelings about physical appearance with someone more specialized in this domain, e.g., a psychologist or social worker. Julia agrees to think about being referred.

Test Your Knowledge and Comprehension

1. The size of labia minora width varies between 0.7 and 3.5 cm.
   (a) True
   (b) False
2. The majority of the women requesting labia reduction surgery have physical complaints of their labia minora.
   (a) True
   (b) False
3. Peripheral resection of the labia minora can cause formation of neuromas and scarring.
   (a) True
   (b) False

4. Women with chronic vulvar pain might be candidates for labia reduction surgery.
   (a) True
   (b) False
5. Genital appearance satisfaction and sexual function have been shown to improve after labia reduction surgery.
   (a) True
   (b) False
6. Which of the following circumstances is *not* associated with hypertrophic labia?
   (a) Chronic irritation due to rubbing in incontinence diapers
   (b) Frequent sexual intercourse
   (c) Lymphedema of the labia minora
   (d) Manually elongating labia minora
7. Which kind of physician is most inclined to perform labia reduction surgery?
   (a) Male gynecologist
   (b) Female gynecologist
   (c) Male plastic surgeon
   (d) Female plastic surgeon
8. Which aspects are more reported in women asking for labia reduction surgery compared with controls?
   (a) Negative comments concerning their labia
   (b) Anxiety
   (c) Depression
   (d) Adverse childhood events
9. Concerning the medical-ethical principles, the following is *true*:
   (a) *Autonomy* is hierarchically the most important medical-ethical principle; therefore the patient may choose for the operation, even when the doctor disagrees with it.
   (b) Since labia reduction surgery is elective surgery, the doctor is the one to decide on it based on the *justice* principle.
   (c) Even though *autonomy* is the first medical-ethical principle, on the basis of *non-maleficence*, the doctor may refrain from operation, if he/she thinks that the operation might harm the patient.
   (d) If the results of surgery are not satisfying to the patient, she can accuse the doctor for malpractice based on the principle of *beneficence*.
10. Which of the following is not a contraindication for labia reduction surgery?
    (a) Chronic vulvar pain
    (b) Discrepancy between complaints and aspect of labia
    (c) Trauma of the labia after vaginal delivery
    (d) Unreal expectations of surgery

Answers

1. False
2. False
3. True
4. False
5. True
6. b
7. c
8. a
9. c
10. c

References

1. Bramwell R, Morland C, Garden A. Expectations and experience of labial reduction: a qualitative study. BJOG. 2007;114(12):1493–9.
2. Liao LM, Creighton SM. Requests for cosmetic genitoplasty: how should healthcare providers respond? BMJ. 2007;334(7603):1090–2.
3. Bagnol B, Mariano E. Vaginal practices: eroticism and implications for women's health and condom use in Mozambique. Cult Health Sex. 2008;10(6):573–85.
4. Koster M, Price LL. Rwandan female genital modification: elongation of the labia minora and the use of botanical species. Cult Health Sex. 2008;10(2):191–204.
5. Lloyd J, Crouch NS, Minto CL, Liao LM, Creighton SM. Female genital appearance: "normality" unfolds. BJOG. 2005;112(5):643–6.
6. Crouch NS, Deans R, Michala L, Liao LM, Creighton SM. Clinical characteristics of well women seeking labial reduction surgery: a prospective study. BJOG. 2011;118:1507–10.
7. Women's Health Victoria. Women and genital cosmetic surgery. Women's Health Issues Paper; 2013. Report No: 9.
8. Koning M, Zeijlmans IA, Bouman TK, van der Lei B. Female attitudes regarding labia minora appearance and reduction with consideration of media influence. Aesthetic Surg J. 2009;29:65–71.
9. Rouzier R, Louis-Sylvestre C, Paniel BJ, Haddad B. Hypertrophy of labia minora: experience with 163 reductions. Am J Obstet Gynecol. 2000;182(1 Pt 1):35–40.
10. Veale D, Eshkevari E, Ellison N, Costa A, Robinson D, Kavouni A, et al. Psychological characteristics and motivation of women seeking labiaplasty. Psychol Med. 2014;44(3):555–66.
11. Onden-Lim M, Wu R, Grisham JR. Body image concern and selective attention to disgusting and non-self appearance-related stimuli. Body Image. 2012;9(4):535–8.
12. American Psychiatric Association. Desk reference to the diagnostic criteria from DSM-5. Arlington: American Psychiatric Publishing; 2013.
13. Barrett MM, Carlson JA. A clinicopathologic study of labia minora hypertrophy: signs of localized lymphedema were universal. J Low Genit Tract Dis. 2014;18(1):13–20.
14. Kato K, Kondo A, Gotoh M, Tanaka J, Saitoh M, Namiki Y. Hypertrophy of labia minora in myelodysplastic women. Labioplasty to ease clean intermittent catheterization. Urology. 1988;31(4):294–9.
15. Reitsma W, Mourits MJE, Koning M, Pascal A, van der Lei B. No (Wo)man is an island – the influence of physicians' personal predisposition to labia minora appearance on their clinical decision making: a cross-sectional study. J Sex Med. 2011;8:2377–85.
16. Veale D, Eshkevari E, Ellison N, Costa A, Robinson D, Kavouni A, et al. A comparison of risk factors for women seeking labiaplasty compared to those not seeking labiaplasty. Body Image. 2014;11(1):57–62.

17. Wilson EO. Sociobiology: the new synthesis. Boston: Harvard University Press; 1975.
18. Paarlberg KM, Weijenborg PTM. Request for operative reduction of the labia minora; a proposal for a practical guideline for gynecologists. J Psychosom Obstet Gynaecol. 2008;29(4): 230–4.
19. Martoredjo D, Laan E. De invloed van blootstelling aan foto's van ongewijzigde vulva's op het genitale zelfbeeld van vrouwen. Tijdschrift voor Seksuologie. 2015;39:1–6.
20. Hage JJ, Maas SM. Aesthetic reduction of labia minora – oral presentation at the 10th annual meeting of the European Association of Plastic Surgeons (EURAPS). Madrid, Spain; 1999.
21. Ostrzenski A. Cosmetic gynecology in the view of evidence-based medicine and ACOG recommendations: a review. Arch Gynecol Obstet. 2011;284:617–30.
22. Veale D, Naismith I, Eskevari E, Ellison N, Costa A, Robinson D, et al. Psychosexual outcome after labiaplasty: a prospective case-comparison study. Int Urogynecol J. 2014;25(6):831–9.
23. Hamori CA. Postoperative clitoral hood deformity after labiaplasty. Aesthet Surg J. 2013; 33(7):1030–6.
24. Blanks J. Femalia. San Francisco: Down There Press; 1993.

A Woman Struggling for Control: How to Manage Severe Eating Disorders

9

Beate Wimmer-Puchinger and Eva Thurner

9.1 Introduction and Aims

The term "eating disorders" commonly refers to the cluster of 3 illnesses in the domain of food intake: anorexia nervosa (AN), bulimia nervosa (BN), and binge eating disorder (BED).

In terms of behavior:

- AN means eating extremely small amounts of food with the lowest calorie content possible. The thoughts of these patients are fixed on eating/postponement of eating and control, e.g., they are weighing themselves several times a day. They are dominated by compulsive thoughts and suffer from an extreme compulsion to exercise. A specific feature of AN is a distorted body image, i.e., the patient perceives their body as too fat and ignore their actual underweight.
- BN means that food is gorged hastily, which in turn triggers feelings of guilt and disgust and leads to an extreme preoccupation with purging the food that has just been eaten. This leads to a perpetual circle of uncontrolled eating and subsequent secret vomiting and/or laxating.
- BED means an extreme intake of food but without the purging. This means of course a high risk to become overweight or even obese.

B. Wimmer-Puchinger, PhD (✉)
Department of Applied Psychology, University of Salzburg, Salzburg, Austria
e-mail: beate@wimmer-puchinger.at

E. Thurner, MD
Department of Obstetrics and Gynecology/Psychosomatic Outpatient-Clinic for Women, State Hospital Korneuburg/Teaching Hospital of Medical University of Vienna (MUW), Korneuburg, Austria
e-mail: Eva.thurner@korneuburg.lknoe.at

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_9

Common to all patients with eating disorders is a basic feeling of inner emptiness, self-depreciation, depression, self-punishment, and excessive self-control.

9.2 Definition in Lay Terms

Eating disorders are severe psychiatric disorders characterized by an unnatural high or low weight or significant weight changes, a negative body image, and an eating pattern marked by restrictive food intake and/or binge eating, eventually followed by compensation mechanisms such as purging, excessive sporting, or laxative abuse.

9.3 Didactical Goals

After reading this chapter, you will know:

- When you should think of an eating disorder in a patient
- How common eating disorders are and which women are affected by them
- What are important issues taking the patient's history
- What physical examination should be carried out
- What secondary diseases may arise
- The psychodynamic background of eating disorders
- Which cultural aspects of body image play a role in eating disorders
- Which measures are effective in treatment of eating disorders

Case History

Sarah Violet, a 21-year-old woman, accompanied by her mother, comes to the psychosomatic outpatient department 7 months after the birth of her baby, which was delivered by a caesarean section because of labor arrest and a birth weight of 4.5 kg. She did not start breastfeeding after delivery. Linda Cerise, the gynecologist, is also informed that Sarah has had sleep disorders, gastric pain, amenorrhea, and mood swings ranging from depression to overexcitement since her pregnancy. She has lost 25 kg within just a few months and now weighs 85 kg.

What Linda knows from the patient's medical records is that there was a report to the Youth Welfare Office during pregnancy because of the difficult social background (unemployment, parental alcoholism, and difficult relationship to the father of the baby). Sarah's mother took custody of the baby. Moreover, Linda reads in the records that Sarah was already obese as a child and suffered from learning and concentration problems. What strikes Linda the most is the fact that the trauma surgery department's records show around 60(!) visits between the age of 10 and 20 because of different

Table 9.1 SCOFF questions

*S*ick	Do you make yourself *s*ick because you feel full?
*C*ontrol	Have you lost *c*ontrol over how much you eat?
*O*ne stone	Have you lost more than *o*ne stone (6.35 kg/14 lbs) recently?
*F*at	Do you believe yourself to be *f*at when others say you are thin?
*F*ood	Does *f*ood dominate your life?

Used with permission of BMJ Publishing from Morgan et al. [33]

injuries. Linda remembers her professor instructing her about diagnosing patients at risk for an eating disorder, "always differentiate the following fields of problems: (1) menstrual cycle, (2) check the SCOFF questions,[1] (3) check for sexual and/or domestic violence, (4) sleeping pattern, and (5) possible mood disorder."

Linda finds out that for Sarah the main problem is amenorrhea, since she is afraid of a new pregnancy but also afraid of gaining weight if Linda would treat her with oral contraception in order to control her menstrual cycle. After answering the "SCOFF questions" (Table 9.1), Sarah admits having frequent periods of "overeating" and self-induced vomiting since the age of 14. This started during her first relationship, had recovered after separation, and got worse after pregnancy again. She merely admits that she was regularly beaten by her first boyfriend.

Sleep and mood disorders let Linda think of sending Sarah to a mental health specialist. During this consultation, Sarah Violet realizes that she has severe problems—bulimia is just one of them. She agrees with at least 5 meetings at the psychosomatic outpatient department to work out a management plan. The sessions are planned with a 2–3-week interval.

9.4 Facts and Figures

9.4.1 What Are the Definitions of Eating Disorders?

Eating disorders represent a severe morbidity with a wide spectrum of subclinical to psychiatric symptoms. Please see *Diagnostic and Statistical Manual of Mental Disorders*, *Fifth Edition* (DSM-5), for the different definitions of anorexia (307.1), bulimia nervosa (307.51), and binge eating disorder (307.51).

[1] SCOFF questions: see Table 9.1.

9.4.2 How Common Are Eating Disorders?

Epidemiological studies are still needed to investigate the prevalence of eating disorders in a large population [1, 2]. Community studies assessing the incidence of eating disorders are limited [3]. As the Workgroup on Eating Disorders points out, "estimates of the incidence or prevalence vary depending on the sampling and assessment methods and many gaps exist in our current knowledgebase" [4]. The range of reported lifetime prevalence of AN among women is between 0.3 and 3.7 [5]. The median age for onset of AN in the general population is 18 years [5]. The lifetime prevalence of BN ranges from 1 to 4.2 %. For BN, the mean age of onset is 20.6 years. In a community survey with 24 124 respondents (average age 18+) across 14 developed countries, the lifetime prevalence for BN is 0.8 % on average and for BED 1.4 % [6]. The median age of onset of binge eating disorder is about 23 years [7].

9.4.3 What Are Special Risk Groups?

9.4.3.1 Adolescents and Young Women

In 90 % of the cases, eating disorders have their onset in girl's adolescence (before 25 years) [7]. Girl's adolescence has been regarded as the central time of onset of the disease, because the body's appearance changes significantly within a short period of time and the changes are more visible in girls than in boys. Moreover, especially in adolescence, young women are preoccupied with their looks. This makes them vulnerable for the media hype about perfect looks and normalized, shaped, overly slim bodies. This kind of stereotyping has a high risk of getting internalized as mental images and probably aggravates body dissatisfaction [8–11]. A last cause, which makes especially adolescent girls vulnerable for developing eating disorders, is that adverse or traumatic life events, such as physical and sexual abuse, often because of severe family problems, cannot be resolved in a normal way. They have to take their refuge in pathological coping mechanisms such as eating disorders, self-harm, suicide, addiction, and depression.

9.4.3.2 Middle Age

Recent literature addresses an increase of eating disorders in middle-aged patients [12]. For 69 % of these women, the first onset of the disease started at this age, while 21 % had a chronic eating disorder. In an Austrian study of 1500 women between the ages of 40 and 60 years, 4.6 % of these women had an eating disorder, mainly BN and BED [13]. Reported risk factors for eating disorders at this age are unresolved mourning, body image concerns, and conflicts with aging, loneliness, depression, and anxiety disorders [14, 15].

9.4.3.3 Pregnant Women

Pregnancy is another very sensitive period. The transition of social role, adapting emotionally to becoming a mother as well as to the physical changes, is challenging for many women. In this respect, weight gain during pregnancy may be difficult to handle for pregnant women with a history of eating disorder [16–18]. Furthermore,

spontaneous abortion and hyperemesis gravidarum occur significantly more often in this patient group [19, 20]. Another aspect that occurs more frequently in women with eating disorders is fertility problems [21]. Some women who have had an in vitro fertilization (IVF) have a medical history of eating disorder. Steward et al. found that 7.6 % patients of a fertility clinic suffered from BN [22]. Moreover, in pregnant women, negative feelings toward the pregnancy have been described. And after delivery, difficulties with bonding with the infant and feeding problems are quite common. These effects are due to the mother's own fear of gaining weight being projected onto the baby. Normal weight babies are perceived as having too much weight [23–25].

9.4.4 Which Physical Complications May Occur?

Eating disorders may cause a number of complications. Table 9.2 shows a list of these complications, as well as the examinations that can be carried out.

Case History: Continued

In the second meeting, gynecologist Linda Cerise discusses Sarah Violet's eating behavior in more detail. Sarah understands that she uses food as a "mood regulator" and that her gastric pain is related to bulimia nervosa, due to excessive induced vomiting resulting in acid erosion of the esophagus. Meanwhile, Linda gets the results from laboratory tests as well as hormone levels and abdominal and renal sonography, all of which are normal. To enhance compliance, Linda explains to Sarah the effects and side effects of oral contraception.

While talking with Sarah, Linda experiences that it is difficult to convince Sarah to see a mental health professional. However, Sarah describes to Linda that she wants first and foremost to gain better control over her emotional outbursts, which lead to severe disputes with her partner. Following that, she acknowledges that she has problems getting out of bed and feels unable to cope with the needs of her child. Mostly, her mother takes care of these tasks.

Linda explains that she is a gynecologist who may be able to suspect a mental health problem but is not able to diagnose or treat such a problem. Sarah understands that and finally agrees to a consultation.

The next appointment takes place after Sarah's consultation with a psychiatrist and psychotherapist who prescribes sertraline. Because he also considers Sarah to have a personality disorder of a compulsive type, he also prescribes quetiapine (an atypical antipsychotic drug).

The third meeting with Sarah and her mother makes clear that outpatient treatment will not be sufficient. Sarah is not able to structure her daily life nor keep any agreement with members of her family nor take the remedies regularly. This means she will need a more continuous treatment. She agrees to be admitted at a day care department of the social-psychiatric ward. The referral was, of course, done in Sarah's presence and with her explicit consent.

Table 9.2 Physical complications of eating disorders

Organ systems	Signs and symptoms	Laboratory studies/physical examination
Whole body	Low body weight; dehydration, weakness; lassitude; hypothermia	Check weight every visit; make sure patient has not artificially increased weight by drinking water or putting objects in her clothes
Cardiovascular	Orthostatic hypotension, palpitations, arrhythmias, bradycardia, dizziness, mitral valve prolapse, chest pain, cardiomyopathy in ipecac abusers	ECG; prolonged PR and QTc intervals; ST-T wave abnormalities Chest X-ray: small heart
Endocrine, metabolic, reproductive	Fatigue; cold intolerance, low body temperature; oligomenorrhea; amenorrhea; decreased libido; infertility; arrested sexual development; increased pregnancy and neonatal complications	Decreased T3, T4, hypokalemia (with hypokalemic hypochloremic alkalosis), hypomagnesemia, hypophosphatemia, increased serum cortisol, increased serum cholesterol, decreased estrogen, prepubertal patterns of LH, FSH Pelvic ultrasound: lack of follicular development
Musculoskeletal	Weakness, muscle wasting, bone pain, pathological fractures, point tenderness	DEXA scan reveals osteopenia or osteoporosis in hip and lumbar spine
Central nervous system	Depression, cognitive and memory dysfunction, irritability, apathy, seizures (rare), obsessiveness	Cortical atrophy, ventricular enlargement in CT and MRI, abnormal cerebral blood flow in PET scan, abnormal EEG Vitamin deficiencies, increased serum carotene
Gastrointestinal	Bloating, abdominal pain, Mallory-Weiss tears; constipation, pancreatitis	Occasionally abnormal liver functions, increased serum amylase, abnormal bowel sounds
Hematologic	Bruising/clotting abnormalities	Anemias (normocytic, microcytic, macrocytic), decreased sedimentation rate, thrombocytopenia, decreased B_{12}, decreased folic acid

ECG electrocardiography, *LH* luteinizing hormone, *FSH* follicle-stimulating hormone, *DEXA* dual energy X-ray absorptiometry, *CT* computed tomography, *MRI* magnetic resonance imaging, *PET* positron emission tomography, *EEG* electroencephalography
Used with permission of Elsevier from Zerbe [33]

9.5 Etiology and Pathogenesis

Eating disorders may result from different causes, and often, like in our case description, there seems to be a confluence of comorbidity and psychosocial risk factors. Because no large-scale or long-term epidemiological studies are available, etiology is described in terms of risk factors.

9.5.1 What Are the Symptoms of an Eating Disorder (AN, BN, BED)?

Eating disorders may cause gynecological, fertility, and obstetrical symptoms.

When one wants to understand eating disorders, the most apparent symptoms are a negative body image, body dissatisfaction, and a basic feeling of lacking self-confidence. Next to these three most prominent symptoms, a wide variety of other symptoms may occur, as depicted in Table 9.3. Table 9.3 shows an overview of risk factors and symptoms of the somatic, the mental, and the social level.

Table 9.3 Symptoms and characteristics of eating disorders

Below you will find a list of symptoms and characteristics at the *somatic*, *mental*, *and social levels*, which may also occur *in early stages of an eating disorder* and may point to this type of psychological disease
Somatic level
Amenorrhea
Weight loss
Weight gain
Digestion problems (particularly meteorism—raw fruit and vegetables, increased food intolerances)
Dysphagia
Nausea
Destruction of dental enamel
Rhagades of the corner of the mouth
Chemical burns on hands from vomiting
Hair loss
Deficiencies revealed by blood tests (cave: hypokalemia, hyponatremia)
Decreased urine specific gravity—polydipsia
Cardiovascular problems
Tachycardia
Low blood pressure
Fainting
Sleep disorders
Excessive exercising
Underweight after delivery
Mental level
Compulsive thoughts
Compulsive behavior
Depression
Anxiety
Other comorbidities: drugs, alcohol, pharmaceuticals
Strong performance orientation
Strong body awareness
Low self-confidence despite obvious skills and abilities
Dependent personality
High degree of adaptability

(continued)

Table 9.3 (continued)

Weight monitoring (extremely accurate and fast provision of weight information)
Strong preoccupation with food
Excessively healthy diet
Social level
Critical life events
Traumatic experiences (sexual abuse)
Life transition crises
Separation crises
Crises at school or at the workplace
Change of residence
Social withdrawal
"Picture book family"
"Façade family"
Apparently harmonious relationships but with symbiotic ties

Courtesy of the Wiener Programm für Frauengesundheit, Vienna, Austria: http://www.frauengesundheit-wien.at/

Anorexia nervosa is characterized by being severely underweight, which suppresses the hypothalamic hypopituitary axis. Gynecological, fertility, and obstetrics effects of AN are:

- Gynecological effects: menstrual abnormalities, such as amenorrhea, oligomenorrhea, or irregular menses
- Fertility effects: infertility due to amenorrhea or oligomenorrhea
- Obstetrical effects: increased risk of fetal growth retardation and vitamin deficiencies resulting in reduced birth weight and preterm delivery
- Postpartum: increased risk of feeding problems and an increased risk to suffer from postpartum depression

In bulimia nervosa, women are rarely underweight. Therefore, in only half of the women, suppression of the hypothalamic hypopituitary axis is present. Gynecological, fertility, and obstetrics effects of BN are:

- Gynecological effects: menstrual abnormalities, such as amenorrhea, oligomenorrhea, or irregular menses
- Fertility effects: infertility due to amenorrhea or oligomenorrhea
- Obstetrical effects: increased risk of fetal growth retardation and vitamin deficiencies resulting in preterm delivery

In binge eating disorder, women are usually obese. In this group, insulin resistance is more apparent. This leads to increased insulin levels, elevating androgen production. Polycystic ovary syndrome (PCOS) and hyperandrogenism are clinical

features of this phenomenon, which frequently occurs in women. Gynecological, fertility, and obstetrics effects of BED are:

- Gynecological effects: menstrual abnormalities, such as amenorrhea, oligomenorrhea, or irregular menses. Hyperandrogenism leading to hirsutism, acne, acanthosis nigricans, and, less commonly, clitoromegaly
- Fertility effects: infertility due to amenorrhea or oligomenorrhea
- Obstetrical effects: increased risk of pre-eclampsia, fetal macrosomia, fetal growth retardation, gestational diabetes, and obstructed labor with an increased risk for instrumental delivery or emergency caesarean section

9.5.2 Which Risk Factors Are Associated with Eating Disorders?

Risk factors of eating disorders are the following:

- Patient histories may show family conflicts or so-called façade families, which means that at first glance, everything looks great, but at a closer look, a pathological pattern can be identified (e.g., overprotection of children or even sexual abuse). Frequently, alcohol abuse in one parent and/or neglect during childhood has been present.
- Sexual, physical, or mental violence during childhood and adolescence is seen more frequently in women with eating disorders than in women without these disorders [26, 27].
- Self-harm behaviors, such as cutting arms or thighs, are more frequently seen, which may be a sign of borderline disorder and/or depersonalization as a consequence of a traumatic experience.
- An underlying depression must be assumed as an essential risk factor [5, 28].

All in all, the pathogenesis may vary depending on different comorbidities. More detailed psychodynamic explanation patterns would go beyond the scope of this chapter.

9.5.3 Which Sociocultural Factors May Play a Role?

A precursor to eating disorders has found to be previous dieting [29]. A current survey conducted in Vienna among 1427 girls and boys, aged 13–15 years, at 33 schools revealed that nearly one-third of the girls (31 % [95 % *CI*: 27–34 %]) is afraid or very afraid of gaining weight compared to 15 % of the boys [95 % *CI*: 12–17 %]), and 40 % [95 % *CI*: 36–43 %] of the girls reported that weight and shape influence their self-esteem considerably. Weight and shape are permanently checked, and eating behavior is dictated by calories, resulting in a destabilization of the hunger and satiety mechanism. Two-thirds of the girls surveyed often or constantly think about their appearance (95 % *CI*: 65–72 %), 16 % of the girls (95 % *CI*:

14–19 %) avoid specific foods due to weight and shape concerns, 11 % (95 % *CI*: 9–13 %) skip meals, 13 % (95 % *CI*: 11–16 %) use appetite suppressants, and another 13 % (95 % *CI*: 11–16 %) reported 24-h fasting [30].

There is evidence that there are links between body image dissatisfaction on the one hand and images in Western media and fashion industry of perfectly slim female bodies on the other, which can result in eating disorders [11, 31]. Women with different ethnicities and cultural backgrounds are also vulnerable for eating disorders [14, 28, 32]. Quite recently, eating disorders in middle-aged women have been recognized. This has to be explained by a culture of "young forever" as well as age discrimination. Since women's identities are more closely connected to their bodies and appearance, it is particularly they who feel the pressure.

Case History: Continued

Shortly after her stay at the day care unit, Sarah Violet comes to the psychosomatic outpatient department. Her hospital discharge letter states that she suffers from an emotionally unstable personality disorder. She received citalopram and quetiapine as well as chlorprothixene to be taken as needed. Sarah looks to be in a better state—optimistic—but has discontinued her stay without follow-up care; Linda had tried to convey to her the importance of follow-up care.

Eighteen months later Sarah comes again to the gynecological outpatient department with shifting symptoms of gastric and pelvic pain and spotting. She is afraid of pregnancy because she forgot to take her oral contraceptive. It seems she has fallen back to her former eating behavior. Examinations are without pathological findings.

Sarah gained a lot of weight and is in a very bad state. She has not taken her medication regularly for several months. The exam turns out to be difficult, spanning the requested decrease of her stay and the unwanted implications such as being addiction prone and gaining weight. Her relationship is at the brink of breaking up. She is constantly quarrelling with her parents. It seems that her wish for another child is ambivalent. Linda discusses Sarah with the psychiatrist, and he decides to refer Sarah to a long-term stay in a psychiatric hospital with a specialization in eating disorders.

9.6 Specific Diagnostic Aspects

9.6.1 What Are the Diagnostic Key Questions?

Zerbe [1] offers the following key questions for initiating a talk with patients when an eating disorder is suspected:

- Has there been any change in your weight in the past 6–12 months?
- Do you ever feel out of control with respect to your eating?

- Do you ever use laxatives or diuretics or vomit in order to lose weight?
- Do friends/family members tell you that you overexercise or don't eat enough?
- Do you spend a lot of time worrying about your appearance or thinking you are fat?

Also the SCOFF questionnaire [33] may be used as a screening instrument. See Table 9.1. A result of ≥ 2 "yes" answers indicates a likely case of AN, BN, or BED [33]. The sensitivity of the screening tool is quite high.

9.6.2 Which Symptoms Have to Be Checked?

Table 9.4 gives an overview of the symptoms that have to be checked and need further examination.

9.6.3 Which Physical and Laboratory Examinations Should Be Made?

In Table 9.5, the most important examinations are given.

Table 9.4 Symptoms of eating disorders prompting further examination

Weight loss more than 10 % within a month
Pulse under 60/min
Frequent collapses
Amenorrhea longer than 6 months
Frequent vomiting, constipation, or diarrhea
Cardiac rhythm disorder
Permanent sleep disorder
Bad teeth
Bad physical condition

Table 9.5 Examinations carried out in eating disorders

Physical examinations	Laboratory examinations
Weight check	Na+, K+, Ca+, Cl+, Mg+, phosphate, Fe+; hemoglobin level, coagulation tests, cholesterol, serum protein, blood glucose, ALAT, ASAT, gGT, amylase, urea, creatinine, vitamins B6, B12
ECG because of higher risk of arrhythmia	Hormones: estrogen, LH, FSH, TSH, T3, T4, cortisol.
Vital parameters: temperature, pulse, blood pressure	
Pelvic ultrasound in order to look for polycystic ovary syndrome (PCOS)	
DEXA scan	
EEG	
Gastroscopy	
Dentist	

ECG electrocardiography, *DEXA* dual energy X-ray absorptiometry, *EEG* electroencephalography

9.7 Specific Therapeutic Aspects

9.7.1 Which Specific Therapeutic Aspects Need to Be Considered?

9.7.1.1 Interdisciplinary Collaboration

When an eating disorder is suspected, it is important to follow an interdisciplinary approach in an outpatient setting And to strive for inpatient daytime care.

The separation of medical and psychotherapeutic functions may facilitate the process and may particularly help to avoid being involved in the patient's psychodynamics, for example, when "alliances" between parents, teachers, partners, and therapists are formed or when the patient seems to lack compliance.

The exchange between the different partners must be handled very sensitively in order to not compromise the working alliance with the patient. The unmasking of eating disorders is usually linked with shame and embarrassment and may therefore result in the patient's opposition to or rejection of the therapy. The main principle is to speak with the patient and not about her. The first step is to detect what the patient agrees to, such as preventing the body from dehydration, etc. The working alliance will be revised regularly during the therapeutic process.

9.7.1.2 Need of Hospitalization

In Table 9.6, the symptoms that are considered to be a serious reason for hospitalization are given.

9.7.2 What Is Required for a Successful Outpatient Setting?

- It is important for the patient to know that she is suffering from an eating disorder and the severity of it. She should be informed about its health consequences.
- Get a general idea of the duration and severity of the disease. For this purpose, family members or partners may be consulted after consent of the patient.

Table 9.6 Symptoms that should be regarded as reason for hospitalization

Weight loss more than 30 % within 3 months
Severe disorders of endocrinological and cardiorespiratory system
Hypopotassemia below 2.5 mmol/l
Hyponatremia below 125 mmol/L
Pulse under 40 bpm or blood pressure under 70 mmHg systolic
Frequent vomiting, constipation, or diarrhea
Blood urea nitrogen (BUN) more than 30 %
Body temperature under 36 °C
Severe depression
Suicidality
Psychosis

- Treatment begins with a specialized nutritionist who will give information about metabolic processes and nutrients and a nutrition schedule.
- Treatment steps have to be transparent.
- Schedule regular appointments in order to monitor her physical functions and mood.
- Maybe the patient needs medical support. If there are signs of post-traumatic stress disorder, depression, anxiety or distress, there is an indication to see a psychiatrist.
- Family members are frequently also in need of support. Joining a self-help group or attending family therapy may provide help and relief. Recommend self-help books.

Case History: Continued

Two years later: Sarah Violet is now 28 years old and comes to the gynecological outpatient department several times because she is pregnant again after having tried to conceive for a rather long time. She comes to the psychosomatic outpatient department one more time. Sarah brings in a new partner and seems to be relatively stable. She has her own flat (apartment). She takes sertraline as medical treatment and occasionally undergoes psychiatric and psychotherapeutic treatment. Her 7-year-old son lives with his grandmother, her mother.

The appointment at the psychosomatic outpatient department is about the pending birth of Sarah's baby, her urgent wish for analgesia during labor and her increasing states of anxiety. For this reason, her psychiatrist prescribed her fluoxetine (an anxiolytic) instead of sertraline. Linda discusses a birth plan with her, including the possibilities of induction of labor and epidural analgesia with support of an experienced midwife.

A pediatrician will be on standby in case of adaption problems of the baby's respiratory system, which occur more often as a consequence of her medication.

Sarah does not know if she wants to start breastfeeding after delivery. Linda Cerise discusses this subject with her and leaves it open for after delivery. There is an increased risk of postpartum depression; breastfeeding could be an avoidable additional stressor. She now is better able to control her eating behavior and to verbally express her wishes without showing massive physical symptoms.

9.8 Critical Reflections and Conclusive Remarks

The prognosis of eating disorders depends on the stage of the disorder at diagnosis, the severity of the symptoms, and possible comorbidities. In cases of discontinued treatment and change of care providers, which sometimes cannot be prevented even if the patient transfer is a "hand-to-hand" process, the prognosis may be worse.

It is important that psychiatric hospitals that treat women with eating disorders pay sufficient attention to nutritional programs. Long-term hospital stays sometimes counter the development of patients' autonomy and create new dependencies.

Medication-based treatment (e.g., with tranquilizers) may be overlooked or underestimated as a new potential for abuse as soon as the patient is discharged or experiences a life event.

In a number of patients, treatment is not very successful.

Here we have to ask the question: What should be considered as a "success"? All-too-rigid ideas entertained by care providers might be counterproductive. Sometimes a "holding pattern to prevent worse development" is all that can be achieved.

In conclusion, obstetricians and gynecologists should be aware of eating disorders in their patients, since these disorders are prevalent among women. Additionally, eating disorders may cause gynecological and obstetrical disorders. Gynecologists may help to detect eating disorders early, which improves the prognosis because the sooner women are diagnosed and treated the better the prognosis!

Tips and Tricks

When healthcare workers in obstetrics and gynecology suspect an eating disorder, they may use the SCOFF questionnaire [34] as a useful screening instrument (Table 9.1). A result of 2 or more "yes" answers indicates a likely case of AN, BN, or BED [36].

When women are screened positive, this has to be taken seriously leading to adequate referral to specialists in the field.

Test Your Knowledge and Comprehension

1. One of the possible consequences of bulimia nervosa in pregnant women is hyperemesis gravidarum.
   (a) True
   (b) False
2. You should think of hospitalization of a woman with anorexia nervosa if she loses weight of more than 10 % within 3 months.
   (a) True
   (b) False
3. One complication in a woman with bulimia nervosa is dental problem.
   (a) True
   (b) False
4. A frequent comorbidity in women with eating disorders is substance abuse.
   (a) True
   (b) False

5. One of the risk factors that may lead to an eating disorder is the excessive preoccupation with feeding and saturation in the mother-baby interaction.
   (a) True
   (b) False
6. A known risk factor for bulimia is (2 correct answers):
   (a) A personal history of posttraumatic stress disorder
   (b) Sleeping disorder
   (c) Familial history of eating disorder
   (d) Schizoaffective disorder
7. The percentage of women with infertility problems suffering from bulimia is about (1 correct answer):
   (a) 1 %
   (b) 7 %
   (c) 25 %
   (d) Same as the average of fertile women
8. Which treatment regimen does not have clear evidence of efficacy for bulimia? (2 correct answers)
   (a) Psychotherapy only
   (b) Nutrition rehabilitation only
   (c) Pharmacotherapy only
   (d) Psychotherapy as well as nutrition rehabilitation
9. Proposed guidelines for pregnant women or patients trying to conceive with a body mass index (BMI) under 18 are (2 correct answers):
   (a) Laboratory check for electrolytes
   (b) History of mental health treatment
   (c) Hormonal therapy
   (d) In vitro fertilization
10. Warning signs that a women with amenorrhea may have an eating disorder include (1 correct answer):
    (a) Sickness
    (b) Constipation
    (c) Feels fat at a BMI less than 18.5 kg/m^2
    (d) Collapses

Answers

1. True
2. False
3. True
4. True
5. True
6. (a) and (c)

7. (b)
8. (a) and (b)
9. (a) and (b)
10. (c)

References

1. Telch CF, Stice E. Psychiatric comorbidity in women with binge eating disorder. Prevalence rates from a non-treatment-seeking sample. J Consult Clin Psychol. 1998;66(5):768–76.
2. Spitzer RL, Kroenke K, Linzer M, deGruy F, Hahn SR, Brody D, Davies M. Health-related quality of life in primary care patients with mental disorders: results from the PRIME-MD 1000 Study. J Am Med Assoc. 1996;274:1511–7.
3. Smink FRE, Hoeken D, Hoek HW. Epidemiology of eating disorders: incidence, prevalence and mortality rates. Curr Psychiatry Rep. 2012;14:406–14.
4. American Psychiatric Association Workgroup on Eating Disorder. Practice guideline for the treatment of patients with eating disorders (revision). Am J Psychiatry. 2006;163:1–39.
5. Hudson JI, Hiripi E, Pope Jr HG, Kessler RC. The prevalence and correlates of eating disorders in the National Comorbidity Survey Replication. Biol Psychiatry. 2007;61(3):348.
6. Kessler RC, Berglund PA, Chiu WT, Deitz AC, Hudson JI, Shahly V, Aguilar-Gaxiola S, Alonso J, Angermeyer MC, Benjet C, Bruffaerts R, de Girolamo G, de Graaf R, Maria Haro J, Kovess-Masfety V, O'Neill S, Posada-Villa J, Sasu C, Scott K, Viana MC, Xavier M. The prevalence and correlates of binge eating disorder in the World Health Organization World Mental Health Surveys. Biol Psychiatry. 2013;73(9):904.
7. Anderson A, Ryan G. Eating disorders in the obstetric and gynecological patient population. Obstet Gynecol. 2009;114:1353–67. Cited by Fornari V, Dancyger I, Renz J, Skolnick R, Rochelson B. Eating disorders and pregnancy: proposed treatment guidelines for obstetricians and gynecologist. Open J Obstet Gynecol. 2014;4:90–4.
8. Becker AE, Burwell RA, Herzog DB, Hamburg P, Gilman SE. Eating behaviours and attitudes following prolonged exposure to television among ethnic Fijian adolescent girls. Br J Psych. 2002;180:480–2.
9. Orbach S. Bodies. London: Profile Books Ltd; 2009.
10. Grabe S, Hyde LM, Ward JS. The role of media in body image concerns among women: a meta-analysis of experimental and correlation studies. Psychol Bull. 2008;134(3):460–6.
11. Barlett CP, Vowels CL, Saucier DA. Meta-analysis of the effects of media images on men's body image concerns. J Soc Clin Psychol. 2008;27(3):279–310.
12. Lapid MI, Prom MC, Burton MC, McAlpine DE, Sutor B, Rummans TA. Eating disorders in the elderly. Int Psychogeriatr. 2010;22(4):523–36.
13. Mangweth-Matzek B, Hoek HW, Rupp CI, Lackner-Seifert K, Frey N, Whitworth AB, Pope HG, Kinzl J. Prevalence of eating disorder in middle-aged women. In J Eat Disord. 2014;47(3):320–4.
14. Zerbe KJ. Eating disorders in middle and later life. A neglected problem. Prim Psych. 2003;10(6):80–2.
15. Forman ME, Davies WN. Characteristics of middle-aged women in inpatient treatment of eating disorders. Eat Disord. 2005;13(3):231–43. Cited by Zerbe KJ. Eating disorders in the 21st century: Identification, management, and prevention in obstetrics and gynecology. Best Pract Res Clin Obstet Gynaecol. 2007;21(2):331–43.
16. Lemberg R, Phillips J. The impact of pregnancy on anorexia nervosa and bulimia. Int J Eat Disord. 1989;8(3):285–95.
17. Crow SJ, Agras WS, Crosby R, Halmi K, Mitchell JE. Eating disorder symptoms in pregnancy: a prospective study. Int J Eat Disord. 2008;41(3):277–9.

18. Fornari V, Dancyger I, Renz J, Skolnick R, Rochelson B. Eating disorders and pregnancy: proposed treatment guidelines for obstetricians and gynecologist. Open J Obstet Gynecol. 2014;4:90–4.
19. Micali N, Simonoff E, Treasure J. Risk of major adverse perinatal outcomes in women with eating disorders. BJP. 2007;190:255–9.
20. Micali N. Eating disorders and pregnancy. Psychiatry. 2008;7(4):191–3.
21. Easter A, Treasure J, Micali N. Fertility and prenatal attitudes towards pregnancy in women with eating disorders: results from the Avon Longitudinal Study of Parents and Children. BJOG: Int J Obstet Gynaecol. 2011;118(12):1491–8.
22. Stewart DE, Robinson E, Goldbloom DS, Wright C. Infertility and eating disorders. AM J Obstet Gynecol. 1990;163:1196–99. doi:10.1016/0002-9378(90)90688-4. Cited by Micali N. Eating disorders and pregnancy. Psychiatry. 2008;7(4):191–3.
23. Cooper PJ, Whelan E, Woolgar M, Morrell ML. Association between childhood feeding problems and maternal eating disorders: the role of the family environment. BR J Psych. 2004;184:210–5.
24. Kouba S, Hällström T, Lindholm C, Hirschberg AL. Pregnancy and neonatal outcomes in women with eating disorders. Obstet Gynecol. 2005;105:255–60.
25. Little L, Lowkes E. Critical Issues in the care of pregnant women with eating disorders and the impact on their children. J Midwifery Wom Health. 2000;45:301–7.
26. Zerbe KJ. Eating disorders in the 21st century: identification, management, and prevention in obstetrics and gynecology. Best Pract Res Clin Obstet Gynaecol. 2007;21(2):331–43.
27. Wonderlich S, Crosby R, Mitchell J, Thompson K, Redlin J, Demuth G, Smyth J, Haseltine B. Eating disturbance and sexual trauma in childhood and adulthood. Int J Eat Disord. 2001;30(4):401–12.
28. Mischoulon D, Eddy K, Keshaviah A, Dinescu D, Ross S, Kass A, Franko D, Herzog D. Depression and eating disorders: treatment and course. J Affect Disord. 2011;130(3):470–7.
29. Liechty JM, Lee MJ. Longitudinal predictors of dieting and disordered eating among young adults in the U.S. Int J Eat Disord. 2013;46(8):790–800.
30. Wimmer-Puchinger B, Langer M, Rathner E-M. Körperbild. Selbstwert und Essstörungen bei Wiener Jugendlichen: Unpublished Study; 2013.
31. Rohde P, Stice E, Marti N. Development and predictive effects of eating disorder risk factors during adolescence: implications for prevention efforts. Int J Eat Disord. 2015;48(2):187–98.
32. Gordan RA. Eating disorders: anatomy of a social epidemic. 2nd ed. Oxford: Blackwell; 2000.
33. Morgan JF, Reid F, Lacey HJ. The SCOFF questionnaire: assessment of a new screening tool for eating disorders. BMJ 1999;319:1467–68. Cited in Zerbe KJ. Eating disorders in the 21st century: Identification, management, and prevention in obstetrics and gynecology. Best Pract Res Clin Obstet Gynaecol 2007;21(2):331–43.

A Woman with Inexplicable Mood Swings: Patient Management of Premenstrual Syndrome

10

Teri Pearlstein and Shaughn O'Brien

10.1 Introduction and Aims

Premenstrual disorders are a combination of emotional, behavioral, and physical symptoms that are present in the days prior to and resolve shortly after menses. In some women, the severity of symptoms causes clinically significant distress and interferes with relationships and role functioning. This chapter discusses the definition of premenstrual disorders and how to determine the diagnosis, differential diagnoses, etiopathologic theories, and treatment options including antidepressant medications, hormonal strategies including suppression of ovulation, and nonpharmacological strategies.

10.2 Definition in Lay Terms

Premenstrual disorders are a combination of emotional, behavioral, and/or physical symptoms that are present in the days prior to menses and resolve shortly after menses. The severity of the symptoms causes clinically significant distress and interferes with relationships and role functioning. When premenstrual symptoms exist but are not problematic for a woman, no disorder should be diagnosed.

T. Pearlstein, MD (✉)
Women's Medicine Collaborative,
Department of Psychiatry and Human Behavior,
Alpert Medical School of Brown University, Providence, RI, USA
e-mail: Teri_pearlstein@brown.edu

S. O'Brien, DSc, MB, BCh, MD, FRCOG
Department of Obstetrics and Gynecology, University Hospital North Staffordshire,
Maternity Hospital UHNS, Stoke on Trent, UK
e-mail: Shaughn.obrien@uhns.nhs.uk

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_10

10.3 Didactic Goals

After reading this chapter you:

- Are able to describe the diagnostic procedure to confirm the diagnosis
- Are familiar with different classification schemes of premenstrual disorders (PMDs)
- Are familiar with the possible etiologies of PMD
- Are familiar with nonpharmacological strategies to treat PMD
- Are familiar with psychotropic medications to treat PMD
- Are familiar with hormonal strategies to treat PMD

Case History
Phyllis Ruby, a 30-year-old married woman with 2 children, presents for her annual exam with her general practitioner (GP). She tells her GP that 5–7 days prior to each menses, she has mood swings with sudden tearfulness, irritability, lack of patience with her husband and children, anger outbursts, sensitivity to criticism, and isolating herself in her bedroom when she can. She states that she previously had 2–3 premenstrual days of milder symptoms, but the symptoms have been more problematic since resuming menses following the birth of her second child 18 months ago. She asks her GP about treatment options since the symptoms are now interfering with her relationships with her husband and her children and her functioning as a homemaker. Phyllis and her husband are currently using condoms for birth control since they may want to conceive a third child in the next year. She denies previous psychiatric or medical problems.

10.4 Facts and Figures: Definitions, Classification, and Prevalence

10.4.1 What Is the Formal Definition of Premenstrual Disorder?

Premenstrual disorders are a combination of emotional, behavioral, and/or physical symptoms that are present in the days prior to menses and resolve shortly after menses. The severity of the symptoms causes clinically significant distress and interferes with interpersonal and role functioning. The symptoms typically peak near the onset of menses.

10.4.2 What Proportion of Menstruating Women Has Problematic Premenstrual Emotional and/or Somatic Symptoms?

Premenstrual symptoms occur in the general population of reproductive-age women on a continuum. Approximately 5% of women have several severe emotional, behavioral, and/or physical premenstrual symptoms that may last several days and

cause clinically significant distress and interfere with interpersonal and role functioning. In the *Diagnostic and Statistical Manual of Mental Disorders*, *Fifth Edition* (DSM-5) published by the American Psychiatric Association in 2013, this disorder is classified as premenstrual dysphoric disorder (PMDD) [1]. The degree of symptom severity and functional impairment is similar to other mood and anxiety disorders. Between 20 and 40% of women have premenstrual syndrome (PMS) with fewer, shorter-duration, or less severe symptoms, but the symptoms, though less debilitating, are still problematic and cause distress. Up to 40% of women have one or a few mild premenstrual symptoms that do not interfere with their quality of life or functioning, and they are unlikely to seek treatment.

10.4.3 What Is the Difference Between Premenstrual Syndrome and Premenstrual Dysphoric Disorder and Between Core Premenstrual Disorder and Variant Premenstrual Disorder?

In 2011, the International Society for Premenstrual Disorders published a classification of premenstrual symptoms that includes core premenstrual disorders (PMD) and variant PMD (Table 10.1) [2]. Core PMD is a classification system that includes both premenstrual dysphoric disorder (PMDD) and premenstrual syndrome (PMS).

10.4.3.1 Core Premenstrual Disorders

Core PMD is characterized by:

- Symptoms occur in ovulatory cycles.
- Symptoms are not specified—somatic and/or psychological.
- Number of symptoms not specified.

Table 10.1 Classification of premenstrual disorders

PMD category	Symptom characteristics
Core PMD	Occur in ovulatory cycles
	Type not specified—may be somatic and/or psychological
	Number not specified
	Absent after menstruation and before ovulation
	Recur in the luteal phase of the cycle
	Prospectively rated for two cycles
	Cause significant impairment (work, school, hobbies, interpersonal relationships, distress)
Variant PMD	
PMD due to nonovulatory ovarian activity	Symptoms arise from ovarian activity other than those of ovulation (rare)
Premenstrual exacerbation	Symptoms of an underlying psychological or somatic disorder significantly worsen premenstrually
Progestogen-induced PMD	Symptoms result from exogenous progestogen administration
PMD with absent menstruation	Symptoms arise from continued ovarian activity though menstruation is suppressed/eliminated

Used with permission of Springer Science + Business Media from O'Brien et al. [2]

- Symptoms are absent after menstruation and before ovulation (i.e., there is no underlying disorder).
- Symptoms must recur in the luteal phase.
- Symptoms must be prospectively rated for a minimum of 2 menstrual cycles.
- Symptoms must cause significant distress and/or impairment in work, school, social, and interpersonal roles.

See DSM-5 [1] for the diagnostic criteria for premenstrual dysphoric disorder (PMDD).

10.4.3.2 Variant Premenstrual Disorders

Variant PMD includes four subtypes (Table 10.1) [2]:

- Premenstrual exacerbation (of an underlying psychological or somatic disorder).
- PMD with absent menstruation, which occurs in women whose ovarian cyclicity is maintained but menstruation has been suppressed or eliminated by: (1) hysterectomy (with ovarian conservation), (2) endometrial ablation, or (3) endometrial suppression with intrauterine progestogen-containing contraceptive systems.
- Progestogen-induced PMD (from exogenous progestogen administration).
- PMD due to nonovulatory ovarian activity—this classification is poorly defined, and there are no clear mechanisms by which this occurs.

10.5 Etiology and Pathogenesis

10.5.1 What Are Some of the Pathogenetic Theories of Premenstrual Disorder?

There is no known exact cause of PMDs and the etiology is assumed to be multifactorial. Fluctuations in sex steroids are presumed to be involved in the pathogenesis of symptoms of PMD due to the appearance of symptoms during the luteal phase; the absence of symptoms with ovulation suppression, in anovulatory cycles, and after ovariectomy; and the induction of premenstrual symptoms by exogenous hormone administration in susceptible women [3]. Studies have consistently not demonstrated abnormalities in follicle-stimulating hormone (FSH), luteinizing hormone (LH), estrogen, or progesterone levels in women with PMDs compared to control women.

PMD is thought to involve altered serotonin activity, which could influence mood, aggression, and modulation of sex-steroid-driven behavior. Evidences for this etiological theory include: (1) effectiveness of serotonin-enhancing treatment such as selective serotonin reuptake inhibitors, (2) provocation of premenstrual symptoms with decrease in serotonin transmission, and (3) altered indices of serotonergic transmission in women with PMDs.

Allopregnanolone is a metabolite of progesterone that is a positive modulator of the gamma-aminobutyric acid (GABA) inhibitory neurotransmitter system. PMD

may involve altered allopregnanolone or GABA levels during the luteal phase and possible reduced sensitivity of the $GABA_A$ receptor to allopregnanolone (and its anxiolytic effects) during the luteal phase.

Neuroimaging studies have suggested altered brain neurocircuitry in women with PMDs with abnormal patterns of activation or excitability in the dorsolateral prefrontal cortex and cerebellum, decreased top-down control, and dysregulation in working memory neural circuitry compared with healthy controls. There have also been reports of increased reactivity to negative or emotional social stimuli during the luteal phase and an increased acoustic startle response in women with PMD.

Other systems that have been theorized to be involved include calcium, altered circadian rhythms, noradrenergic neurotransmission, beta-endorphins, and brain-derived neurotrophic factor.

10.5.1.1 Risk Factors

Previous major depressive disorder has been reported as a risk factor in several studies. Some studies also report previous postpartum depression.

Possible other risk factors include interpersonal trauma history, current stress, and seasonal changes.

Heritability for premenstrual symptoms ranges between 30 and 80 %.

10.5.1.2 Onset Characteristics

- Onset of moderate to severe premenstrual symptoms can occur at any point after menarche.
- Prevalence of PMD and severity of symptoms may vary from adolescence through perimenopause, but this has not been well studied.
- Premenstrual disorders occur in multiple cultures. Some cultures report a preponderance of somatic symptoms compared to emotional symptoms. Seeking treatment is influenced by cultural factors.

10.5.1.3 Working Model

Premenstrual symptoms occur during ovulatory cycles and likely involve a differential sensitivity to exposure and/or withdrawal of circulating ovarian sex steroids. Levels of ovarian sex steroids are generally normal in women with PMDs. Both abnormalities in serotonergic transmission and reduced sensitivity of the $GABA_A$ receptor during the luteal phase to allopregnanolone are likely etiological factors. It has been postulated that the serotonin reuptake inhibitor antidepressants may be effective both by increasing serotonin synaptic availability as well as increasing the availability of allopregnanolone [4]. It also has been postulated that the rapid action of antidepressants in PMD may involve the interaction of serotonin and estrogen receptors and response. The evidence for these theories is largely indirect (peripheral, not central nervous system [CNS], levels) to date.

Suppression of ovulation will precisely eliminate symptoms in women with core PMD. However, gonadotropin-releasing hormone (GnRH) analogues eliminate all ovarian sex steroids markedly, so the efficacy is not conclusively the result of suppression of ovulatory progesterone or its metabolites. Anecdotally, “add-back”

estrogen (without the normally required) progestogen appears to maintain symptom suppression in many women. Administration of progestogen during hormone replacement can frequently result in the generation or regeneration of "PMS-like" symptoms (progestogen-induced PMD; see Table 10.1).

10.6 Specific Diagnostic Aspects

10.6.1 What Diagnostic Tool Is Confirmatory for Diagnosis of a Premenstrual Disorder (PMD)?

- Diagnosis is made by clinical interview and review of prospective charting of mood, behavioral, and physical symptoms for two symptomatic menstrual cycles. The prospective charting allows the clinician and patient to confirm the specifics, severity, and timing of the premenstrual symptoms and the assessment of any underlying symptoms during the follicular phase. In some cases, the charting allows the clinician to demonstrate to the patient the noncyclical nature of symptoms, which can lead to an alternative diagnosis and workup. Several rating forms exist for prospective ratings, e.g., Daily Record of Severity of Problems (Fig. 10.1) [5] or the Visual Analogue Scales for Premenstrual Mood Symptoms [6].
- Medical disorders that should be considered in the differential diagnosis include dysmenorrhea, endometriosis, polycystic ovary disease, thyroid disorders, adrenal system disorders, hyperprolactinemia, and panhypopituitarism. It is also possible that women on oral contraceptives or other hormones (including hormone replacement therapy [HRT]) have induced premenstrual symptoms. Symptom reassessment following discontinuation of the hormone may be indicated, with discussion about possible need for alternative contraception.
- Psychiatric disorders that should be considered in the differential diagnosis include major depressive disorder, persistent depressive disorder (dysthymia), bipolar disorder, panic disorder, generalized anxiety disorder, and personality disorder.
- If symptoms are present through the follicular phase and are exacerbated during the luteal phase, the woman is considered to have premenstrual exacerbation of an underlying disorder. Conditions that may exhibit premenstrual exacerbation include mood and anxiety disorders, substance misuse, binge eating, migraines, asthma, epilepsy, irritable bowel syndrome, chronic fatigue syndrome, allergies, and autoimmune disorders. The underlying condition should be treated first, and then patients can chart their symptoms again if they feel premenstrual symptoms are still problematic.
- If a core premenstrual disorder is confirmed by prospective charting, treatment options can be discussed. Since there are few predictors of response to treatment type, women should be informed about nonpharmacological strategies, antidepressant medications, and hormonal strategies that suppress ovulation.

DAILY RECORD OF SEVERITY OF PROBLEMS

Please print and use as many sheets as you need for at least two FULL months of ratings.

Name or Initials _____

Month/Year _____

Each evening note the degree to which you experienced each of the problems listed below. Put an "x" in the box which corresponds to the severity: 1 - not at all, 2 - minimal, 3 - mild, 4 - moderate, 5 - severe, 6 - extreme.

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
Enter day (Monday="M", Thursday="R", etc) >																																
Note spotting by entering "S" >																																
Note menses by entering "M" >																																
Begin rating on correct calendar day >		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
1 Felt depressed, sad, "down,", or "blue" or felt hopeless; or felt worthless or guilty	6																															
	5																															
	4																															
	3																															
	2																															
	1																															
2 Felt anxious, tense, "keyed up" or "on edge"	6																															
	5																															
	4																															
	3																															
	2																															
	1																															
3 Had mood swings (i.e., suddenly feeling sad or tearful) or was sensitive to rejection or feelings were easily hurt	6																															
	5																															
	4																															
	3																															
	2																															
	1																															
4 Felt angry, or irritable	6																															
	5																															
	4																															
	3																															
	2																															
	1																															
5 Had less interest in usual activities (work, school, friends, hobbies)	6																															
	5																															
	4																															
	3																															
	2																															
	1																															
6 Had difficulty concentrating	6																															
	5																															
	4																															
	3																															
	2																															
	1																															
7 Felt lethargic, tired, or fatigued; or had lack of energy	6																															
	5																															
	4																															
	3																															
	2																															
	1																															
8 Had increased appetite or overate; or had cravings for specific foods	6																															
	5																															
	4																															
	3																															
	2																															
	1																															
9 Slept more, took naps, found it hard to get up when intended; or had trouble getting to sleep or staying asleep	6																															
	5																															
	4																															
	3																															
	2																															
	1																															
10 Felt overwhelmed or unable to cope; or felt out of control	6																															
	5																															
	4																															
	3																															
	2																															
	1																															
11 Had breast tenderness, breast swelling, bloated sensation, weight gain, headache, joint or muscle pain, or other physical symptoms	6																															
	5																															
	4																															
	3																															
	2																															
	1																															
At work, school, home, or in daily routine, at least one of the problems noted above caused reduction of productivity or inefficiency	6																															
	5																															
	4																															
	3																															
	2																															
	1																															
At least one of the problems noted above caused avoidance of or less participation in hobbies or social activities	6																															
	5																															
	4																															
	3																															
	2																															
	1																															
At least one of the problems noted above interfered with relationships with others	6																															
	5																															
	4																															
	3																															
	2																															
	1																															

Fig. 10.1 Daily Record of Severity of Problems (DRSP) (Used with permission from Endicott et al. [5] Copyright J Endicott, W. Harrison)

10.6.2 Indication Phase

- Indications for treatment of premenstrual symptoms are the symptoms causing distress for women or interfering with relationships and role functioning.
- Some women prefer to pursue nonpharmacological strategies first. If these strategies are not beneficial, there is an indication for antidepressant medication or a hormonal strategy to suppress ovulation.

10.6.3 Informed Consent Phase

- Women with a premenstrual disorder should be informed that there are dietary, herbal, and other nonpharmacological treatment options that can be tried prior to taking psychotropic or hormonal medication. When women choose pharmacological options, since there are no studies predicting treatment response, the choice of antidepressant versus hormonal strategy is generally individually determined.
- Side effects with antidepressants include nausea, fatigue, decreased energy, sweating, and decreased libido. Long-term side effects that can be problematic include weight gain, decreased libido, and delayed orgasm. Intermittent dosing may decrease side effect burden, but this has not been systematically studied.
- Women who may become pregnant should be counseled about the risks with antidepressants during pregnancy. Tapering and discontinuing the antidepressant (if clinically appropriate) should occur once the pregnancy is confirmed to limit the duration of fetal exposure to the medication. Women planning to conceive should not choose paroxetine as first-line treatment or other antidepressants with minimal safety data.
- Women choosing to take an oral contraceptive should be counseled about the usual potential side effects. Oral contraceptive medications containing drospirenone may be differentially more effective for PMD, but they have an increased risk of venous thromboembolism.
- Ovulation suppression with estrogen needs uterus protection with a progestogen (systemic or intrauterine). However, the progestogen carries the risk of regeneration of premenstrual symptoms.
- GnRH agonists and hysterectomy and bilateral salpingo-oophorectomy need hormone replacement ("add-back") strategy or medication for bone health.
- Benzodiazepines may cause sedation and should not be a first-line option in women with a substance misuse disorder.
- Doses of vitamin B6 in excess of 200 mg daily may cause peripheral neuropathy.

10.7 Specific Therapeutic Aspects

10.7.1 Treatment Summary

Premenstrual syndrome is a psychosomatic disorder in that the symptoms involve both mind and body. Treatment includes nonpharmacological strategies, antidepressant medications, and strategies (hormonal or surgical) that suppress/eliminate ovulation.

10.7.2 Problem and Patient Orientation

Women with premenstrual symptoms often report symptoms for several years prior to seeking treatment. It is possible that symptoms increase in severity with age or after giving birth and resuming menses, but these reports need study. It is also possible that premenstrual symptoms become more problematic as women assume multiple roles with a partner, children, and employment. A single woman who is a teacher may find that her premenstrual irritability and lack of patience interfere with her teaching role, but she can manage her life outside of the classroom during those days. A married woman with 3 children at home may find that she can function well at her job during the days prior to menses, but her irritability, anger outbursts, and mood swings become apparent when she gets home at the end of the day and feels pressured to prepare a meal and attend to the needs of her family. Many women with severe premenstrual symptoms report reduced quality of life and significant disruption to their interpersonal relationships during the symptomatic days. A small subset of women has anger outbursts and aggressive actions that can lead to significant negative consequences. Some women with severe premenstrual low mood may spend days in bed and miss social obligations and work responsibilities and may wrestle with hopelessness and suicidal thoughts each month.

Many women with premenstrual symptoms view their symptoms as "hormonal" since the symptoms appear prior to menses and resolve after menses. Most women seek treatment recommendations from their GP or gynecologist. If an underlying or concurrent psychiatric disorder is detected, referral to a psychiatrist is recommended.

10.7.3 What Are the Therapeutics That Have the Most Robust Evidence Base?

10.7.3.1 Antidepressants (Level A)

- It is well established that selective serotonin reuptake inhibitors (SSRIs) lead to substantial reduction in the emotional, behavioral, and physical symptoms of a core premenstrual disorder [7, 8]. Many studies have demonstrated 60–90 %

response rate with fluoxetine, sertraline, and paroxetine compared to placebo. Efficacy has also been reported with escitalopram and citalopram.
- SSRIs can be effective when taken every day of the menstrual cycle (continuous dosing), from ovulation to menses (intermittent or luteal phase dosing), or from the start of symptoms in the luteal phase to menses (symptom-onset dosing).
- Recommended doses are similar to doses used for the treatment of major depressive disorder.
- Continuous dosing may be superior to luteal phase or symptom-onset dosing for severe symptoms, multiple symptoms, and physical symptoms.
- Initial studies suggested some efficacy with venlafaxine and clomipramine; these medications are not as well studied as the SSRIs.
- Nonserotonergic antidepressants (e.g., bupropion, desipramine, maprotiline) are not recommended for the relief of premenstrual symptoms.
- There is no recommended length of treatment, but recurrence of premenstrual symptoms is common following discontinuation of SSRI.
- In many countries, the use of SSRIs for PMDs is off-license. Escitalopram has regulatory approval in Sweden. Fluoxetine, sertraline, and paroxetine CR have regulatory approval for continuous and luteal phase dosing in the United States.

10.7.3.2 Oral Contraceptives (Level A)

- Oral contraceptives containing drospirenone 3 mg/ethinyl estradiol 20 μg administered in a 24/4 regimen have been demonstrated to improve premenstrual emotional and physical symptoms when compared to placebo with a 60–70 % response rate [9].
- In the United States, a Food and Drug Administration (FDA) warning was issued in 2012 about an increased risk of venous thromboembolism in continuous oral contraceptives (COCs) containing the progestin drospirenone compared to COCs containing the progestin levonorgestrel or some other progestins.
- Oral contraceptives not containing drospirenone may also be effective, but this needs systematic study, and progestogenic regeneration of symptoms may occur despite the suppression of ovulation.
- Continuous use of oral contraceptives with induction of withdrawal bleeding 2–4 times per year is commonly done in practice, but such regimens deserve further study.

10.7.3.3 Estrogen (Level B)

- Transdermal estrogen (100 μ[mu]g–200 μ[mu]g) twice a week or estradiol subcutaneous implant every 6 months suppresses ovulation, and early studies reported efficacy for reducing premenstrual symptoms [3, 10].
- A progestogen is required to prevent endometrial hyperplasia. This can be administered orally daily for approximately 1 week every month or every few months to promote a withdrawal bleed. Alternatively, endometrial protection can be achieved with a levonorgestrel-containing intrauterine system.
- A subset of women will have progestogen intolerance with depressed mood and other "PMS-like" symptoms. Intrauterine systems may offer an advantage.

10.7.3.4 Gonadotropin-Releasing Hormone (GnRH) Agonists (Level A)

- GnRH agonists suppress ovulation, and several studies have demonstrated improvement of premenstrual emotional and physical symptoms compared to placebo; response rates are 60–75 % [11].
- Early side effects may include significant hot flushes and night sweats, insomnia, and onset of depressive symptoms.
- Long-term risks of estrogen deficiency include vaginal atrophy, cardiovascular risks, osteopenia, and osteoporosis.
- Add-back hormone replacement therapy, administered to reduce the long-term risks of estrogen deficiency, may induce "PMS-like" symptoms in a subset of women.

10.7.3.5 Hysterectomy and Bilateral Salpingo-Oophorectomy (BSO) (Level C)

- This is a successful treatment for severe PMS but should not be considered unless a woman has not responded to pharmacological and nonpharmacological treatments [12].
- A GnRH agonist trial, usually for 6 months, is often conducted in practice to predict the potential effect of surgery on symptom relief. This "presurgery trial" needs systematic study.
- Estrogen replacement therapy should be started postsurgery to prevent the complications of long-term estrogen deficiency. There is no need to give progestogen replacement for protection of the endometrium posthysterectomy, and "PMS-like" symptoms should not be generated.

10.7.3.6 Anxiolytics (Level B)

- Alprazolam 0.25 mg up to 3 times a day during the luteal phase, with a tapering after menses, has been reported to be helpful for premenstrual symptoms in several but not all studies. Alprazolam is generally used as an adjunctive medication for irritability and anxiety symptoms that have not responded fully to SSRIs or hormonal strategies.
- Buspirone has been reported to be helpful all cycle as well as during the luteal phase only. Due to the few reports with this medication, it is considered a second-line treatment.

10.7.3.7 Nonpharmacological [10, 13]

- Chasteberry or *Vitex agnus-castus* has been demonstrated to reduce premenstrual emotional and physical symptoms compared to placebo. Dosages and preparations of chasteberry vary widely by manufacturer (Level B).
- Calcium 600 mg PO twice a day has been reported to decrease premenstrual emotional and physical symptoms compared to placebo (Level B).
- Cognitive-behavior therapy (CBT) has some support for improving premenstrual emotional symptoms (Level B).
- Vitamin B6 or pyridoxine has weak support for improving premenstrual mood symptoms compared to placebo (Level C).

- Dietary recommendations include frequent snacks or meals, increased complex carbohydrate, decreased refined sugar, reduced salt, and elimination of caffeine. Specific dietary recommendations have anecdotal support but have been minimally studied (Level C).
- Exercise has been reported to be helpful for reducing premenstrual symptoms, but exercise has not been studied in women with core premenstrual disorders (Level C).

10.7.3.8 Other Treatments

- Bromocriptine, luteal phase danocrine/danazol, or gamma-linolenic acid (found in the oil of evening primrose) may be helpful for premenstrual mastalgia.
- Aldosterone antagonists such as spironolactone may be helpful for premenstrual bloating.
- Nonsteroidal anti-inflammatory medications may be helpful for cramps and abdominal pain.
- Further study is needed of specific dietary recommendations, exercise, relaxation, light therapy, acupuncture, magnesium, transmagnetic stimulation, hypericum, and other herbal preparations.

10.8 Evaluation Phase

10.8.1 Does It Matter Whether Women Try a Psychotropic or Hormonal Treatment First?

Women with premenstrual disorders should be seen 1–2 menstrual cycles following initiation of an SSRI to monitor response and tolerability. Although women may choose to continue to chart their symptoms daily, most women verbally report on the severity of their premenstrual symptoms in the follow-up interview. Partial response to continuous dosing suggests increasing the dose of the SSRI. Partial response to intermittent dosing suggests switching to continuous dosing or increasing the dose of the SSRI. Women with an underlying mood or anxiety disorder that has premenstrual exacerbation may do well with a lower SSRI dose during the follicular phase, then "bumping up" the dose during the luteal phase, and decreasing back to the lower dose at menses [14]. If side effects have occurred with an SSRI, switching to another SSRI may avoid the same side effects. Informed consent about risks of exposure to an antidepressant with pregnancy should be ongoing. Women who have failed two or more SSRI trials should pursue hormonal treatment.

Women with premenstrual disorders who choose ovulation suppression should be seen by their gynecologist regularly. A woman who cannot tolerate or does not respond to ovulation suppression fully should try a serotonergic treatment if she has not already done so.

10.8.2 Should Women with Premenstrual Disorders Pursue Treatment with a Mental Health Clinician, a General Practitioner, or a Gynecologist?

If premenstrual symptoms have not responded to more than one pharmacological treatment, a reassessment should be conducted of a potential missed underlying psychiatric or medical disorder.

Case History: Continued

Prospective charting confirms the absence of psychological and somatic symptoms during the follicular phase and moderate to severe irritability, mood swings, anger outbursts, bloating, breast tenderness, headaches, and increased appetite for a full week prior to menses for two menstrual cycles. Phyllis Ruby was informed about nonpharmacological options such as dietary changes, exercise, calcium, and chasteberry. She was presented with the data about SSRIs and oral contraceptives and estrogen. Given the potential of wanting to conceive in the next year, and the appeal of taking a medication only during the symptomatic phase of the cycle, the patient gave informed consent to a luteal phase sertraline 50 mg PO daily trial from ovulation (measured by 13–15 days from prior onset of menses) to onset of menses. Phyllis was seen in F/U after three menstrual cycles, and she reported marked reduction in her mood, anxiety, and most physical symptoms. Only her headaches, increased appetite, and cravings for sweets remained. Phyllis opted to continue luteal phase sertraline until her next pregnancy.

10.9 Critical Reflection and Conclusive Remarks

It is important to realize that a patient seeing a general practitioner, gynecologist, or psychiatrist may have a straightforward Core PMD. However, frequently a patient's clinical picture is more complex. She may have premenstrual exacerbation of an underlying disorder or she may have premenstrual symptoms with an unrelated comorbid psychological or somatic condition. She may have a disorder that has symptoms similar to PMDs and she incorrectly attributes the symptoms to PMD, but the symptoms are noncyclical, such as a mood disorder or an anxiety disorder. Many women would prefer a gynecological or "hormonal" label for their symptoms rather than a psychiatric diagnosis. Other women may present with mild physiological symptoms, the absence of psychological symptoms, without significant impairment, yet they desire treatment.

Treatment options fall into those that eliminate/suppress ovulation or reduce sensitivity to the ovulatory ovarian steroids. Many treatment options are unlicensed but effective. Progesterone and progestogens are licensed in the United Kingdom but

are ineffective. SSRIs are usually considered the first-line treatment option. However, up to one-third of women will not achieve symptom relief with SSRIs. Drospirenone-containing oral contraceptives may be a first- or second-line option; again, up to one-third of women will not respond to this regimen. Some women need both an antidepressant and hormonal regimen that suppresses ovulation to achieve response. Some women achieve symptom relief with a combination of prescription and nonpharmacological strategies. Predictors of treatment response are poorly defined to date, so therapeutic approaches must be "trial and error" and individualized at this point.

Knowledge about variant PMDs is important. Being cognizant about progestogen-induced PMD in women who are intolerant of progestogen should be helpful to clinicians prescribing oral contraceptive pills or HRT. Women who continue to have premenstrual symptoms after their uterus has been removed (ovaries conserved), endometrial ablation, or insertion of an intrauterine system, are frequently overlooked by clinicians because there is a lack of menses to serve as an identifiable time point each month. Removal of the uterus and both ovaries is rarely justified, but it may be helpful to women with very severe debilitating symptoms who have not responded to multiple other treatment regimens.

Tips and Tricks

Prospective charting may be perceived as burdensome to the patient and clinician, but it is the diagnostic standard for documenting premenstrual symptoms, their timing in the cycle, and their severity. A validated retrospective premenstrual symptoms screening tool (PSST) [15] may also have utility.

Women should have a general medical and pelvic exam and assessment of thyroid status.

First-line treatments could be SSRIs, oral contraceptives, or nonpharmacological strategies. In most cases, the treatment is tailored to the individual woman's treatment preferences, conception plans, and responses to previous trials.

Test Your Knowledge and Comprehension

1. The diagnosis of a premenstrual disorder should be confirmed by prospective charting of emotional and somatic symptoms for two menstrual cycles.
   (a) True
   (b) False
2. The differential diagnosis would include an underlying depressive or anxiety disorder.
   (a) True
   (b) False
3. First-line treatment options include a benzodiazepine and magnesium.
   (a) True
   (b) False

4. Problematic side effects with antidepressants include weight gain and sexual dysfunction.
   (a) True
   (b) False
5. Continuous oral contraceptives (COCs) that include drospirenone may have an increased risk of venous thromboembolism compared to COCs with other progestogens.
   (a) True
   (b) False
6. Premenstrual dysphoric disorder occurs in ____% of menstruating women?
   (a) 0.5%
   (b) 5%
   (c) 15%
   (d) 40%
7. A known risk factor for PMDD is a personal history of:
   (a) Phobia of public speaking
   (b) Bulimia nervosa
   (c) Major depressive episode
   (d) Schizoaffective disorder
8. Etiological theories explaining the development of premenstrual disorders include:
   (a) Dopamine system abnormalities
   (b) Serotonin system abnormalities
   (c) Vagal nerve abnormalities
   (d) Glutamate system abnormalities
9. Which serotonin reuptake inhibitor does not have clear evidence of efficacy for premenstrual disorders?
   (a) Fluvoxamine
   (b) Sertraline
   (c) Paroxetine
   (d) Escitalopram
10. Which hormonal regimen does not have clear evidence of efficacy for premenstrual disorders?
    (a) COCs containing ethinyl estradiol and drospirenone
    (b) GnRH agonist
    (c) Transdermal estrogen
    (d) Progesterone suppositories

Answers

1. True
2. True
3. False
4. True

5. True
6. (b)
7. (c)
8. (b)
9. (a)
10. (d)

References

1. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. Arlington: American Psychiatric Publishing; 2013.
2. O'Brien PM, Bäckström T, Brown C, Dennerstein L, Endicott J, Epperson CN, Eriksson E, Freeman E, Halbreich U, Ismail KM, Panay N, Pearlstein T, Rapkin A, Reid R, Schmidt P, Steiner M, Studd J, Yonkers K. Towards a consensus on diagnostic criteria, measurement and trial design of the premenstrual disorders: the ISPMD Montreal consensus. Arch Womens Ment Health. 2011;14(1):13–21.
3. Yonkers KA, O'Brien PM, Eriksson E. Premenstrual syndrome. Lancet. 2008;371(9619):1200–10.
4. Steiner M, Li T. Luteal phase and symptom-onset dosing of SSRIs/SNRIs in the treatment of premenstrual dysphoria: clinical evidence and rationale. CNS Drugs. 2013;27(8):583–9.
5. Endicott J, Nee J, Harrison W. Daily Record of Severity of Problems (DRSP): reliability and validity. Arch Womens Ment Health. 2006;9(1):41–9.
6. Steiner M, Streiner DL. Validation of a revised visual analog scale for premenstrual mood symptoms: results from prospective and retrospective trials. Can J Psychiatry. 2005;50(6): 327–32.
7. Marjoribanks J, Brown J, O'Brien PM, Wyatt K. Selective serotonin reuptake inhibitors for premenstrual syndrome. Cochrane Database Syst Rev. 2013;(6):CD001396.
8. Shah NR, Jones JB, Aperi J, Shemtov R, Karne A, Borenstein J. Selective serotonin reuptake inhibitors for premenstrual syndrome and premenstrual dysphoric disorder: a meta-analysis. Obstet Gynecol. 2008;111(5):1175–82.
9. Lopez LM, Kaptein AA, Helmerhorst FM. Oral contraceptives containing drospirenone for premenstrual syndrome. Cochrane Database Syst Rev. 2012;(2):CD006586.
10. Nevatte T, O'Brien PM, Bäckström T, Brown C, Dennerstein L, Endicott J, Epperson CN, Eriksson E, Freeman EW, Halbreich U, Ismail K, Panay N, Pearlstein T, Rapkin A, Reid R, Rubinow D, Schmidt P, Steiner M, Studd J, Sundström-Poromaa I, Yonkers K. Consensus Group of the International Society for Premenstrual Disorders. ISPMD consensus on the management of premenstrual disorders. Arch Womens Ment Health. 2013;16(4):279–91.
11. Wyatt KM, Dimmock PW, Ismail KM, Jones PW, O'Brien PM. The effectiveness of GnRHa with and without 'add-back' therapy in treating premenstrual syndrome: a meta analysis. BJOG. 2004;111(6):585–93.
12. Reid RL. When should surgical treatment be considered for premenstrual dysphoric disorder? Menopause Int. 2012;18(2):77–81.
13. Pearlstein T. Psychotropic medications and other non-hormonal treatments for premenstrual disorders. Menopause Int. 2012;18(2):60–4.
14. Steiner M, Pearlstein T, Cohen LS, Endicott J, Kornstein SG, Roberts C, Roberts DL, Yonkers K. Expert guidelines for the treatment of severe PMS, PMDD, and comorbidities: the role of SSRIs. J Womens Health. 2006;15(1):57–69.
15. Steiner M, Macdougall M, Brown E. The premenstrual symptoms screening tool (PSST) for clinicians. Arch Womens Ment Health. 2003;6(3):203–9.

A Woman Who Suffers Always and Forever: Management of Chronic Pelvic Pain

11

P.T.M. Weijenborg and Moniek M. ter Kuile

11.1 Introduction and Aims

Chronic pelvic pain (CPP) in women affects about a quarter of women in the general population. The pathogenesis is poorly understood. The aim of this chapter is to provide insight into the role of various somatic factors and psychosocial variables as possible causal or contributing factors to pelvic pain. Cognitive behavioral approach of CPP women is advocated and illustrated.

11.2 Definition in Lay Terms

Chronic pelvic pain (CPP) in women is commonly described as a continuous or intermittent pain in the lower abdomen not exclusively related to menstrual period (dysmenorrhea) or sexual intercourse (dyspareunia) and which lasts for at least 3 months [1]. This description does not go into what the experience of pain might be. Fortunately, the definition of *chronic pain* by the International Association for the Study of Pain (IASP) gives some more information, as chronic pain is characterized as *an unpleasant sensory and emotional experience* associated with actual or potential tissue damage or described in terms of such damage.

P.T.M. Weijenborg, MD, PhD (✉) • M.M. ter Kuile, PhD
Department of Gynecology, Leiden University Medical Centre, Leiden, The Netherlands
e-mail: p.t.m.weijenborg@lumc.nl; m.m.ter_kuile@lumc.nl

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_11

11.3 Didactic Goals

After reading this chapter, you:

- Will be familiar with the definition of chronic pelvic pain and chronic pain
- Will be familiar with the epidemiology of chronic pelvic pain in women
- Will be familiar with the etiologies of chronic pelvic pain in women
- Will be familiar with the results of different treatment modalities and its effectiveness in women with CPP
- Will be familiar with a structured interview according to the "model of consequences" to address the complaint and its impact in everyday life
- Will be familiar with those specific conversational skills to motivate a CPP patient for pain management

Case History

Renata Emerald is 43 years old and has suffered from pelvic pain for 2 years. She lives with her husband and two daughters, 11 and 9 years old. The complaint started following a common urinary tract infection. Pain persisted despite two additional courses of antibiotics. Renata consulted three medical professionals: urologist, gastroenterologist, and gynecologist. Blood and urine analyses were done as well as abdominal and vaginal ultrasound, cystoscopy, laparoscopy, coloscopy, gastroscopy, computed tomography (CT) scan, and magnetic resonance imaging (MRI) with contrast. So far, these investigations have not shown any abnormality that could be associated with the complaint. Only a small uterus myomatosus was found.

Now, Renata asks for a second opinion because she wants a hysterectomy to solve her chronic pelvic pain.

11.4 Facts and Figures: Definitions, Classification, and Prevalence

Pelvic pain is a common experience for most women of reproductive age. However, 5–26 % of women in the general population report that they suffer long-lasting pelvic pain complaints [2]. Studies on the prevalence rates in less and least developed countries are scarce but show similar data. The variation in rates of CPP worldwide was found to be due to variable study quality. Of these women in the general population, a minority asks for help from the general practitioner. For instance, in the United Kingdom with a prevalence rate of CPP in women in the general population of 24 %, an annual incidence rate of 3.7 % is

found in primary care, which is comparable with figures for asthma (3.8 %) and back pain (4.1 %). About 40 % of these CPP women are referred to secondary or tertiary care for further investigations and treatment. In the UK studies, chronic pelvic pain was defined as a recurrent or constant pelvic pain of at least 6 months' duration, unrelated to periods, intercourse, or pregnancy. These figures indicate that gynecologists as well as other medical specialists are likely to be confronted with a selected group of all women suffering from CPP. Moreover, CPP is a costly condition since it results in frequent use of healthcare resources and absence from work.

11.4.1 The Course of Chronic Pelvic Pain

No studies describe the *natural* course of chronic pelvic pain. Four uncontrolled follow-up studies investigated the *clinical* course of CPP [3–6]. In these studies, the chronicity of symptoms was confirmed. Risks for pain persistence, such as sociodemographic variables, complaint characteristics (i.e., duration and severity of pain), or the kind of treatment provided (surgical or nonsurgical) could not be identified. However, it was demonstrated that severe catastrophizing at baseline predicted less improvement at 1-year follow-up in women suffering pelvic pain associated with endometriosis. In women with CPP not specifically related to endometriosis, a reduction in pain catastrophizing was related to a decrease in pain intensity over a 3-year period. These findings concur with results of studies in other chronic pain conditions that demonstrated the important role of catastrophizing and its often negative effect on pain-related outcomes [7, 8]. Pain catastrophizing is characterized by the tendency to magnify the threat value of the pain stimulus and to feel helplessness in the context of the pain and by a relative inability to inhibit pain-related thoughts in anticipation of, during, or following a painful encounter.

Examples are: "I cannot bear this pain any longer," "I keep thinking how much it hurts…," or "Something has to be done, I am feeling so desperate…."

11.4.2 Pain Persistence

Recent data show that persistence of pain following diagnosis and treatment because of *acute* abdominal pain occurs in nearly one-third of those women who visited an emergency department about 2 years previously. Low educational level and a history of sexual abuse at younger age were shown to be significant risk factors. This result concurs with findings of other studies on persistence of pain complaints following an acute episode [9]. More research is warranted because increased knowledge about these factors may lead to early identification of patients at risk for the development of chronic pain and might, through early and appropriate intervention, reduce this risk.

11.5 Etiology and Pathogenesis

The pathogenesis of CPP is poorly understood. At the same time, it has become apparent that somatic, psychological, and social factors are intertwined. Although being discussed separately for didactical reasons, these factors cannot be treated as isolated entities.

11.5.1 Somatic Factors

A laparoscopy is considered an essential tool to diagnose abdominal and pelvic pathology. However, in about 40 % of the laparoscopies in women with CPP, no somatic explanation can be demonstrated. Even if an (gynecological) abnormality—such as endometriosis, adhesions, ovarian cysts, myoma uteri, or pelvic congestion—is observed, the association between pathology and the site or severity of the pain is not significant. What is more, the same type of pathology is also noted in pain-free women. If pathology is identified, it may be coincidental rather than causal.

In women with CPP, comorbid (pain) symptoms, such as dysmenorrhea and dyspareunia, as well as comorbid syndromes, such as irritable bowel syndrome, interstitial cystitis, chronic fatigue syndrome, and fibromyalgia, are frequently observed.

11.5.2 Psychological Factors

CPP can have a significant impact on the physical and mental health of the affected women and results in an impaired quality of life, specifically in those women who are seen in secondary or tertiary medical care centers. For instance, most CPP women suffer from higher levels of anxiety and depression, are disabled, and have more sexual problems than pain-free controls. Furthermore, as in other chronic pain conditions, CPP women are more likely to have a history of physical and especially sexual abuse than women without CPP. So far, the underlying processes that could explain an association between a history of sexual abuse and chronic (pelvic) pain are unclear.

11.5.3 A Biopsychosocial View

From clinical, experimental, as well as brain imaging studies that focus on chronic pain, a growing body of evidence emerges that demonstrates how somatic, psychological, and social factors can interact—partly mediated by various brain processes involved in chronic pain [10]. Also chronic pelvic pain is associated with alterations in the behavioral and central responses to noxious stimulation, changes in

brain structure, and altered activity of both the hypothalamic-pituitary-adrenal axis and the autonomic nervous system and psychological distress [11]. Further studies are needed to be able to explain, for instance, the experience of pain in the absence of peripheral pathology, and also to understand the discrepancy between the amount of tissue damage and the level of pain and disability as experienced by CPP women.

In clinical practice, study findings are reflected in a biopsychosocial view on chronic pelvic pain resulting in specific steps for diagnosis and treatment [10]. CPP women will benefit if attention is paid to the somatic factors as well as to the psychosocial aspects associated with the experience of pelvic pain, such as pain adjustment (i.e., anxiety and depression and health-related quality of life) to pain appraisals (i.e., attributions and expectancies about pain, catastrophizing) and pain-coping strategies (i.e., increase or decrease activity in response to pain, diverting attention, relaxation). By paying attention to these different aspects, the patient feels that her pain is taken seriously and is validated because not only the physical aspects are addressed but also her concerns, her thoughts, and her ways of coping with pain.

11.6 Specific Diagnostic Aspects

Women suffering from CPP are difficult to treat for healthcare professionals. At the same time, many women with CPP feel dissatisfied with the management of their symptoms. In their opinion, healthcare professionals have no genuine interest in them and dismiss or do not believe their complaints [12]. A cognitive behavioral (CB)-based "model of consequences" for the assessment, as explained briefly above, will meet these difficulties.

The first steps of treatment comprise a systematic and detailed interview with the patient about her pain, her ideas about pain, and the way she is coping with her pain in day-to-day life (i.e., step 1 and step 2).

11.6.1 Step 1: Pain History

History taking starts with an account of the patient's pain. As in other pain conditions, the characteristics, location, and description of current pain and the pattern of pain severity during the day, week, and month need full attention. Current pain can be recorded using a visual analogue scale (VAS) score on a scale from 0 to 10 (0 = no pain at all, 10 = worst pain imaginable). Also, comorbid symptoms such as dyspareunia and/or dysmenorrhea, associated bowel and urinary problems, as well as other chronic (pain) conditions are assessed. Apart from pain history, all diagnostics and treatments by previous medical specialists as well as complementary or alternative care providers are recapitulated. The effects of these interventions on pain and on other complaints are addressed.

11.6.1.1 What Should Be Known About Pain When a Patient Presents with the Complaint of Chronic Pelvic Pain?

Case History: Continued

The pain started with a urinary tract infection about 2 years ago. Renata Emerald describes the pain as a nagging pain located in her lower pelvis, which typically increases during the day and coincides with a bloating of the abdomen. At unexpected moments, the pain can grow worse, about 3 times a week for 1–5 h, sometimes for a whole day. On average, Renata is without pain for only 6 days a month. Changes in the severity of the pain are not related to an uncomplicated micturition, defecation, menstrual period, or sexual intercourse.

Up till now, all investigations done by different specialists did not reveal a specific abnormality, except for a small uterus myomatosus. Her gynecologist prescribed prostagens for 6 months, which initially resulted in some pain relief. However, after 3 months, Renata stopped taking this medication because she disliked a weight gain of 10 lb, because this increased her low self-esteem.

11.6.2 Step 2: Ideas About Pain and Coping with Pain

The patient is explicitly asked about those factors that, as she presumes, cause her chronic pelvic pain complaints. Later on, this information can be used to give a further explanation about a potential association between abnormalities and pain complaints. Thereafter, the patient's usual way of dealing with an increase or decrease in symptoms, determined by pain appraisals and pain-coping strategies, needs explicit attention. The term "pain appraisals" refers to a patient's opinions and beliefs about pain. Examples are "pain can cause damage," "activity should be avoided," "pain leads to disability," and/or "pain is uncontrollable." The term "pain coping" covers intended behavior or cognitions for dealing with pain, such as pain medication use, diverting attention from pain, increasing or decreasing activity, relaxation, or praying. The previously discussed "catastrophizing" of pain is an important psychological factor that is related to various levels of pain severity, distress, and disability.

11.6.2.1 What Are the Questions to Address a Patient's View on Pain and the Way She Is Coping with Pain When a Patient Presents with the Complaint of Chronic Pelvic Pain?

Case History: Continued

Renata Emerald is convinced that her uterus is the cause of her pain. Therefore, she argues that she wants a hysterectomy; she wants "…to get rid of this useless organ."

She does not take any pain killers because she experiences no pain relief when using these on a regular basis. Only when the pain is getting really worse and she starts sweating and feeling feverish, she will take an opioid. Thereafter, she sleeps for hours and has to recuperate for days. Such an episode occurs once every 2 weeks. Renata does not know which factors contribute to this deterioration of her pain. About 1 year ago, she had to go on sick leave because she could not concentrate on her job as the increase of pain and the time needed for recovery were so unpredictable.

During the next step (step 3) of the interview with the patient, the consequences of having to live in pain are addressed and elaborated. The healthcare professional will understand the impact of pain for this particular patient. The patient recognizes the genuine interest of the professional. She gets the feeling of being understood.

11.6.3 Step 3: Consequences

A variety of sequelae of "living in pain" are uncovered if the cognitive, emotional, behavioral, physical, and social consequences are addressed. Examples of the questions that should be asked are shown in Table 11.1. The consequences of living in pain might prolong and even worsen the complaint and become linked in self-perpetuating vicious circles. Specific patterns of associations between specific beliefs, emotions, and specific behavior can be recognized in each woman suffering from CPP, even though these patterns might be subject to fluctuation within one person.

11.6.3.1 What Are the Questions to Address the Cognitive, Emotional, Behavioral, Physical, and Social Consequences of Living in Pain?

Case History: Continued

When asked for, Renata Emerald mentions some of the consequences of her pain, which in turn lead to more pain. She is feeling really desperate at some times. When she experiences more severe pain she feels burdened by her pain. She cannot accept that the pain influences her everyday life to such an extent, and as a result, she gets angry. In its turn, this anger causes tension everywhere in her body. She recognizes that this increased bodily tension might have a negative effect on the level of experienced pain.

With great effort, she succeeds in fulfilling her regular household duties, but still she is convinced that she fails as a partner and mother. When the pain obliges her to rest, she blames herself for her inactivity. As soon as the symptoms improve, she resumes her activities and tries to catch up on lost time. Subsequently, the pain might increase as a result of overexertion. A vicious

circle can be drawn and illustrates a pattern that emerges when someone has "nonaccepting thoughts about pain" (Fig. 11.1).

Moreover, since she had to go on sick leave, contacts with her former colleagues are becoming less and less over time. This increases her feelings of despair.

Another example of a vicious circle is shown in Fig. 11.2. Catastrophizing appraisals and cognitions may maintain and even increase pain.

Table 11.1 Assessment question guide for women with chronic pelvic pain

Pain complaint	
Intensity of pain at this moment on a scale of 10 (0=no pain, 10=excruciating pain)	
Location of pain, with radiation	
Description of pain, kind of pain	
Course of pain during the day	
Chronicity of pain (continuous, intermittent, exact duration)	
History of pain	
Since when have you had pain complaints?	
Previous diagnostic tests by a doctor?	
If so, what were the results?	
Previous treatment?	
If so, what were the results?	
Ideas about pain	
What is in your opinion the cause of your pelvic pain?	
Pain-coping strategies	
What do you do when the pain increases?	
What do you do to prevent the pain increasing (medication, taking rest)?	
What do you do when the pain has decreased, when you are improving?	
Consequences	
Cognitive	What are your thoughts when pain exacerbates? Do you worry about (the (consequences of) your pain? To what extent do you feel able to influence pain? Do you feel helpless regarding your pain?
Emotional	Do you feel anxious, depressed, irritated, annoyed, distressed, or unhappy?
Behavioral	Do you go on with your activities despite pain or do you stop because of pain? How many prescribed and nonprescribed drugs do you use and what is the effect on pain? Current or past alcohol abuse and use of other psychoactive drugs? Do you visit complementary healthcare providers?
Physical	Do you experience accompanying symptoms such as sweating, nausea, and a high heart rate? Do you feel tired or exhausted? Do you experience muscle tension? Is your participation in physical exercise and/or sexual functioning affected by pain experience? Can you fulfill your household duties?
Social	Do you experience problems in your relationship with your partner, relatives, or friends and/or in your job? Does pain affect your participation in pleasurable activities, going on vacation?

Reprinted with permission of Informa Healthcare from [17]

The most difficult but also the most essential step during this interview is the next step (step 4) because the patient is encouraged to change her biomedical view on pain into a biopsychosocial perspective.

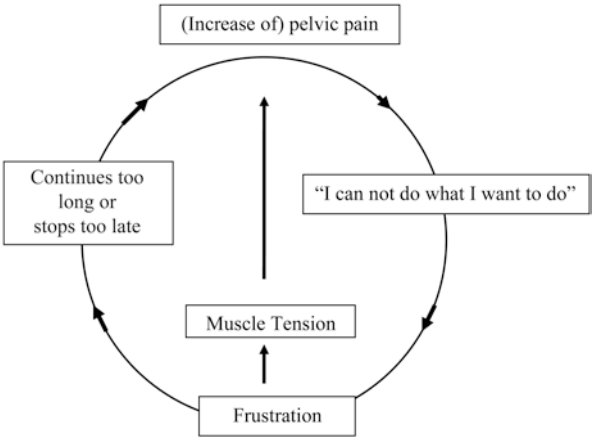


Fig. 11.1 "Nonaccepting thoughts about pain." An example of a vicious circle between cognitive, emotional, behavioral, physical, and social consequences and chronic pelvic pain

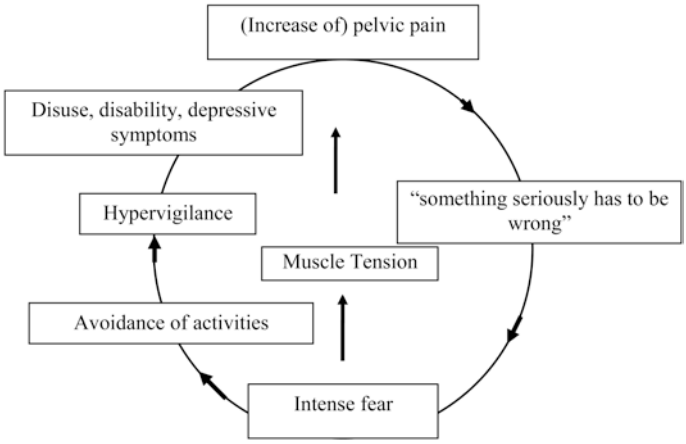


Fig. 11.2 Catastrophizing: "Anxious thoughts and avoidance behavior." An example of a vicious circle between cognitive, emotional, behavioral, physical, and social consequences and chronic pelvic pain (Used with permission of Informa Healthcare from [17])

11.6.4 Step 4: Reorientation

After a summary of the findings of the consultation so far, specific points are communicated to the patient:

1. An explanation of current views on chronic (pelvic) pain is given. "Being in pain" is an unpleasant sensory and emotional, thus *subjective experience*. An objective quantification of the severity of pain as experienced by the patient is impossible, but the consequences of CPP for everyday life illustrate the impact and burden of these complaints. Moreover, the patient is informed that only a minority of patients suffering from CPP will recover over time, taking a narrow definition of recovery as complete relief of pain.

2. Further examinations are considered to be of minor value because each imaging investigation or invasive technique evaluates only the shape or size of the internal organs. If an abnormality is diagnosed, it is judged coincidental rather than causal. That the cause of CPP cannot be explained properly is "bad news" and might lead to deterioration of the patient's condition because her expectations of a specific diagnosis and subsequent medical solution for her pain are not met.
3. By recapitulating the medical aspects and psychosocial consequences of the patient's complaint, the gynecologist expresses and demonstrates his or her genuine interest in and acknowledgment of the patient and her pain. Using one of the vicious circles as an example, the gynecologist can explain how the consequences of pain in everyday life can prolong and even worsen her pain.
4. At this stage, the patient is given the opportunity to reorientate her thinking about chronic pain. She is encouraged to change her view from the former dualistic biomedical way of thinking toward a multidimensional biopsychosocial perspective.

For some women, it is easy to make this reorientation, because they have experienced again and again that most investigations and medical treatment did not help to relieve her complaints. They recognize and understand that the impact of their pain is reflected in the consequences of pain in day-to-day life, which in its turn are linked to the experienced pain. Other women find it really difficult to hear that from a medical point of view "nothing more can be done." They need time to be able to make a reorientation. Only a minority, for instance, those women who are involved in labor law procedures, will not be able to follow another point of view on chronic pain.

11.6.4.1 What Are Essential Ingredients to Be Able to Support the Patient with Chronic Pelvic Pain to Change Her View on Pain from a Biomedical Toward a Biopsychosocial View on Pain?

Case History: Continued

Renata Emerald recognizes herself in the summary of her pelvic pain history, current pain experience, and the impact of her pain on everyday life. She is really disappointed to hear that further investigations and a surgical treatment will not be provided. It is really difficult for her to give up her quest for this supposed cure, immediately. It becomes clear that Renata needs time to reconsider her former beliefs and to accept a new perspective. After having read some parts of the self-help book *The Pain Survival Guide* [13], she recognizes how she is troubled by her pain, like others with chronic pain. She also realizes that she has to start to live with her pain. She makes a new appointment with her gynecologist although she is rather reserved about the new direction.

11.6.5 Step 5: Pain Management

If the patient is willing to identify with and accept the CB model as previously presented, the gynecologist is in a position to explain what can be achieved with pain management based on this model. Referral to a cognitive behavioral psychologist with special chronic pain expertise is recommended for further evaluation. This should also include the assessment of psychological comorbidity such as anxiety and depressive disorders.

In this way, it is possible to tailor pain management to the needs of a particular patient. This approach aims to alleviate the impact of pain on daily life. A combination of medical (pain medication), physical (functional restoration, i.e., graded activity and graded exposure to stimuli that may generate pain), and psychological modalities can be offered that can help to live with pain (such as goal setting, problem solving, relaxation training, development of effective coping strategies, changing maladaptive beliefs about pain). These ingredients aim to help the patient reclaim her own life despite chronic pain. At the start of this trajectory, it is difficult to predict to what extent the patient will recover from her pain. Medical consultation has to continue on a regular basis during treatment to provide support for the pain management program and to preempt any perception of feeling dismissed. If complaints should increase at a given point in time, a thorough medical examination remains mandatory, as some underlying conditions such as endometriosis can manifest new symptoms.

11.7 Specific Therapeutic Aspects

Treatment modalities for CPP that are studied so far vary and depend on a different point of view on chronic pelvic pain and supposed action of the intervention.

11.7.1 Surgical Treatment

Any surgical interventions, for instance, uterine nerve ablation and presacral neurectomy, are designed to disrupt the nerve plexus that may be involved with the perpetuation of the perception of pelvic pain [14]. In the same way, adhesiolysis can be performed to disrupt the nerve fibers found in adhesions. The role of pelvic venous congestion in the pathogenesis of pain remains unclear. So far, no benefits on pain for any specific surgical intervention have been demonstrated in surgical treatment outcome studies.

11.7.2 Nonsurgical Treatment

Other kinds of treatment also are offered to women with CPP, focusing on medical, psychological, and social factors associated with CPP [15]. The Cochrane Review

on this topic shows that there is evidence of moderate quality supporting progestogen as a treatment option for CPP with efficacy reported during treatment. However, this option may be only acceptable among women unconcerned about the progestogenic adverse effects (i.e., weight gain, bloatedness). Some evidence suggests possible benefit of goserelin when compared with progestogen, gabapentin compared with amitriptyline, reassuring counseling and ultrasound versus "wait and see," and writing therapy versus nondisclosure. All studies included in this Cochrane Review are randomized controlled trials (RCTs). Each study focuses on a different treatment that is related to a possible hypothesized working mechanism to explain chronic pelvic pain.

11.8 Conclusion

There is a paucity of studies on the effectiveness of surgical as well as nonsurgical treatment modalities for women suffering from CPP. Based on evidence in chronic pain patients, it seems valid to concentrate treatment on pain-maintaining factors [16]. A cognitive behavioral (CB) model that focuses on thoughts, feelings, and behavior that may increase and/or maintain (pain-related) distress and disability can be used for the assessment of chronic pain conditions and of CPP women as well [17]. Following this CB-based model, the so-called model of consequences as illustrated in Fig. 11.3, a tailored pain management program becomes apparent.

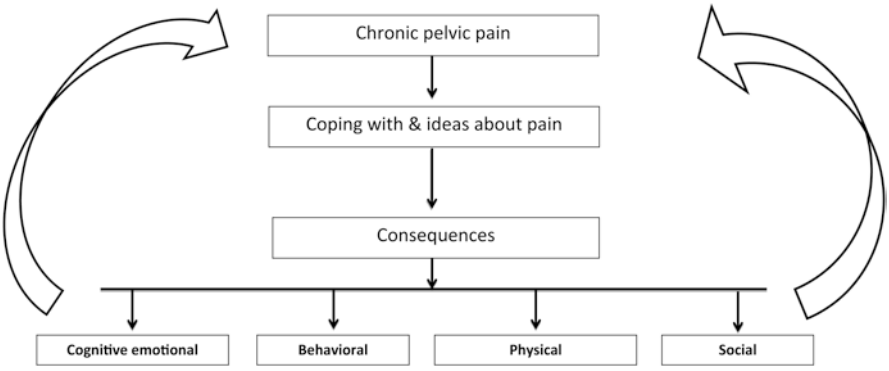


Fig. 11.3 Model of consequences (Used with permission of Informa Healthcare from [17])

Case History: Continued

After repeated consultations, Renata Emerald accepts the offer to be assessed by a psychologist. The results of self-report measures on pain, adjustment to pain, and pain appraisals and coping strategies endorse the burden of her chronic pelvic pain condition. They indicate high scores for depressive symptoms and impaired physical health. The ways she is coping with pain are ineffective, with a tendency to catastrophize pain.

Renata accepts a pain management program and she anticipates feeling better in the end. Her gynecologist instructs her to take pain medication periodically on fixed times instead of "on demand" if pain is unbearable.

The psychologist recommends a graded activity program to get a better physical condition, discusses items associated with over- and underactivity and her energy balance. She also gives her instructions for relaxation training and assists her to develop new more helpful and effective pain-coping strategies. Gradually, Renata realizes that it takes time to get a better life despite her chronic pelvic pain.

At a follow-up visit, 2 years thereafter, Renata still suffers from pelvic pain complaints, but the impact of pain on her life has decreased substantially. She has found a new balance between rest and activity. She no longer feels depressed and has started a new job on a part-time basis.

11.9 Critical Reflection and Conclusive Remarks

The use of a model based on cognitive behavioral principles for the assessment of CPP patients has great advantages for the gynecologist as well as the patient.

The model provides the gynecologist with an elegant and sufficiently inclusive method of understanding patients' symptoms and its impact on everyday life. Furthermore, the patient feels that her pain is taken seriously and is validated because not only the physical aspects are addressed but also her concerns, her thoughts, and her ways of coping with pain. In addition, by labeling the pain-related sequelae as consequences rather than as potential etiological agents, the gynecologist can avoid fruitless discussions about the causality of a number of somatic or psychological factors.

This CB-based assessment according to the model of consequences is one of the strategies to motivate the patient for pain management referral and can be applied by each gynecologist dealing with CPP patients. For patients suffering chronic pain, a CB-based management has been found to be an effective approach regarding improving pain and disability [18]. Further studies are warranted to demonstrate its

putative clinical benefits for women with CPP. Additionally, other specific questions are of interest and need further study, for instance, the health service issues arising from the need to devote more time than is allotted to a normal consultation when using this model. What should be the appropriate management pathway for patients who insist on further medical treatment to the exclusion of psychological intervention? How to cope with patients' stated or unstated inappropriate ideation about chronic pain based on the traditional biomedical view, for example, that extreme pain indicates pathology? And how can practitioners be best equipped to handle the emotional challenges arising from interactions with patients such as feeling frustrated, angry, or helpless?

Tips and Tricks
It is good to realize that:

- Gynecologists as well as other medical specialists are likely to be confronted with a small and selected group of women suffering from CPP.
- Given the prevalence and healthcare costs associated with CPP in women, RCTs of surgical, medical, psychological, and lifestyle interventions are urgently required.
- The step-by-step assessment, based on cognitive behavioral principles, provides information about the impact of chronic pelvic pain on the daily lives of women with CPP.
- CPP women for whom no somatic explanation for their pelvic pain is found, as well as CPP women whose complaints persist despite adequate treatment of the initial diagnosis, might benefit from a cognitive behavioral assessment.
- It takes time to support the patient to change her perspective on chronic pain.
- The use of a structured CB model facilitates referral for pain management, tailored to patients' needs.

Test Your Knowledge and Comprehension

1. What do you feel when the last patient of your office hours is a 35-year-old woman who complains about chronic pelvic pain and requires a hysterectomy? Give an illustration how you are coping with these feelings.
2. Give five items that are essential to be informed about regarding the pain experience of your patient.
3. Which five items have to be addressed to know more about the impact of chronic pelvic pain in the everyday life of your patient? Give an example of a question that addresses each item.
4. Give an example of how you would explain to your patient how a vicious circle has been started between (the severity of) pelvic pain and one of the consequences of pain that she has told you.
5. What can be considered as "bad news" during the interview with the patient suffering chronic pelvic pain?

6. Chronic pelvic pain is a subjective experience.
   (a) True
   b. False
7. To diagnose chronic pelvic pain in women, a CT scan is needed.
   (a) True
   (b) False
8. A history of sexual abuse is a risk factor to develop chronic pelvic pain after an acute episode of pelvic pain.
   (a) True
   (b) False
9. 40 % of all women in the general population experience chronic pelvic pain.
   (a) True
   (b) False
10. Full recovery from chronic pelvic pain is possible in 80 % of the cases.
    (a) True
    (b) False
11. Catastrophizing plays an important role in pain persistence in women with CPP.
    (a) True
    (b) False
12. Laparoscopy is an essential tool to be able to find an abnormality in women suffering CPP. In 20 % of the cases, no abnormality is found.
    (a) True
    (b) False

Answers

1. I am feeling desperate, a bit exhausted and tired, and in a hurry, and I don't want to go into details with her. When I have read the letter of referral sent by her GP, I first drink a cup of coffee and try to relax. I realize that also this woman must have the opportunity to visit a doctor who has genuine interest in her and her chronic pain.
2. When using the well-known seven dimensions of pain, one has to be informed about:
   (a) A detailed description of the pain experience; how would you describe your kind of pain?
   (b) When did the pain complaint start and what was the course?
   (c) How is the pain severity on this moment (VAS score)? Continuously, intermittent?
   (d) Describe the location of pain.
   (e) Does the pain radiate through your abdomen, along legs, etc.?
   (f) Associated complaints, other pain complaints.
   (g) Factors that influence the severity of pain.
3. The cognitive, emotional, behavioral, physical, and social consequences of pain have to be addressed during the interview. Examples of specific questions are summarized in Table 11.1.

4. (Extreme) tiredness is very often mentioned by patients with chronic pelvic pain as one of the consequences in daily life. Everyone has the experience that feeling tired influences the capacity to encounter pain and vice versa.
5. That the cause of CPP cannot be explained properly is "bad news." Moreover, that only a minority of patients suffering from CPP will recover over time, taking a narrow definition of recovery as complete relief of pain, makes it even worse.
6. True
7. False
8. True
9. False
10. False
11. True
12. False

References

1. Williams RE, Hartmann KE, Steege JF. Documenting the current definitions of chronic pelvic pain: implications for research. Obstet Gynecol. 2004;103:686–91.
2. Latthe P, Latthe M, Say L, Gülmezoglu M, Khan KS. WHO systematic review of prevalence of chronic pelvic pain: a neglected reproductive health morbidity. BMC Public Health. 2006;6:177.
3. Lamvu G, Williams R, Zolnoun D, Wechter ME, Shortliffe A, Fulton G, et al. Long-term outcomes after surgical and nonsurgical management of chronic pelvic pain: one year after evaluation in a pelvic pain specialty clinic. Am J Obstet Gynecol. 2006;195:591–8.
4. Weijenborg PT, Greeven A, Dekker FW, Peters AA, ter Kuile MM. Clinical course of chronic pelvic pain in women. Pain. 2007;132 Suppl 1:S117–23.
5. Weijenborg PT, ter Kuile MM, Gopie JP, Spinhoven P. Predictors of outcome in a cohort of women with chronic pelvic pain – a follow-up study. Eur J Pain. 2009;13:768–75.
6. Martin CE, Johnson E, Wechter ME, Leserman J, Zolnoun DA. Catastrophizing: a predictor of persistent pain among women with endometriosis at 1 year. Hum Reprod. 2011;26:3078–84.
7. Sullivan MJL, Bishop SR, Pivik J. The pain catastrophizing scale: development and validation. Psychol Assess. 1995;7(4):524–32.
8. Wideman TH, Sullivan MJ. Reducing catastrophic thinking associated with pain. Pain Manag. 2011;1:249–56.
9. Keefe FJ, Rumble ME, Scipio CD, Giordano LA, Perri LM. Psychological aspects of persistent pain: current state of the science. J Pain. 2004;5:195–211.
10. Gatchel RJ, Peng YB, Peters ML, Fuchs PN, Turk DC. The biopsychosocial approach to chronic pain: scientific advances and future directions. Psychol Bull. 2007;133:581–624.
11. Brawn J, Morotti M, Zondervan KT, Becker CM, Vincent K. Central changes associated with chronic pelvic pain and endometriosis. Hum Reprod Update Adv Acc. 2014;20(5):737–47.
12. Souza PP, Romao AS, Rosa-e-Silva JC, Dos Reis FC, Nogueira AA, Poli-Neto OB. Qualitative research as the basis for a biopsychosocial approach to women with chronic pelvic pain. J Psychosom Obstet Gynecol. 2011;32:165–72.
13. Turk DC, Winter F. The pain survival guide: how to reclaim your life. Washington, DC: APA; 2005.
14. Cheong YC, Singh S, Stones W. Surgical interventions for the management of chronic pelvic pain in women (Protocol). Cochrane Database Syst Rev. 2010;(1):Art.No.:CD008212.

15. Cheong YC, Smotra G, Williams ACDC. Non- surgical interventions for the management of chronic pelvic pain. Cochrane Database Syst Rev. 2014;(3):Art.No.:CD008797.
16. Gatchel RJ, McGeary DD, McGeary CA, Lippe B. Interdisciplinary chronic pain management. Am Psych. 2014;69:119–30.
17. Weijenborg PTM, ter Kuile MM, Stones W. A cognitive behavioural based assessment of women with chronic pelvic pain. J Psychosom Obstet Gynecol. 2009;30:262–8.
18. Williams AC de C, Eccleston C, Morley S. Psychological therapies for the management of chronic pain (excluding headache) in adults. Cochrane Database Syst Rev 2012;(11):Art. No.:CD007407.

A Woman Who Has Been Cut: Female Genital Mutilation from a Global Perspective

12

M. Caroline Vos and Zahra Naleie

12.1 Introduction and Aims

In this chapter, female genital mutilation (FGM) is discussed with its obstetrical, gynecological, and psychosocial consequences. An overview of the international movement against FGM is given. Furthermore, social causes for medical conditions and their consequences are depicted.

12.2 Definition in Lay Terms

Female genital mutilation (FGM) includes all kinds of procedures that intentionally alter or cause injury to the female genital organs for nonmedical reasons.

12.3 Didactic Goals

After reading this chapter:

- You will be familiar with the classification of FGM.
- You will be familiar with the medical, obstetric, and psychosocial consequences of FGM.

M.C. Vos, MD, MSc (✉)
Department of Obstetrics and Gynecology, Elisabeth Tweesteden Hospital, Tilburg, The Netherlands
e-mail: c.vos@etz.nl

Z. Naleie, MA
FGM, Federation of Somali Associations in The Netherlands (FSAN), Amsterdam, The Netherlands
e-mail: z.naleie@fsan.nl

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_12

- You will be aware of the possibility of reconstructive surgery.
- You will understand the background of FGM as well as the movement to end FGM in Africa and the European Union (EU).

Case History

Faduma Erin is a 25-year-old primigravid woman around 32 weeks gestation, who recently arrived from Sudan. Her husband got lost during the migration. His location is unknown. No exact dates for the pregnancy are known, so the date was set by ultrasound examination. Faduma underwent FGM as a little girl, like all girls in her village. The type of FGM is type III, where part of the clitoris was removed as well as the labia minora. The remaining tissue was stitched together to create a small vaginal opening. However, coitus was possible and she conceived soon after her marriage.

For the midwife, Faduma is the first woman in her practice with FGM and though she was trained, she felt insecure about it and felt she may say or do inappropriate things. The midwife investigated Faduma during pregnancy and made use of a professional interpreter to explain her situation to her and how to proceed during pregnancy and childbirth. She explained that if she gave birth vaginally, she may need to perform an episiotomy anterior. Faduma was happy with the information the midwife gave, because she had heard that being circumcised can cause difficulties at birth, especially at the first birth. The pregnancy went otherwise uneventfully.

Shortly before her due date, her husband arrived in the Netherlands. At term, she started with spontaneous labor, but needed labor augmentation with oxytocin at the hospital. Finally, she delivered spontaneously of a healthy daughter after episiotomy anterior. A conventional episiotomy was not necessary.

During labor, Faduma had a panic attack because of lively memories of the sexual trauma she endured during the flight. This came as a surprise to the obstetrical team. The obstetrical team suspected a posttraumatic stress disorder (PTSD) given the reaction Faduma had during delivery. She agreed on referral to a therapist specializing in trauma therapy (for more specific information about PTSD, see Chap. 2 in this book). The midwife provided counseling regarding prevention of FGM for the baby girl postpartum.

At her last checkup, Faduma told the midwife she was happy with the care she got from the obstetrical team and that she would not let her little girl be circumcised.

12.4 Facts and Figures: Definitions, Classification, and Prevalence

12.4.1 What Is the Background of Female Genital Mutilation?

12.4.1.1 Rituals Around Pregnancy and Childbirth

In most societies, rituals around pregnancy and childbirth indicate the importance of these events in human life. They are so-called rites de passage. By definition, a ritual

is "a sequence of activities involving gestures, words, and objects, performed in a sequestered place, and performed according to set sequence." Some of these rituals are harmless, such as eating special foods or giving a party like a baby shower. However, other rituals are harmful, such as treating the umbilical cord with cow dung causing tetanus infections [1] and FGM. Also in care practices, rituals exist that may be harmful for mothers and babies as is illustrated by the classical story of Semmelweis, where medical students transported the bacteria from the anatomical lessons to the delivery rooms without washing their hands in between. The scientific evidence of the preventive effect of desinfection was overruled by "medical tradition" for a long time, resulting in numerous unnecessary maternal deaths.

With the example of FGM and the fight against FGM in Africa and Europe, a sociological perspective on medicine is provided. It is illustrated that not only medical or psychological factors influence patients and care practices, but social factors such as migration and societal factors such as politics and legislation can have strong influences as well.

12.4.2 How Is Female Genital Mutilation Classified and Described?

Female genital mutilation is classified into four major types according to the World Health Organization (WHO) [2] (Fig. 12.1):

1. Clitoridectomy: partial or total removal of the clitoris and, in very rare cases, only the prepuce.
2. Excision: partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora.
3. Infibulation: narrowing of the vaginal opening through the creation of a covering seal. The seal is formed by cutting and repositioning the inner or outer labia, with or without removal of the clitoris.
4. Other: all other harmful procedures to the female genitalia for nonmedical purposes, e.g., pricking, piercing, incising, scraping, and cauterizing the genital area.

12.5 Sociological Aspects

12.5.1 Why Is Female Genital Mutilation a Violation Against Human Rights?

Female genital mutilation (FGM) includes procedures that intentionally alter or cause injury to the female genital organs for nonmedical reasons (WHO) [2]. The procedure has no health benefits for girls and women.

These procedures can cause severe bleeding and problems urinating and later cysts, infections, and infertility as well as complications in childbirth and increased risk of perinatal or newborn deaths. More than 125 million girls and women alive today underwent FGM in the 29 countries in Africa and the Middle East where

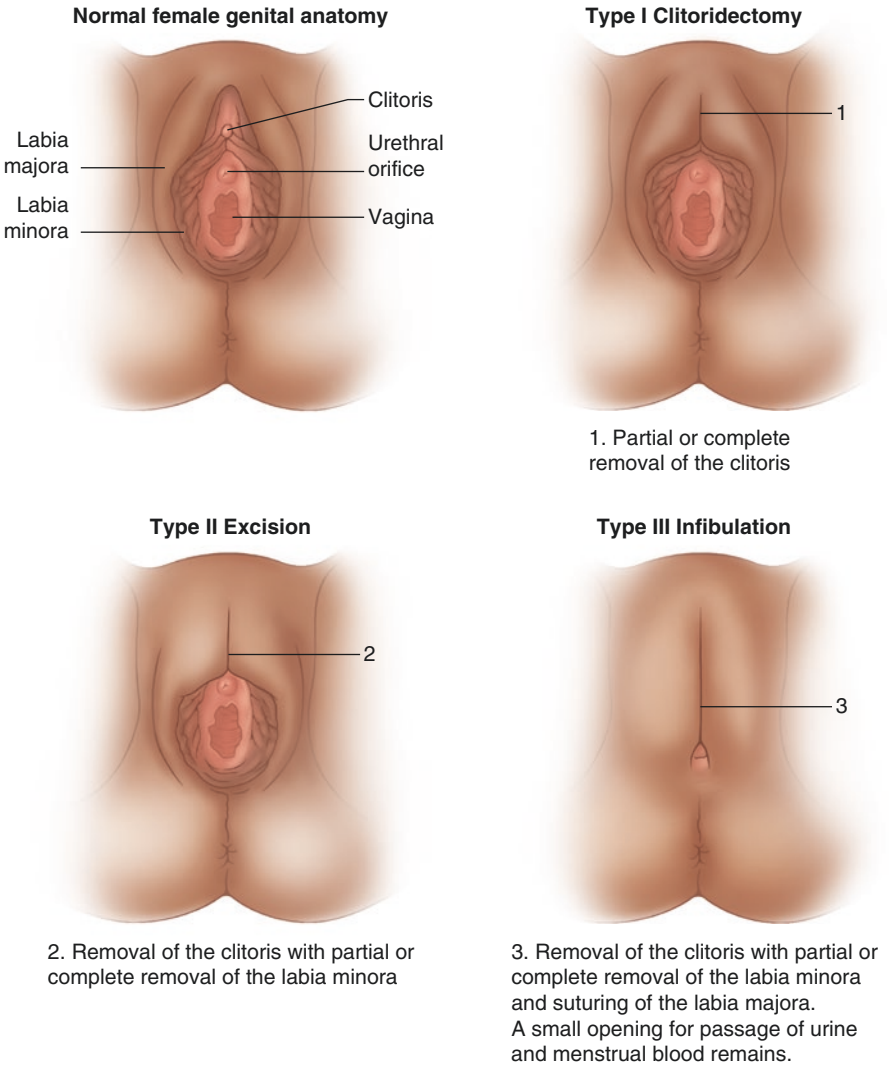


Fig. 12.1 Classification of female genital mutilation

FGM is concentrated. FGM is mostly carried out on young girls somewhere between infancy and age 15 [2].

FGM is a violation of the following articles in the United Nations Universal Declaration of Human Rights [3]:

- Article 3: Everyone has the right to life, liberty and security of person.
- Article 5: No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.

- Article 25: Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.

12.5.2 What Is the Effect of Migration on the Women Who Underwent Female Genital Mutilation?

12.5.2.1 Migration and FGM in Western Europe: In the Context of African Women

Most West-European countries are multicultural societies, but FGM was an unknown phenomenon in these countries until the late 1980s. In the past 3 decades, immigrants, refugees, and asylum seekers entering Europe brought this practice with them. Healthcare providers were shocked to learn of this practice, primarily taking notice of it from African women refugees. On the other hand, these newly arrived African women were ashamed and concerned about how their European doctors might react.

The Somali community is one of the largest communities in Western Europe that practices this harmful tradition, mostly in the form of infibulation (FGM type III). Most of the Eritreans are Tigrigna, orthodox Christians. They mainly perform clitoridectomy and this is done while the child is still a baby. Sudan is one of the countries where FGM is widely practiced as a very strong, deeply rooted tradition, which has been carried out for centuries. Most of the Sudanese women migrants have been circumcised in Sudan. Besides that, in Europe after delivery, re-stitching is not allowed, but there are some Sudanese women who are traveling back to their country in order to become re-infibulated. In West Africa, FGM is also widely practiced but the type of FGM is usually less mutilating. Apart from in Africa, FGM is also practiced in some places in Latin America, the Middle East (i.e., Yemen and Iraq), Indonesia, and other Asian countries.

Several African women commented that as a result of migration, the situation within their families changed compared to the situation at home, where the practice of FGM was self-evident. They now know “that it is not allowed” in Europe and that you end up in prison if you have your daughter cut genitally. Despite these measurements, some of them said that for their family members back home, FGM in young girls is still important and relevant because it is deep-rooted and a significant African custom.

12.5.2.2 Fighting Against FGM in the African Context

On 6 February 2003, the Inter-African Committee (IAC) held an international conference in Addis Ababa, Ethiopia [4]. Delegates from 30 African countries discussed the tradition of FGM. The members were unanimous; this tradition in Africa and the rest of the world must come to an end. Therefore, the IAC proposed a common agenda on worldwide policy between 2003 and 2015.

The first lady of Nigeria, the late Mrs. Stella Obasanjo, officially declared 6th of February as “Zero Tolerance Day to FGM.” In her statement, Mrs. Obasanjo praised

the work that had been done since the early 1970s at the local, regional, and international levels. She added, "IAC has come to a stage where a paradigm shift would move the gains we have made so far by having a common agenda which will provide a common framework to intensify and collaborate our activities at the different levels while respecting our diversities"[4].

Subsequently, the 6th of February was adopted by the UN Sub-Commission on Human Rights as the International Day of Zero Tolerance (ZTD) to FGM, and ceremonies marking this day have taken place around the world [5, 6].

12.5.2.3 Fighting Against FGM in the European Context

The European Parliament adopted its first resolution on female genital mutilation in 2001(2001/2035[INI]) [7]. In this resolution, the European Parliament strongly condemned FGM as a violation of fundamental human rights for the first time. After that, the European Parliament has repeatedly called for action in the field of FGM. From 2002 to 2007, several resolutions and a regulation were adopted by the European Parliament dealing with sexual and reproductive health, the situation of women from minority groups, population and development, violence against women, and the rights of the child, each including FGM in their body of work.

In 2008, the European Parliament adopted the resolution toward an EU strategy on the rights of the child (2007/2093[INI0]) [8]. In this resolution, the European Parliament called for community legislation that prohibits all forms of violence and harmful tradition practices, including FGM. The European Parliament also called member states "either to implement specific legal provisions on female genital mutilation or to adopt laws under which any person who carries out genital mutilation may be prosecuted" and drew attention to the role of education on FGM.

In March 2009, the European Parliament adopted the resolution on combating FGM in the EU (2008/2071[INI]) [9]. This was the second resolution at the EU level that specifically dealt with FGM. A number of issues that were dealt with in the first resolution of 2001 were reiterated; however, the second resolution marked the first time that the European Parliament addressed asylum as it pertains to FGM.

The most recent resolution on FGM—the European Parliament of June 14, 2012 on ending female genital mutilation—can be considered a further landmark in the fight against FGM. It clearly stipulates that "any form of FGM is a harmful traditional practice that cannot be considered part of a religion, but is an act of violence against women and girls which constitutes a violation of their fundamental rights" [10]. In this resolution, the European Parliament also called on the member states to take firm action to combat this illegal practice.

To respond to the resolutions from the European Parliament, some of the member states took actions against FGM based on mainly the *four Ps approach*: prevention, protection, prosecution, and provision of services.

12.6 Prevention

12.6.1 How Can Female Genital Mutilation Be Prevented?

The UN Secretary General's report on ending female genital mutilation highlights that "prevention is a core component of any strategy to end FGM and it needs to complement legislation and other measures in order to effectively eliminate the practice" [5]. In general, any prevention measures against FGM should aim at the transformation of social beliefs and behavior. The prevention activities are mainly awareness raising for communities from practicing countries, training key figures from migrant groups, and training professionals in different fields. Civil society organizations (CSOs) with key figures are the main actors working on FGM prevention programs.

12.6.2 The Netherlands: The Dutch Chain Approach

In the early 1990s in the Netherlands, prevention programs were started, and the Dutch Obstetrical and Gynecological Society issued a moratorium on re-infibulation in 1993 [11].

The chain approach is a method of working together among a number of key actors dealing with FGM in order to spread responsibility over different institutions. The members of the different chain approaches include youth health care, medical professionals (midwives, general practitioners [GPs], gynecologists, and pediatricians), child protection institutions, advice and reporting points on child abuse, and key persons from FGM-practicing communities and community-based organizations. The collaboration between actors from different sectors is indispensable in order to provide adequate prevention, protection, prosecution, and provision of services. The chain approach is further characterized by the use of protocols for each sector as well as other instruments to guide the work of actors involved. The first lines in the chain approach are the key individuals from the communities at the grass roots level who are committed to fight all forms of FGM. Their main role is to provide relevant FGM information to their communities through information sessions, home visits, and living room conversations. In addition to that, they function as a liaison between these communities and professionals.

12.6.3 Belgium: Multidisciplinary Guidelines for Professionals

The Belgium Ministry of Health published guidelines (2011) developed by CSOs targeting all professionals working with practicing communities [12]. This includes health professionals, psychosocial workers, teachers, lawyers, and police. The main objectives of the guidelines are to help professionals to better understand the issue of FGM (prevalence, geographic distribution, and medical and psychological consequences) and social-cultural aspects.

12.6.4 Cyprus, Portugal, Italy, Ireland: United to End FGM (UEFGM)

In March 2013, END FGM European campaign and partner organizations from the aforementioned countries launched an e-learning tool, offering information and practical advice on FGM in Europe [13]. The training is supported and endorsed by the Office of the United Nations High Commissioner for Refugees (UNHCR).

The e-learning course aims to raise awareness and enhance skills of health professionals, asylum officers, and social welfare officers supporting women and girls affected by FGM. More information is available at www.uefgm.org.

12.7 Protection

The aim of protection is to prevent FGM in girls at risk of being subjected to FGM, focusing on the safety of girls and addressing specific needs of this target group. Protection within the EU is firstly achieved by recognizing the transnational nature of FGM and that it mainly occurs outside of the EU. There are two types of protection most relevant to FGM: (1) child protection and (2) international or asylum protection. Regarding international protection, special attention is given to the recognition of gender-based violence, and in particular FGM, as a form of persecution and serious harm requiring protection. The following are a number of interventions in different countries, which are given to illustrate how FGM may be prevented and prosecuted:

12.7.1 The Netherlands: Document "Statement Opposing FGM"

In 2011 the Dutch Ministry of Health, Welfare, and Sport and Ministry of Justice and Security have developed a document called "Statement Opposing Female Circumcision" [14]. This document is signed by various Dutch Civil Institutions and Medical Societies and some immigrant organizations, and also provides a space for the parents' signatures. The aim of the document is to help parents resist family pressure related to FGM when visiting their families back home.

The UK and Belgian governments replicated this document by respectively issuing a "Statement opposing female genital mutilation" [15] and a "Stop FGM" passport [16] which were signed by different ministries including Home Affairs, Justice, Health, and Foreign affairs.

12.7.2 United Kingdom (UK): Asylum Policy Instruction

In 2004, the Home Office in the UK launched "The Asylum Policy Instruction: Gender Issues in the Asylum Claim" [17]. This instruction was revised and updated in 2006 and in 2010. The Asylum Policy Instruction is the UK government policy on asylum and is followed by asylum caseworkers within the UK Border Agency (UKBA). The aim of the instruction is to ensure that all caseworkers are aware of gender-specific issues related to women seeking asylum, including gender-based violence and FGM, which is specifically mentioned numerous times within the instruction. The instruction

also contains guidance on how caseworkers should deal with asylum applications by women and the need to utilize gender-sensitive procedures.

12.8 Prosecution

Prosecution involves not only the legal proceedings against those suspected of having subjected a girl or woman to FGM but also includes judicial proceedings and court cases. In related investigation and prosecution, the Council of Europe Convention on preventing and combating violence against women (also known as the "Istanbul Convention") said, "Where suspicions arise that a girl or a woman is at risk or is affected by violence against women, including FGM, protection systems that help with identification, reporting, referral and support are required to trigger a coordinated action that would prevent violence from taking place and protect the girl or women in question (Articles 18, 49, 50, 51 and 53)" [18].

12.8.1 Belgium: Female Genital Mutilation Prevention Kit, Decision Tree

In 2014, Belgian CSOs developed a decision tree as part of an "FGM prevention kit" [19] to guide professionals in detecting FGM and supporting girls affected by or at risk of the practice. The decision tree is a protocol describing the protection measures that professionals need to adopt when confronted with a risk or an act of FGM. The decision tree is supplemented by risk assessment indicators and a risk scale, which professionals are advised to consider before reporting. Risk indicators aim to help professionals in making an objective assessment of the situation and have been designed to be culturally and child sensitive. Protection measures as described in the decision tree are then determined according to the level of risk identified by the professionals.

Finally, prosecution requires a number of fundamental steps: reporting of suspected FGM cases, investigation of FGM, including evidence gathering (gynecological checkups for girls and women), utilizing a legislative framework that allows for prospection in the cases of FGM, and bringing cases into court. Each of these steps requires knowledge, information, and procedures to ensure that FGM cases are adequately responded to and subsequent steps can be followed [20].

12.9 Provision of Services

12.9.1 How Should Healthcare Givers Respond to Women Who Underwent Female Genital Mutilation?

Provision of services refers to the services offered to women and girls who have undergone FGM. CSOs, key figures from the communities, and professionals are the leading actors involved with the provision of services across all European Union member states. Services provided by CSOs and key figures include awareness raising among communities and the general public.

Specialized health centers for women who have undergone FGM have been established in a few countries, such as Belgium, Italy, Sweden, and the UK. These centers are usually multidisciplinary and free of charge and may offer translation services. In France, several hospitals have set up multidisciplinary teams to provide surgical repair of the clitoris and psychosexual counseling for victims of FGM. In addition to that, all the consultations and surgery are fully reimbursed by the French social security system. However, the focus of many of the specialized services is de-fibulation procedures for women victims of type III.

In conclusion, research has shown that there are still many challenges in Europe that need to be addressed in order to develop adequate national and European policies on FGM. These are:

- The lack of data and research to properly determine the prevalence of FGM and to assess related needs for the state policies and services in Europe
- The need to take preventive measures and to evaluate their impact in order to ensure they are organized in a sustainable way
- The lack of a systematic approach to the provision of services relating to FGM and the need for culturally sensitive services
- The need for better involvement of affected communities and the development of partnerships between relevant stakeholders, including civil society organizations (CSOs), key figures from the communities, governments, and relevant professionals

Case History: Continued

In the family of Faduma Erin and her husband, a baby boy was born after 2 years. After his birth, Faduma came back to see her gynecologist Lesley Coral. She has learned to speak the language, and the children and her husband are doing well. She has heard about the new possibilities for reconstruction after FGM and she has sexual complaints.

The panic attacks were treated by eye movement desensitization and reprocessing (EMDR) therapy in the meantime and did not reoccur during the second delivery (see Chap. 2 for more information about this intervention). Her husband claims that she should be operated upon to have better sex. Lesley doubts whether her complaints are due to the former infibulation. Also ordinary gynecological or sexual problems can be underlying causes for her complaints.

First, Lesley decides to explore the complaint and perform a general history. Lesley realizes that she may find it difficult to deal with a woman after FGM, because her knowledge of the subject is small due to its rare occurrence. On the other hand, she realizes that the psychological consequences of being a refugee and the trauma Faduma may have endured during her flight also need proper evaluation and treatment. Furthermore, she notices that the consequences of FGM for a woman have a big impact, and she may feel inadequate as a health practitioner to take care of this particular patient.

12.10 Specific Diagnostic Aspects

12.10.1 What Are the Medical, Obstetrical, and Psychosocial Consequences of Female Genital Mutilation?

The main medical consequences are:

- Menstrual disorders, mainly dysmenorrhea. This is found more often after infibulation.
- Difficulties with micturition. Both menstrual disorders and micturition problems are not always seen as a complaint, because other women in the vicinity of the patient have it as well.
- Urinary tract infections.
- Chronic abdominal pain.
- Chronic vaginal infections.
- Keloid and cyst formation due to abnormal healing of the scars.
- Vaginal stones.
- Urethral and/or meatus stenosis.
- Increased risk of human immunodeficiency virus (HIV) and hepatitis B infection due to increased risk of vaginal wounds.
- Difficulties with gynecological examination.
- Medical interventions for sexual contact and delivery may be necessary [21].

The main obstetrical complications are:

- Subfertility.
- Increased cesarean section rate.
- Increased risk of hemorrhagia postpartum.
- Increased newborn death rate [22].

The main psychosocial and sexual consequences are:

- Anxiety and depression coexist with little future perspective.
- Posttraumatic stress syndrome can occur, also on important moments later in life, such as the first sexual encounter or delivery.
- Predictors for anxiety and depression are a clear memory of the circumcision, the form of FGM, and coping with drugs.
- More than 50 % of women have pain on first intercourse, which is higher than in women who did not undergo FGM.
- The complete sexual response cycle can occur (the clitoris can never be removed completely).
- Patients can be ashamed about FGM [23].

12.10.2 Which Issues Have to Be Addressed in History Taking?

The history of the patient should include:

- Type of FGM.
- Age the patient underwent FGM.
- Situation in which she has had FGM; was any anesthesia given?
- Conviction about FGM of the patient herself.
- How easy is it for her to discuss FGM?
- Attitude of partner towards FGM.
- Use of drugs such as qat [21].
- Did she experience sexual violence or physical abuse? Are her complaints related to the abuse?

12.10.3 What Items Should Be Paid Attention to at Physical Examination?

During physical examination attention should be paid to:

- The area around the clitoris
- The presence or absence of the labia minora and majora
- The vaginal introitus and its size
- The scar tissue and its possible complications [24]
- A medical gaze as if the patient is something odd should be avoided. As a health provider, you may feel uncomfortable dealing with patients who underwent FGM, especially since its prevalence is low in the Western world. Still, the patient is not an object, and introducing many trainees to see her may make her feel uncomfortable.

12.11 Specific Therapeutic Aspects

12.11.1 Which Therapeutic Measures Can Be Taken if There Are Complications?

After a thorough history and physical examination, the findings of these need to be discussed with the patient and relevant others as she wishes. The potential measures to relieve her symptoms can be taken. First of all, an explanation of the particular situation of the patient and the potential relationship with FGM needs to be given. From there, an inventory of possibilities and "personal wishes and needs" for care needs to be drawn up. The possibilities can include simple gynecological diagnostic and therapeutic measures. The widening of the vaginal opening by defibulation can be planned if the patient wishes that, and it is expected to relieve her symptoms. Defibulation means that the anterior part of the vulvar septum is carefully cleaved

by a scissor or a knife, after which the remaining tissue is sutured for hemostasis. Apart from the medical possibilities, other possibilities such as psychological counseling and sex therapy can be offered.

12.11.2 Is Reconstructive Surgery Possible?

Recently, the possibility of reconstructive surgery of the clitoris and labia minora has been made available. In different countries, gynecologists, urologists, and plastic surgeons have collaborated with each other to make this possible. Patients need proper evaluation to decide together with their doctor whether reconstruction is a good option for her. Apart from the medical possibilities and surgical and psychosocial risks of the operation, expectations about the result and the aftercare need to be discussed with the patient [25].

Case History: Continued

Faduma Erin tells gynecologist Lesley Coral that one of her sisters was operated in Paris for reconstructive surgery. It was an intensive recovery period, but in the end she was very happy. Faduma wonders whether this would be a good idea for her as well. The rest of the history mentioned several urinary tract infections that were treated by her general practitioner. These episodes have led to dyspareunia, which did not disappear fully after antibiotic treatment.

On examination, Lesley diagnoses a type III FGM. After the pregnancies and deliveries, the vaginal opening was wide enough for intercourse, but she notices hyperactivity of the pelvic floor muscles.

A urine sample does not show any abnormalities. Lesley explains to Faduma that the recurrent urinary tract infections may well be the cause of her dyspareunia and that a reconstructive operation will not resolve that. The recurrent infections may have led to a vicious circle of pelvic floor muscle hyperactivity.

Lesley proposes an examination by the urologist and treatment by the pelvic floor physical therapist combined with a sexologist. Lesley schedules an appointment after the physical therapy and the sexological intake to keep an eye on her. Faduma agrees with this plan.

12.12 Critical Reflection and Conclusive Remarks

Working with women who underwent FGM is an interesting journey. You need an open mind, because the situation of the particular woman might be different than you suppose. No standard guidelines give direction to the care you are giving, so good care requires rethinking and inquiring again [26]. A good collaboration with experienced psychologists, sexologists, and physical therapists is necessary. In

intercultural communication, the language abilities of the patient, the taboo around FGM, and the opinion of society can interfere in the conversation. Avoid clichés that you might use with other patients and use your common sense.

Tips and Tricks

When a patient with questions about FGM enters your office, please note the following:

1. The history of the patient should include:
   - Type of FGM.
   - Age the patient underwent FGM.
   - Situation in which she has had FGM; was any anesthesia given?
   - Conviction about FGM of the patient herself.
   - How easy is it for her to discuss FGM?
   - Attitude of partner toward FGM.
   - Use of drugs such as qat [21].
   - Did she experience sexual violence or physical abuse? Are her complaints related to the abuse?
2. During physical examination attention should be paid to:
   - The area around the clitoris
   - The presence or absence of the labia minora and majora
   - The vaginal introitus and its size
   - The scar tissue and its possible complications [24]
   - A medical gaze as if the patient is something odd should be avoided. As a health provider you may feel uncomfortable dealing with patients who underwent FGM, especially since its prevalence is low in the Western world. Still, the patient is not an object, and introducing many trainees to see her may make her feel uncomfortable.
3. Work closely together in collaboration with experienced psychologists, sexologists, and physical therapists.

Test Your Knowledge and Comprehension

1. What is the definition of female genital mutilation?
2. What are the obstetrical consequences of FGM according to its classification?
3. What are the 4 Ps that are important to eliminate FGM and give an example ofone of these?
4. What are the most common medical consequences of FGM?
5. Are special obstetrical interventions necessary at delivery?
6. What is the definition of female genital mutilation?
   (a) Female genital mutilation includes all procedures to the female genital organs with or without medical intention.
   (b) Female genital mutilation (FGM) includes all kinds of procedures that intentionally alter or cause injury to the female genital organs for nonmedical reasons.

(c) Female genital mutilation includes all cosmetic procedure to the female genital organs.

7. What are the obstetrical consequences of FGM according to its classification?
   (a) With a more extended form of FGM, only more cesarean sections are performed.
   (b) With a more extended form of FGM, more obstetrical complications such as increased incidence of cesarean section and perinatal deaths are described.
   (c) With a more extended form of FGM, more fear of childbirth is described.
   (d) No obstetrical consequences of FGM are found.
8. The elimination of FGM can be described with the four Ps approach.
   (a) The Dutch chain approach is an example of the P of prevention.
   (b) The multidisciplinary guidelines in Belgium are an example of the P of provision of services.
   (c) Prosecution is dependent on local laws and not supported by an EU Convention.
   (d) The UK Asylum Policy Instruction contains only information on FGM for women from risk countries.
9. What are the characteristics of psychosocial problems after FGM?
   (a) A clear memory of FGM predicts less anxiety and depression.
   (b) Orgasm is never possible after FGM.
   (c) PTSD can reoccur at key moments later on such as marriage or childbirth.
   (d) The attitude of women toward FGM is always shameful.
10. Which human rights from the Universal Declaration on Human Rights are violated by FGM?
   (a) Article 3: Everyone has the right to life, liberty and security of person.
   (b) Article 5: No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment.
   (c) Article 25: Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection.
   (d) All of the above.

Answers

1. Female genital mutilation (FGM) includes all kinds of procedures that intentionally alter or cause injury to the female genital organs for nonmedical reasons.
2. With a more extended form of FGM, more obstetrical complications such as increased incidence of cesarean section, hemorrhagia postpartum, and perinatal deaths are described.
3. Prevention, protection, prosecution, and provision of services. One example of prevention is the Dutch chain approach (other examples are, of course, also correct).
4. Menstrual disorders, micturition problems including recurrent UTI, chronic pain, problems with gynecological investigation, and sexological problems.

5. If an episiotomy is needed, first an episiotomy anterior is performed before the necessity of a conventional mediolateral episiotomy is assessed.
6. (b)
7. (b)
8. (a)
9. (c)
10. (d)

References

1. Meegan ME, Conroy RM, Lengeny SO, Renhault K, Nyangole J. Effect on neonatal tetanus mortality after a culturally-based health promotion programme. Lancet. 2001;358(9282):640–1.
2. WHO Factsheet 241. Female genital mutilation. www.who.int/mediacentre/factsheets/fs241/en.
3. United Nations Universal Declaration of Human Rights. http://www.un.org/en/universal-declaration-human-rights/.
4. Inter-African Committee on Traditional Practices (IAC) Zero Tolerance Day. http://iac-ciaf.net/index.php?option=com_content&view=article&id=25&Itemid=13.
5. UN Commission on the Status of Women. Fifty-Sixth session. "Ending female genital mutilation-Report of the Secretary General." Dec 2011.
6. UN General Assembly Resolution on intensifying global efforts for the elimination of FGM. Adapted 20 Dec 2012.
7. European Parliament resolution on female genital mutilation (2001/2035(INI)). http://www.europarl.europa.eu/sides/getDoc.do?type=TA&language=EN&reference=P5-TA-2001-476.
8. European Parliament resolution of 16 January 2008: Towards an EU strategy on the rights of the child (2007/2093(INI)). http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P6-TA-2008-0012+0+DOC+XML+V0//EN.
9. European Parliament resolution of 24 March 2009 on combating female genital mutilation in the EU (2008/2071(INI)). http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P6-TA-2009-0161+0+DOC+XML+V0//EN.
10. European Parliament resolution of 14 June 2012 on ending female genital mutilation (2012/2684(RSP)). http://www.europarl.europa.eu/sides/getDoc.do?pubRef=-//EP//TEXT+TA+P7-TA-2012-0261+0+DOC+XML+V0//EN.
11. NVOG standpunt Vrouwenbesnijdenis. http://nvog-documenten.nl/index.php?pagina=/richtlijn/pagina.php&fSelectNTG_85=86&fSelectedSub=85.
12. Belgium Ministry of Health. Mutilations genitales feminines. 2011. http://www.strategiesconcertees-mgf.be/wp-content/uploads/guide-mgf-fr_web.pdf.
13. United to End FGM (UEFGM). http://www.uefgm.org/.
14. Dutch Ministry of Health, Welfare and Sport and Ministry of Justice and Security. Statement opposing female circumcision. 2011. http://www.pharos.nl/documents/doc/pp5056-verklaring-uk-2011_definitief.pdf.
15. UK Home Office. Statement opposing female genital mutilation. Accessed 7 Oct 2015. https://www.gov.uk/government/publications/statement-opposing-female-genital-mutilation.
16. Concerted Strategies for fighting female genital mutilation. http://www.strategiesconcertees-mgf.be/en/tool/stop-fgm-passport/.
17. UK Home Office. Asylum policy instruction: gender issues in the asylum claim. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/257386/gender-issue-in-the-asylum.pdf.
18. The Council of Europe. Amnesty International 2014. A tool to end FGM. Istanbul Convention.
19. FGM Prevention Kit decision tree. 2014. http://www.strategiesconcertees-mgf.be/wp-content/uploads/MGF-tryptique_final_RTP.pdf.

20. European Institute for gender Equality-EIGE- (2013). Report: female genital mutilation in the European Union and Croatia.
21. NVOG model protocol Medische zorg voor vrouwen en meisjes met vrouwelijke genitale verminking. http://nvog-documenten.nl/index.php?pagina=/richtlijn/pagina.php&fSelectNTG_85=86&fSelectedSub=85.
22. WHO Guidelines. WHO guidelines on the management of health complications from female genital mutilation. 2016. http://www.who.int/reproductivehealth/topics/fgm/management-health-complications-fgm/en/.
23. Vloeberghs E, Knipscheer J, Van der Kwaak A, Naleie Z, Van den Muijsenbergh M. Veiled pain: a study in the Netherlands on the Psychological, social and relational consequences of FGM. Utrecht: Pharos; 2011.
24. http://www.knov.nl/scholing-en-registratie/tekstpagina/570/vrouwelijke-genitale-verminking-vgv.
25. Foldès P, Cuzin B, Andro A. Reconstructive surgery after female genital mutilation: a prospective cohort study. Lancet. 2012;380(9837):134–41.
26. Abdulcadir J, Rodriguez M, Say L. Research gaps in the care of women with female genital mutilation: an analysis. BJOG. 2015;122(3):294–303.

A Woman with Stress Incontinence: Urogenital Complaints and Psychosexual Consequences

13

Sushma Srikrishna and Linda Cardozo

13.1 Introduction and Aims

Stress urinary incontinence (SUI) is involuntary leakage of urine that occurs with any increase in intra-abdominal pressure such as any physical exertion, coughing, sneezing, running, etc. It is a common and distressing condition known to adversely affect quality of life [1]. Stress urinary incontinence describes a symptom, a sign, and a diagnosis although it is only following urodynamic investigation that a diagnosis of urodynamic stress incontinence (USI) can be made. This condition is defined as "the involuntary leakage of urine during increased abdominal pressure in the absence of a detrusor contraction" [1]. The aim of this chapter is to review SUI and its etiopathogenesis, consider the diagnostic evaluation, and briefly review therapeutic options, with a special emphasis on psychosexual implications.

13.2 Definition in Lay Terms

Urinary incontinence is defined as the complaint of any involuntary leakage of urine [2].

13.3 Didactic Goals

After reading this chapter you should be familiar with:

- The implications of SUI as not only a urogynecological condition, but understand its wider implications on the psychosexual well-being of the affected woman

S. Srikrishna, FRCOG (✉) • L. Cardozo, OBE, MD, FRCOG
Department of Urogynecology, King's College Hospital, London, UK
e-mail: sushmasrikrishna@hotmail.com; Linda@lindacardozo.co.uk

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_13

- Factors implicated in the etiology and pathogenesis of SUI
- Diagnostic evaluation of SUI
- Overview of therapeutic options: conservative, medical, and surgical

Case History
A 30-year-old married housewife, Dana Orange, presents with a history of small episodes of leakage following the birth of a daughter 3 years ago. This was a ventouse delivery of a 3.7 kg baby following induction of labor for postdates. She now finds leakage on exercise becoming more troublesome and has recently experienced urinary leakage during sex. She is very upset with the effect this is having on her general quality of life and specifically on sexual function. She is using the combined oral contraceptive pill (30 μ[mu]g ethinylestradiol/150 μ[mu]g levonorgestrel) and is up to date with her cervical smears, and there is no other relevant history.

13.4 Facts and Figures: Definitions, Classification, and Prevalence

13.4.1 What's the Difference Between SUI, Urgency (Urinary) Incontinence (UUI), and Mixed (Urinary) Incontinence (MUI)?

The terminology used throughout this chapter complies with the International Urogynecological Association (IUGA)/International Continence Society (ICS) joint report on the terminology for female pelvic floor dysfunction [1].

13.4.1.1 Urinary Incontinence (UI)
Urinary incontinence is the complaint of any involuntary loss of urine.

13.4.1.2 Stress Urinary Incontinence (SUI)
Stress urinary incontinence is the involuntary loss of urine on effort or physical exertion, or on sneezing or coughing.

13.4.1.3 Urgency (Urinary) Incontinence (UUI)
Urgency (urinary) incontinence is the involuntary loss of urine associated with urgency.

13.4.1.4 Mixed (Urinary) Incontinence (MUI)
Mixed (urinary) incontinence is the involuntary loss of urine associated with urgency and also with effort or physical exertion, sneezing, or coughing.

13.4.1.5 Coital Incontinence

Coital incontinence is the involuntary loss of urine with coitus. This symptom may be further divided into incontinence occurring with penetration and that occurring at orgasm. A recent systematic review suggests that female ejaculation orgasm (squirting) may manifest as either a female ejaculation (FE) of a smaller quantity of whitish secretions from the female prostate or a squirting of a larger amount of diluted and changed urine. Both phenomena may occur simultaneously. The prevalence of FE is 10–54 %, while the prevalence of coital incontinence is 0.2–66 %. Penetration incontinence occurs more frequently and is usually caused by stress urinary incontinence (SUI). Urodynamic diagnoses of detrusor overactivity (DOA) and SUI are observed in orgasmic incontinence [3].

13.4.2 How Often Do You Think that SUI Occurs in Women in General?

The prevalence of urinary incontinence has been found to vary widely depending on the definition used and on which study is quoted. One of the largest epidemiological studies found that 25 % of women complain of urinary leakage [4]. A more recent study reports a total of 40 % of respondents suffering urinary incontinence, which caused significant problems in 8.5 % [5].

Stress urinary incontinence (SUI) is common and affects many women worldwide. One of the most comprehensive reviews of the epidemiology of SUI has been performed as part of the International Consultation on Incontinence [6], which states that about 50 % of women with UI report SUI as the primary or sole symptom of incontinence. Other large studies have reported a prevalence between 26 and 49 % [7, 8]. Asian and other non-Western countries have also reported a prevalence of SUI between 18 and 46 % of the total female population [9–11]. Few published data are available regarding the prevalence of SUI in other developing economies, although a recent study suggests a lower reported prevalence at 5–61 % of the total female population [12].

Several studies have supported the observation that the prevalence of SUI increases with age initially, peaks around the fourth or fifth decade, and then decreases with increasing age [13–15]. Although there are no proven reasons for this, one could speculate that SUI appears to peak in the perimenopausal period, perhaps as a result of estrogen deprivation. Thereafter, one may hypothesize that women may seek treatment, causing a dip in prevalence, or get “accustomed” to it, not complaining of it anymore, or that with age they become less physically active, which in turn could lead to a decreased perception of SUI.

Several longitudinal surveys and cohort studies have reported incidence rates for SUI of 4–11 % per year [16, 17]. Correspondingly, annual remission rates of SUI have been reported as 4–5 % [13].

13.5 Etiology and Pathogenesis

The etiology of SUI is complex and multicausal and remains poorly understood. Several different pathological processes have been implicated, which are depicted in Table 13.1.

13.5.1 What Are the Psychosexual Implications of Incontinence?

13.5.1.1 Sexual Dissatisfaction

Sexual dysfunction is a common complaint among women suffering from urinary incontinence [18]. Among women who seek medical help for urinary incontinence, 25–64 % report problems associated with sexual function, including decreased sexual desire, anorgasmia, and dyspareunia [15, 19]. Of women suffering from urinary incontinence, 46 % said their symptoms negatively impacted on their sexual function, thus reducing the frequency of sexual intercourse [20]. Symptoms reported included dyspareunia, leaking during coitus, embarrassment, and depression [21]. In addition, this study revealed that women suffering from urge incontinence experienced greater difficulties with sexual incontinence than women with stress incontinence. Of 201 women attending a UK clinic with urinary incontinence, 38 % reported avoiding sexual intercourse due to their condition, because they appraised this phenomenon as a negative stimulus in their sexual relationship [22].

The prevalence of coital incontinence can vary from 10 to 27 % in the total population [23]. Decreased frequency of sexual activity can also be the consequence of fear of leakage, wearing pads during the night, or feeling unattractive. In a systematic review on the prevalence of sexual impairment in women with urinary incontinence and the prevalence of urinary leakage during sexual activity, incontinence was shown to have a negative effect on sexual function in a large subset of the population. Population prevalence was noted to be 2 %, whereas prevalence in clinical samples reached 10–56 %. Studies of impairment in sexual function were more varied and methodologically heterogeneous with reported prevalences from 0.6 to 64 % of women [24]. This broad range of prevalences is a reflection of poor reporting in

Table 13.1 Factors implicated in the etiology of USI

Raised intra-abdominal pressure
Urethral sphincter incompetence
Decreased or absent urethral pressure transmission
Bladder neck hypermobility
Parity
Vaginal (particularly instrumental) delivery
Physical trauma to pelvic floor
History of sexual abuse/violence, in particular if pelvic floor/sphincteric tone has damage
Bladder over distension
Congenital abnormalities
Collagen deficiency
Estrogen deficiency and menopause

the literature. Only a few studies report on this topic, and those that do have very broad inclusion criteria, allowing heterogeneous samples to be compared. This means that this broad figure is the reflection of inadequacies in reporting the data.

13.5.1.2 Sexual Partner Relationship

The relationships of couples can be significantly affected by urinary incontinence. In a study on the impact of female urinary incontinence on partner relationships, 38 % of women and 32 % of men reported that the female partner's incontinence impacted negatively on their relationship. Furthermore, 20 % of women and 17 % of men reported reduced intimacy, affection, and physical proximity [25]. There has been only 1 study that has looked specifically at divorce as an issue relating to incontinence. When asked, several women said that they felt that their incontinence had been a factor in their marriage breakdown and subsequent divorce; others feared that without a cure for their incontinence, their marriage might be in jeopardy [26]. This shows that suffering from incontinence has a very high cost in psychosocial terms.

13.6 Specific Diagnostic Aspects

13.6.1 Which Diagnostics Would You Always Use in SUI and Which Are Optional?

13.6.1.1 History Taking

Diagnosis of UI starts with a clinical interview. This interview should at least contain:

- When in your patient's life did the UI start?
- How did the UI progress or change over time?
- Which situations trigger the UI? This may already give clues to what type of UI your patient has.
- Questions about voiding habits: frequency during day and night, painfulness, feeling of obstruction, use of abdominal pressure, and voiding position.
- How did your patient cope with her UI until now? This helps you to understand the way she views the complaint and about the way she copes with it. Is there shame about the UI, embarrassment, or fear for being smelled or wetting her clothes in public spaces?
- How does the UI interfere with her social and sexual life? This gives you an idea about the way she experiences the burden of incontinence for her social and sexual functioning.

13.6.1.2 Basic Investigations

Midstream Urine (MSU) Sample

Urinary tract infection (UTI) may cause or exacerbate lower urinary tract symptoms, such as dysuria and frequency, urgency, and urinary incontinence; therefore, an MSU sample, or dipstick urinalysis, must be taken from all women presenting with urinary symptoms.

Bladder Diary

A bladder diary completed over a minimum of 3 days covering variations in usual activities, such as both working and leisure days, is a useful tool in the initial assessment of women with UI. While a clinical interview may provide information on the voiding habits of a patient, the impression of symptom severity obtained is largely subjective and to some extent retrospective. There is a tendency for patients to exaggerate their urinary symptoms when giving a history [27], and their recall of incontinent episodes may not be reliable. The frequency volume chart (urinary or bladder diary) provides an objective assessment of a patient's fluid input and urine output.

Urodynamic Testing

The term "urodynamic studies" (UDS) was defined by the International Continence Society (ICS) in 1988 as to "involve the assessment of the function and dysfunction of the urinary tract by any appropriate method" [28].

Urodynamic testing is an examination that assesses how the bladder and urethra are performing their job of storing and releasing urine. A typical urodynamic test takes about 30 min to perform. It involves the use of a small catheter used to fill the bladder and record measurements. This examination is not mandatory prior to conservative therapy, although it should be performed prior to any decision on surgical management, or in the evaluation of complex patients, or those with previous failed continence surgery.

13.6.1.3 Assessment of Quality of Life

Disease-Specific Quality of Life Questionnaires

To improve the sensitivity of quality of life (QoL) questionnaires, disease-specific tools have been developed to assess particular medical conditions more accurately and in greater detail. The questions are designed to focus on key aspects associated with lower urinary tract symptoms, while scoring is performed so that clinically important changes can be detected. There are several Grade A recommended disease-specific QoL questionnaires that can be used in women with lower urinary tract dysfunction (Table 13.2) [1, 29–34].

13.6.1.4 Assessment of Sexual Function

Up to 64 % of sexually active women attending a urogynecology clinic suffer from female sexual disorder (FSD) [19]. Although sexual dysfunction is so prevalent, a recent survey of members of the American [35] and British [36] Urogynecologic Society reported that only a minority of doctors screen all patients for FSD, citing lack of time, uncertainty about therapeutic options, and older age of the patient as potential reasons for failing to address sexual complaints as part of routine history. Seventy-six percent found training for FSD unsatisfactory [34].

Although it is obvious that an optimal clinical interview also contains questions about sexual functioning, after which a patient may be referred to a psychosexual counselor if agreed by the patient. However, as mentioned previously, since many gynecologists do not routinely address these issues in their interviews, it is important to ensure that basic screening for sexual dysfunction is carried out. Therefore,

Table 13.2 Disease-specific quality of life questionnaires

King's Health Questionnaire: now known as ICIQ-LUTs QoL [1]
Bristol Female LUT symptoms questionnaire (BFLUTS): now known as ICIQ-FLUTS [29]
Urogenital Distress Inventory (UDI) [30]
Urogenital Distress Inventory-6 (UDI-6) [31]
ICIQ-UI Short Form [32]
Incontinence Impact Questionnaire (IIQ) [33]
I-QoL (urinary incontinence-specific QoL instrument) [34]

it is "strategic" to detect abnormalities in sexual function in all urogynecological patients by using a validated questionnaire.

Two Grade A recommended questionnaires that may be used are:

1. Female Sexual Function Index [37]: The Female Sexual Function Index (FSFI) is a comprehensive 19-item tool that assesses 6 domains of sexual function: desire, arousal, lubrication, orgasm, satisfaction, and pain.
2. Golombok Rust Inventory of Sexual Satisfaction [38]: The Golombok Rust Inventory of Sexual Satisfaction (GRISS) is a short 28-item questionnaire for assessing the existence and severity of sexual problems. The female version of the GRISS produces a total score as well as subscales of infrequency, avoidance, anorgasmia, noncommunication, non-sensuality, and vaginismus. The GRISS is used by sexual dysfunction clinics and relationship counselors to monitor the state of their patient's sexual function. It has also been used in clinical trials of new treatment approaches and pharmacological products designed for treatment of sexual dysfunction. It is particularly useful in identifying the extent of any change in sexual function as a result of therapy.

13.6.2 Red Flag Symptoms

The following are red flag symptoms:

- Microscopic hematuria in women aged 50 years and older
- Visible hematuria
- Recurrent or persisting UTI associated with hematuria in women aged 40 years and older
- Suspected malignant mass arising from the urinary tract

13.6.3 Consideration for Early Referral to a Specialist Service

These are the indications for early referral to a specialist:

- Persisting bladder or urethral pain
- Clinically benign pelvic masses

- Associated fecal incontinence
- Suspected neurological disease
- Symptoms of voiding difficulty
- Suspected urogenital fistulae
- Previous continence surgery
- Previous pelvic cancer surgery
- Previous pelvic radiation therapy

13.6.4 Most Common Diagnoses Arising from the Diagnostic Process

These are the most common diagnoses we encounter:

- Urine dipstick may reveal a urinary tract infection.
- Hematuria may reveal a bladder infection or a bladder malignancy.
- A bladder diary may reveal excessive fluid intake, wrong kind of fluids, such as caffeine, fizzy pop, etc.
- Urodynamic study may reveal detrusor overactivity and/or voiding dysfunction. Also other incidental findings may be found, such as urethral or bladder diverticulum and urinary reflux.

13.7 Specific Therapeutic Aspects

13.7.1 Which Therapeutics Would You Always Use in SUI and Which Are Optional?

13.7.1.1 Conservative Management

Conservative treatment of USI should be considered in all women presenting with urodynamic stress incontinence and particularly in those women who have not yet completed their family or are unfit for surgery. Conservative management includes:

1. Lifestyle modification such as reducing excessive fluid intake, weight loss [39, 40], and management of other chronic conditions such as chronic cough, constipation, and change in high-impact exercise regimen [41].
2. Pelvic floor muscle rehabilitation remains the first-line conservative measure, with cure rates varying between 21 and 84 % [21, 42, 43]. Evidence would suggest that pelvic floor muscle training (PFMT) is more effective if patients are given a structured program [44], particularly with supervision [45].
3. Pessaries. These devices are believed to work by augmenting urethral closure during increased intra-abdominal pressure and thus increasing urethral resistance [46]. The main benefit of using continence pessaries is the avoidance of morbidity and rarely mortality associated with surgical therapies.
4. Medical treatment:

(a) Duloxetine hydrochloride, a dual serotonin and norepinephrine reuptake inhibitor (SNRI), has been available since 2004. Current evidence would suggest that women with moderate-to-severe SUI can be improved while taking duloxetine 40 mg twice per day. Animal studies have implicated serotonin and norepinephrine in the neural control of lower urinary tract function. In cats, serotonergic agonists suppress parasympathetic activity and enhance sympathetic and somatic activity [47, 48], effects that promote urine storage by relaxing the bladder and increasing outlet resistance. Duloxetine, which is a balanced and potent inhibitor of serotonin and norepinephrine reuptake, has been demonstrated to increase bladder capacity and striated urethral sphincter activity through central actions in the spinal cord in the cat [49]. The ability of duloxetine to stimulate pudendal motor neurons and increase striated urethral sphincter contractility is thought to be the basis for its efficacy in women with SUI [50]. Nausea is the most frequently reported adverse event of duloxetine hydrochloride.

(b) There is no evidence for the use of systemic estrogen therapy in SUI, although vaginal use may benefit women with urogenital atrophy [51].

13.7.1.2 Surgical Management

When offering a surgical procedure, it is important to discuss with the woman the risks and benefits of the different treatment options for SUI, using simple language, avoiding jargon, and supplementing the discussion with patient information leaflets. Although a detailed review of the available surgical options is beyond the scope of this chapter, available options are:

- Synthetic mid-urethral tape
- Open/laparoscopic colposuspension
- Autologous rectus fascial sling
- Periurethral bulking agents

13.7.2 To Whom Would You Refer in Case of SUI and Why?

13.7.2.1 Psychosexual Counseling

Incontinent women may be burdened with anxieties and feelings of embarrassment and shame, and they live in constant fear that others will discover their condition. Women's sexual function and relationships with their partners may be significantly affected by their incontinence, thus augmenting their feelings of low self-confidence. Furthermore, major depression has been shown to be more common in incontinent women, adding to the cycle of low self-esteem, increased social withdrawal, and, ultimately, a reduction in quality of life.

As physicians, we must be prepared to discuss all aspects of women's lives in order to ascertain all their concerns.

Underlying psychiatric disease must be diagnosed and treated appropriately. Early referral to a specialist psychosexual counselor may be of immense benefit.

This can empower women to live active, normal lives and minimize the psychological distress associated with what is a potentially debilitating condition.

Case History: Continued

Dana Orange was seen and assessed in the specialist urogynecology clinic. A detailed history and thorough physical examination confirmed an initial diagnosis of SUI. The QoL assessment showed severe impairment of both general QoL as well as specifically sexual dysfunction leading to distress, avoidance, and non-intimacy. The MSU was negative and the bladder diary showed excessive fluid consumption. Dana responded very well to initial therapy in the form of lifestyle advice by reducing fluid consumption as well as supervised PFMT by a women's health physiotherapist.

She and her husband also were referred to a specialist psychosexual counselor for her ongoing issues with physical intimacy. This counseling was helpful to the couple. Dana was able to speak up about her embarrassment. She told the counselor and her husband that she was terribly afraid to smell and to leak urine during intimacy and especially during intercourse. Talking about this during the counseling was a relief to her. Her husband reacted with understanding and love, which decreased the tension between both partners. Following these measures, Dana reported improvement in both physical and psychosexual symptoms. At present she is planning to have another baby and so decided against surgical therapy.

13.8 Critical Reflection and Conclusive Remarks

It is important to realize that a patient seeing a general practitioner or a gynecologist may have a straightforward presentation of SUI. However, frequently a patient's clinical picture is more complex. She may have specific psychological or sexual dysfunction-related condition, aggravated by or unrelated to the underlying incontinence. She may also have an unrelated comorbid psychological or somatic condition.

It is essential to evaluate every woman thoroughly including her desire for treatment. The aim of therapy is ideally tailored individually, taking into account the individual patient's own symptoms and the impairment of her QoL, aiming to always have a trial of conservative therapies in the first instance.

Tips and Tricks

A detailed history and thorough examination of the abdomen and pelvis in supine and standing position are essential. Symptoms of sexual or psychological burden may not be volunteered unless asked for on direct questioning. It is equally important to rule out common conditions such as UTIs by a simple dipstick. A detailed 3-day bladder diary provides invaluable evidence as does a disease-specific QoL diary.

Test Your Knowledge and Comprehension

1. A recent large-scale epidemiological study found that 25 % of women complain of urinary leakage.
   (a) True
   (b) False
2. Stress urinary incontinence occurs due to uninhibited detrusor contractions.
   (a) True
   (b) False
3. There is no medical therapy available for SUI.
   (a) True
   (b) False
4. Surgery is the first-line option of management for SUI.
   (a) True
   (b) False
5. Sexual dysfunction often coexists and is partly related to SUI.
   (a) True
   (b) False
6. Which of the following is *not* commonly associated with SUI?
   (a) Older age
   (b) Nulliparity
   (c) Menopause
   (d) Collagen disorders
7. Which symptom is most likely associated with SUI?
   (a) Frequency
   (b) Urgency
   (c) Coital incontinence at penetration
   (d) Nocturia
8. Which of the following is not usually used in the investigation of SUI?
   (a) Urine MSU
   (b) Bladder diary
   (c) Magnetic resonance imaging (MRI)
   (d) Urodynamics
9. Concerning the use of quality of life questionnaires, which is not used in SUI?
   (a) King's health questionnaire
   (b) GRISS
   (c) ICIQ-FLUTS
   (d) Manchester bowel questionnaire
   (e) IIQ
10. Which of the following is not a management option for SUI?
    (a) Physiotherapy
    (b) Duloxetine
    (c) Antimuscarinics
    (d) Continence surgery

Answers

1. True
2. False
3. False
4. False
5. True
6. (b)
7. (c)
8. (c)
9. (d)
10. (c)

Disclosure of Possible Conflicts of Interest Sushma Srikrishna: Speaker Honorarium: Recordati; Consultant: Astellas; Travel grant to attend ICS: Boston Scientific, Recordati.

Linda Cardozo: Consultant: Astellas, Pfizer, AMS, Allergan; Speaker Honorarium: Astellas, Pfizer; Trial Participation: Astellas, Pfizer; Research grant: Pfizer.

References

1. Kelleher CJ, Cardozo LD, Khullar V, Salvatore S. A new questionnaire to assess the quality of life of urinary incontinent women. Br J Obstet Gynaecol. 1997;104:1374–9.
2. Haylen BT, de Ridder D, Freeman RM, Swift SE, Berghmans B, Lee J, Monga A, Petri E, Rizk DE, Sand PK. Schaer GN; International Urogynecological Association; International Continence Society. An International Urogynecological Association (IUGA)/International Continence Society (ICS) joint report on the terminology for female pelvic floor dysfunction. Neurourol Urodyn. 2010;29(1):4–20.
3. Pastor Z. Female ejaculation orgasm vs. coital incontinence: a systematic review. J Sex Med. 2013;10(7):1682–91.
4. Hannestad YS, Rortveit G, Sandvik H, Hunskar S. A community-based epidemiological survey of female urinary incontinence: The Norwegian EPINCONT Study. J Clin Epidem. 2000;53:1150–7.
5. Cooper J, Annappa M, Quigley A, Dracocardos D, Bondili A, Mallen C. Prevalence of female urinary incontinence and its impact on quality of life in a cluster population in the United Kingdom (UK): a community survey. Prim Health Care Res Dev. 2015;16(4):377–82.
6. Milsom I, Altman D, Lapitan MC, Nelson R, Sillen U, Thom DH. Epidemiology of Urinary (UI) and Faecal (FI) Incontinence and Pelvic Organ Prolapse (POP). In: Abrams P, Cardozo L, Khoury S, Wein AJ, editors. Incontinence: 4th international consultation on incontinence. Paris: Health Publication Ltd; 2013. p. 35–112.
7. Tennstedt SL, Link CL, Steers WD, Mckinlay JB. Prevalence of and risk factors for urine leakage in a racially and ethnically diverse population of adults: the Boston Area Community Health (BACH) Survey. Am J Epidemiol. 2008;167(4):390–9.
8. Dooley Y, Kenton K, Cao G, et al. Urinary incontinence prevalence: results from the National Health and Nutrition Examination Survey. J Urol. 2008;179(2):656–61.
9. Zhu L, Lang J, Liu C, Han S, Huang J, Li X. The epidemiological study of women with urinary incontinence and risk factors for stress urinary incontinence in China. Menopause. 2009;16(4):831–6.
10. Azuma R, Murakami K, Iwamoto M, Tanaka M, Saita N, Abe Y. Prevalence and risk factors of urinary incontinence and its influence on the quality of life of Japanese women. Nurs Health Sci. 2008;10(2):151–8.

11. Onur R, Deveci SE, Rahman S, Sevindik F, Acik Y. Prevalence and risk factors of female urinary incontinence in eastern Turkey. Int J Urol. 2009;16(6):566–9.
12. Walker GJ, Gunasekera P. Pelvic organ prolapse and incontinence in developing countries: review of prevalence and risk factors. Int Urogynecol J Pelvic Floor Dysfunct. 2011;22(2):127–35.
13. Nygaard I, Thom DH, Calhoun E. Urinary incontinence in women. In: Litwin MS, Saigal CS, editors. Urologic diseases in America. NIH Publication No. 04–5512 ed. Washington, DC: US Government Publishing Office; 2004. p. 71–103.
14. Hannestad YS, Rortveit G, Sandvik H, Hunskaar S. A community-based epidemiological survey of female urinary incontinence: the Norwegian EPINCONT study. Epidemiology of Incontinence in the County of Nord-Trondelag. J Clin Epidemiol. 2000;53(11):1150–7.
15. Lifford KL, Townsend MK, Curhan GC, Resnick NM, Grodstein F. The epidemiology of urinary incontinence in older women: incidence, progression, and remission. J Am Geriatr Soc. 2008;56(7):1191–8.
16. Irwin DE, Milsom I, Chancellor MB, Kopp Z, Guan Z. Dynamic progression of overactive bladder and urinary incontinence symptoms: a systematic review. Eur Urol. 2010;58(4):532–43.
17. Handa VL, Garrett E, Hendrix S, et al. Progression and remission of pelvic organ prolapse: a longitudinal study of menopausal women. AmJ Obstet Gynecol. 2004;190:27–32.
18. Barber MD, Visco AG, Wyman J, Fantl JA, Bump RC. Continence Program for Women Research Group. Sexual function in women with urinary incontinence and pelvic organ prolapse. Am Coll Obstet Gynaecol. 2002;9:281–9.
19. Pauls RN, Segal JL, Andre Silva W, Kleeman SD, Karram MM. Sexual function in patients presenting to a urogynecology practice. Int Urogynecol J Pelvic Floor Dysfunct. 2006;17:576–80.
20. Sutherst JR. Sexual dysfunction and urinary incontinence. BrJ Obstet Gynaecol. 2005;86:387–8.
21. Nygaard I, Girts T, Fultz NH, Kinchen K, Pohl G, Sternfeld B. Is urinary incontinence a barrier to exercise in women? Am J Obstet Gynaecol. 2005;106:307–14.
22. Norton PA, MacDonald LD, Sedgewick PM, Stanton SL. Distress and delay associated with urinary incontinence, frequency and urgency in women. BMJ. 1988;297:1187–9.
23. Serati M, Salvatore S, Uccella S, Nappi RE, Bolis P. Female urinary incontinence during intercourse: a review on an understudied problem for women's sexuality. J Sex Med. 2009;6(1):40–8.
24. Shaw C. A systematic review of the literature on the prevalence of sexual impairment in women with urinary incontinence and the prevalence of urinary leakage during sexual activity. Eur Urol. 2002;42:432–40.
25. Nilsson M, Lalos A, Lalos O. The impact of female urinary incontinence and urgency on quality of life and partner relationship. Neurol Urodyn. 2009;28:976–81.
26. Norton C. The effects of urinary incontinence in women. Int J Disabil Rehab. 1982;4:9–14.
27. Wyman JF, Choi SC, Harkins SW, Wilson MS, Fantl JA. The urinary diary in evaluation of incontinent women: a test-retest analysis. Obstet Gynecol. 1988;71(6 Pt 1):812–7.
28. Abrams P, Blaivas JG, Stanton SL, Andersen JT. The standardisation of terminology of lower urinary tract function. The International Continence Society Committee on Standardisation of Terminology. Scand J Urol Nephrol Suppl. 1988;114:5–19.
29. Brookes ST, Donovan JL, Wright M, Jackson S, Abrams P. A scored form of the Bristol Female Lower Urinary Tract Symptoms questionnaire: data from a randomized controlled trial of surgery for women with stress incontinence. Am J Obstet Gynecol. 2004;191(1):73–82.
30. Shumaker SA, Wyman JF, Uebersax JS, McClish D, Fantl JA. Continence Program in Women (CPW) Research Group. Health-related quality of life measures for women with urinary incontinence: the Incontinence Impact Questionnaire and the Urogenital Distress Inventory. Qual Life Res. 1994;3(5):291–306.
31. Uebersax JS, Wyman JF, Shumaker SA, McClish DK, Fantl JA. Short forms to assess life quality and symptom distress for urinary incontinence in women: the Incontinence Impact Questionnaire and the Urogenital Distress Inventory. Continence Program for Women Research Group. Neurourol Urodyn. 1995;14(2):131–9.

32. Avery K, Donovan J, Peters TJ, Shaw C, Gotoh M, Abrams P. ICIQ: a brief and robust measure for evaluating the symptoms and impact of urinary incontinence. Neurourol Urodyn. 2004;23(4):322–30.
33. Hagen S, Hanley J, Capewell A. Test-retest reliability, validity, and sensitivity to change of the urogenital distress inventory and the incontinence impact questionnaire. Neurourol Urodyn. 2002;21(6):534–9.
34. Wagner TH, Patrick DL, Bavendam TG, Martin ML, Buesching DP. Quality of life of persons with urinary incontinence: development of a new measure. Urology. 1996;47(1):67–71. discussion 71-2.
35. Pauls RN, Kleeman SD, Segal JL, Silva WA, Goldenhar LM, Karram MM. Practice patterns of physician members of the American Urogynecologic Society regarding female sexual dysfunction: results of a national survey. Int Urogynecol J Pelvic Floor Dysfunct. 2005;16:460–7.
36. Roos A, Thakar R, Sultan AH, Scheer I. Female sexual dysfunction: are urogynecologists ready for it? Int Urogynecol J Pelvic Floor Dysfunct. 2009;20(1):89–101.
37. Rosen R, Brown C, Heiman J, et al. The Female Sexual Function Index (FSFI): a multidimensional self-report instrument for the assessment of female sexual function. J Sex Marital Ther. 2000;26(2):191–208.
38. Rust J, Golombok S. The Golombok-Rust Inventory of Sexual Satisfaction (GRISS). Br J Clin Psychol. 1985;24(Pt 1):63–4.
39. Wing RR, West DS, Grady D, Creasman JM, Richter HE, Myers D, Burgio KL, Franklin F, Gorin AA, Vittinghoff E, Macer J, Kusek JW, Subak LL. Program to Reduce Incontinence by Diet and Exercise Group. Effect of weight loss on urinary incontinence in overweight and obese women: results at 12 and 18 months. J Urol. 2010;184(3):1005–10.
40. Kuruba R, Almahmeed T, Martinez F, Torrella TA, Haines K, Nelson LG, Gallagher SF, Murr MM. Bariatric surgery improves urinary incontinence in morbidly obese individuals. Surg Obes Relat Dis. 2007;3(6):586–90. discussion 590-1.
41. Goldstick O, Constantini N. Urinary incontinence in physically active women and female athletes. Br J Sports Med. 2014;48(4):296–8.
42. Bo K, Talseth T, Holme I. Single blind, randomised controlled trial of pelvic floor muscles exercises, electrical stimulation, vaginal cones and no treatment in management of genuine stress incontinence in women. Br Med J. 1999;318:487–93.
43. Bernstein IT. The pelvic floor muscles: Muscle thickness in healthy and urinary incontinent women measured by perineal ultrasonography with reference to the effect of pelvic floor training. Oestrogen receptor studies. Neurourol Urodyn. 1997;16:237–75.
44. Bo K, Hagen RH, Kvarstein B, Jorgensen J, Larsen S. Pelvic floor muscle exercise for the treatment of female stress urinary incontinence. III: Effects of two different degrees of pelvic floor muscle exercise. Neurourol Urodyn. 1990;9:489–502.
45. Hay-Smith EJ, Herderschee R, Dumoulin C, Herbison GP. Comparisons of approaches to pelvic floor muscle training for urinary incontinence in women. Cochrane Database Syst Rev. 2011;12, CD009508.
46. Komesu YM, Ketai LH, Rogers RG. Restoration of continence by pessaries: magnetic resonance imaging assessment of mechanism of action. Am J Obstet Gynecol. 2008;198:563.e1.
47. Espey MJ, Du HJ, Downie JW. Serotonergic modulation of spinal ascending activity and sacral reflex activity evoked by pelvic nerve stimulation in cats. Brain Res. 1998;798:101.
48. Danuser H, Thor KB. Spinal 5-HT2 receptor-mediated facilitation of pudendal nerve reflexes in the anaesthetized cat. Br J Pharmacol. 1996;118:150.
49. Thor KB, Katofiasc MA. Effects of duloxetine, a combined serotonin and norepinephrine reuptake inhibitor, on central neural control of lower urinary tract function in the chloraloseanesthetized female cat. J Pharmacol Exp Ther. 1995;274:1014.
50. Norton PA, Zinner NR, Yalcin I, Bump RC. Duloxetine versus placebo in the treatment of stress urinary incontinence. Am J Obstet Gynecol. 2002;187:40.
51. Cody JD, Jacobs ML, Richardson K, Moehrer B, Hextall A. Oestrogen therapy for urinary incontinence in post-menopausal women. Cochrane Database Syst Rev. 2012;(10):Art. No.: CD001405.

A Couple Who Cannot Conceive: Coping with Infertility

14

Tewes Wischmann and Heribert Kentenich

14.1 Introduction and Aims

Coping is derived from "to cope with" and refers to the way people deal with stressful situations. The process starts with an event that is primarily appraised by the individual as *threatening, harmful, or challenging* [1]. This definition shows that in the case of a couple facing infertility, both partners can show different evaluations of the "nonevent transition" that characterizes infertility, which therefore can be defined as a chronic stressor [2]. In the secondary appraisal step, the individual assesses if he/she is able to cope with the consequences of that event. In a third step ("reappraisal") the individual evaluates if his/her coping abilities and strategies have been successful or not. This chronological description shows that coping is an endless dynamic process of appraisal and reappraisal, which is influenced by many factors. Because the period in which a couple is suffering from infertility encompasses many stressful moments and events, it is difficult, if not impossible, to determine exactly "what causes what." According to the literature, successful coping in this situation of infertility is mainly influenced by the history of the desire for a child, the medical diagnosis, the patients' estimations of treatment success, and the actual strategies of both partners of the couple. As described later, the coping strategies of both partners of the couple are mutually dependent.

As Kentenich and coworkers indicate, doctor and patient often prefer active treatment options. When something is actively being done, there may be no time for consideration or discussion, and there is no time to allow for grief. This unconscious unity may defend them from emotions as, for example, they both want to quickly

T. Wischmann, PD Dr, Dipl-Psych (✉)
Institute of Medical Psychology, University Hospital Heidelberg, Heidelberg, Germany
e-mail: Tewes.wischmann@med.uni-heidelberg.de

H. Kentenich, Prof MD
Fertility Center Berlin, Berlin, Germany
e-mail: kentenich@fertilitycenterberlin.de

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_14

"forget" failures (no pregnancy, miscarriage) and to proceed with medical treatment as soon as possible. The doctor should be aware of this problem with transference and countertransference [3].

Psychosocial infertility counseling can be recommended to both partners of the couple before, during, and after medical treatment [4]. While information gathering and analysis as well as implications and decision-making counseling can be provided by the medical doctor (and partly by other fertility staff), support and crisis counseling will usually be offered by a specially trained psychosocial counselor [5]. Major contents and aims of this counseling should be the discussion of the perceived stress of the medical treatment and the coping abilities of the couple, their social support, the estimations of treatment success, and the development of a treatment plan (including a "plan B" if treatment should finally fail) [6].

Couples should be given the information that meaning-based and active-confronting coping strategies are usually more helpful than active- or passive-avoidance strategies [4]. According to Schmidt [7], *meaning-based coping* is characterized by a positive reappraisal of the situation, by goal-directed, problem-focused coping, making use of spiritual beliefs and practices, and the attempt to infuse ordinary events with a positive meaning. *Active-confronting strategies* include asking other people for advice, talking to other people about emotions related to infertility and about experiences with the medical treatment, to let feelings out, and use humor. *Active-avoidance strategies* encompass avoiding being with children or pregnant women, leaving when people talk about pregnancies and children, and trying to keep feelings private. The fourth coping strategy, *passive-avoidance coping*, is characterized by hoping for a miracle, feeling that the only thing to do is to wait, and avoid reading or hearing about childlessness.

14.2 Definition in Lay Terms

Coping is derived from "to cope with" and refers to the way people deal with stressful situations. The process starts with an event that is primarily appraised by the individual as either *threatening, harmful, or challenging* [1].

14.3 Didactic Goals

After reading this chapter you should know:

- About the relationship between "psychogenic," behavior-related, and somatic factors in infertility
- About the emotional impact of infertility on both partners of the couple
- Which coping strategies most couples use in this situation
- How to address these coping strategies adequately as an OB/GYN professional
- Some of the core elements in infertility counseling in order to improve coping of couples when needed

Case History

Karen (35 years old) and Michael (38 years old) Burgundy have been a couple for 7 years. For the last 2 years both of them have had an unfulfilled wish for a child. Six months ago Karen's hormone status was tested and showed to be normal. The resident gynecologist Andrew Tan counsels the couple to continue with timed intercourse. Two semen analyses within the last 3 months each have shown asthenozoospermia (i.e., semen with reduced sperm motility).

Michael has a stressful job as an investment banker. For a long time he has been smoking 2 packs of cigarettes a day. Unchallenged in her technical job at a television station, Karen does excessive mountain biking for 1 h daily (on weekends even longer). Her body appears slim and sinewy, whereas Michael seems to be rather lacking in power and drive. Over the course of time, most of their friends have become parents and meetings with them have become rare. The couple does not have a "plan B" and still hopes to get pregnant spontaneously. Due to the "unnaturalness" of the procedure, they reject in vitro fertilization. The couple does not agree upon the frequency of intercourse. In Karen's opinion they always complied with the "fertile window" during the last 6 months. To Michael, their chances were at a maximum of 50 % of the possible opportunities.

Diagnostics

Andrew Tan is checking several medical issues: first he checks whether Karen still has regular ovulations, since she might have cycle abnormalities due to her excessive sports. Therefore Andrew monitors the cycle duration, followed by tests of LH and of progesterone in the second half of the menstrual cycle when indicated. The second step is the examination of the permeability of the fallopian tubes. Next to the medical investigations, Andrew asks about several other aspects, focusing on the coping strategies of the couple: "Do sports and smoking have the function of 'stress relief' for you? Have you both become socially isolated? How do you talk about your wish for a child with each other and other people? How is your current sex life?"

Therapeutics

Andrew Tan considers that there is a diagnosis of "behavior-related infertility" due to Karen's excessive sporting and Michael's smoking behavior. This implies that she needs to be urged to reduce her mountain biking activities and he needs to stop (or reduce) smoking [4].

Karen is astonished to hear from Andrew that her sporting behavior would no longer be labeled a healthy lifestyle but a behavior detrimental for her fertility. She agrees with Andrew's suggestion to reduce the mountain biking to 1 h every 2 days. Michael admits that he knew about the negative impact of cigarette smoking on his sperms already but that he has not found any other way of stress relief yet. Andrew provides advice where and how to learn relaxation techniques and asks if Michael could imagine practicing regular but moderate

sporting to reduce his stress. He explains to the couple that social isolation has been shown to be a prominent risk factor in terms of maladaptation to the experience of infertility. Surely, several of their friends would be glad to talk about other issues than napkins and teething. Andrew also suggests to be more open concerning the wish for a child and not to use any white lies [6].

Regarding their sex life, Andrew recommends Karen and Michael make a distinction between target-oriented and pleasure-oriented sexuality and not to make life difficult for themselves by expecting "sex by the clock" to be "spontaneous," romantic, and fulfilling at the same time [8].

The couple's passive-avoiding coping behavior is discussed both in a supportive as well as in a critical way during the medical consultation. First Andrew summarizes their past coping strategies as being sporty for Karen and "wait and see" for Michael. Andrew then continues with depicting both strategies as "effective until now." He says, "You both are successful in your career, personal functioning, etc." Then Andrew points out to Karen and Michael that clinical experience has shown clearly that unfortunately, both coping styles are very ineffective for infertile couples after some years of trying to get pregnant without success. Therefore they are informed about the positive effects of meaning-based coping strategies ("accept and give a positive meaning to childlessness"), and, in their case, especially active-confronting coping strategies ("engage in an active search for alternatives and do not cut yourselves off socially") together as a couple. In this way, a helpful approach is to stimulate patients to prepare roadmaps and to adjust them during the course of infertility treatment. This definitely also means developing a "plan B," a "plan C," etc., starting from the beginning [6].

Therefore Andrew asks the question "What would your life look like in 5 years, provided you remain still childless?" Karen replies that she cannot imagine this situation right now and starts crying. Empathically Andrew agrees that this vision of childlessness may be emotionally threatening to imagine but that this issue should not become a taboo subject for Karen and Michael.

Couples should be reassured that the emotional long-term consequences of involuntary childlessness are not severe as long as the couple will accept this situation and is socially not isolated [4]. Andrew underlines that most couples report that in the medium and long term, coping with the crisis that childlessness represents leads to a strengthening of the partnership [9], and Michael agrees with that because this would be exactly his answer to Andrew's last question of his vision for their future as a couple.

In case of the differential diagnosis "unexplained infertility," Andrew outlines that the next treatment steps—after a specific period of "timed intercourse"—would be intrauterine insemination and eventually in vitro fertilization [10]. He asks what does the couple actually exactly know about assisted reproductive technologies (ART), what kind of misgivings and expectations do Karen and Michael have toward in vitro fertilization, and which

prejudices? Andrew explains that except from 2 to 5 days, where oocytes and semen are cultivated in the petri dish, pregnancies after in vitro fertilization are identical with naturally conceived pregnancies. Only the injection of a single sperm into an oocyte via micromanipulation during intracytoplasmic sperm injection is an artificial procedure. Worldwide, more than 5 million children were born after assisted reproduction, and their development is unremarkable and without pathological findings if the children are singletons, only (high-order) multiples may have an unfavorable prognosis. Concerning the couple's objection to the "unnaturalness" of in vitro fertilization, Andrew explains in detail the process step by step and refers Karen and Michael to information leaflets and up-to-date guidebooks.

14.4 Facts and Figures: Definitions, Classification, and Prevalence

14.4.1 How Many People Suffer from Infertility?

According to the World Health Organization (WHO) definition, involuntary childlessness is defined as not becoming pregnant after 1 year with unprotected sexual intercourse [11]. Since female fertility declines from 25 to 30 years on (and sharply in the late 30s), the age of the women is the most important factor contributing to infertility [12]. In Western countries, more and more women postpone motherhood to a later age, and therefore the prevalence of infertility is rising [13]. Although on average about 1 in 3–4 women waits for a pregnancy up to 1 year, only about 3–9 % of couples are infertile and will presumably need medical help to become pregnant [14].

14.4.2 What Do You Think Are the Success Rates of Infertility Treatment?

After three cycles of assisted reproductive treatment, about half of these couples will have a live birth, and after six cycles—if the couple does not opt out of treatment—nearly 70 % succeed with a live-born child/children [15, 16].

14.4.3 Who Suffers Emotionally More from Infertility: Women or Men?

Infertility is emotionally upsetting for most of the individuals affected [17], and the emotional impact on women and men is very similar [18]. Several typical aspects will be affected through the experience of infertility: emotions such as anxiety,

grief, helplessness, and feelings of guilt are common in both partners. Self-esteem is negatively affected, and since family building is often still seen as a "woman's issue," a decrease in self-esteem and a sense of failure is usually more prominent in the female partner. The partnership is impaired either in a positive way (the infertility crisis "welds" the couples together) or in a negative way (if the partner is blamed for his/her infertility diagnosis). The couple has to be prepared that during medical diagnostics and/or treatment up to 60 % of the couples experience sexual problems [8]. These sexual problems are transitory in general, and only in very few cases will sexual therapy be necessary. At least the social surroundings might be negatively affected. As Wischmann and coworkers point out [19], social pressure can lead to a defensive approach so that neither friends nor parents are informed of the wish for a child or about the medical infertility treatment the couple is undergoing.

As described by Wischmann and Thorn [18], psychosomatic research postulated for decades that women suffer considerably more from infertility than their male partners. Recent research suggests, however, that these differences in men's and women's psychological responses to infertility can be interpreted as broader gender differences in reactions to stress, emotional distress, and grief rather than reactions specific to infertility. The results of much of the formerly available research may reflect differences in the ways men and women have been socialized to cope with negative affect and with distress and that by adhering to masculinity "norms," many men tend to suppress their emotions in an effort to support their partners [18]. As Meyers and colleagues stated, the conflicts generated by infertility may lead to increased polarization and/or protective silence [20]. Figure 14.1 [21] shows the typical polarization that can be found in infertile couples' relationship patterns.

On the basic mood scale, the self-assessments of men and women are very close together, whereas the partner images are positioned toward the carefreeness pole of the scale for the men (as seen by the women) and toward the depressive pole for the women (as seen by the men). As Van den Broeck and colleagues [6] point out, it can be helpful to visualize this polarization pattern (or "role allocation") [19] in couples counseling to normalize its occurrence and to "allow" more flexibility in the allocation of roles. Otherwise the woman may want to talk about her pain and sadness, whereas her partner may feel helpless and withdrawn, resulting in polarization and isolation of both partners at a time where both partners need each other most in their infertility crisis.

14.4.4 What Do You Think Are the Most Helpful Coping Strategies for Infertile Couples?

As Peterson and coworkers could show [22], the coping strategies of both partners in infertile couples are interdependent and do interact. In their study, a partner's use of active-avoidance coping was related to the increased personal, marital, and social distress for both partners. A woman's use of active-confronting coping was related to increased male marital distress, and a partner's use of meaning-based coping was

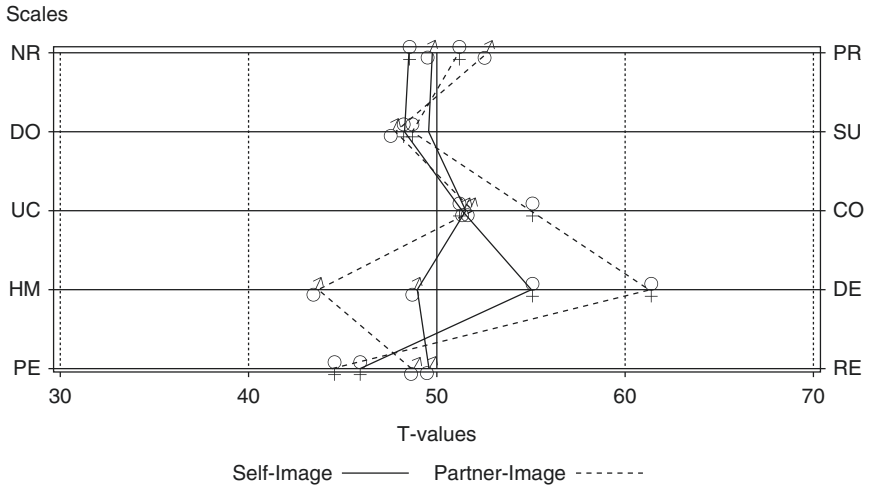


Fig. 14.1 Giessen test profiles of all couples. Typical polarization that can be found in infertile couples' relationship patterns. Self and partner images ($n=500$) (Used with permission of Oxford University Press from Wischmann et al. [21])

associated with decreased marital distress in men and increased social distress in women. The authors concluded that physicians and mental health providers can use the findings from this study to educate their patients regarding the benefits of meaning-based coping for women and their partners, as well as the gender differences that exist when men engage in meaning-based coping. For the authors it is likely that these differences in the effects of meaning-based coping for men and women are reflective of different gender perspectives on the importance of parenthood.

14.5 Etiology and Pathogenesis

Causes for infertility are nearly equally distributed among women and men: about one-third solely female factor infertility, about one-third solely male factor infertility, about one-third mixed factor infertility, and about 10 % unexplained infertility. In about 9 % of diagnoses, behavior-related infertility causes are prominent (e.g., severe underweight or overweight, drug intake, excessive cigarette smoking, nonorganically caused sexual dysfunctions) [23]. There is no empirical evidence for solely "psychogenic" infertility (emotional stress and intrapsychic blockades acting as the only powerful "conception stoppers") [24], for increased psychopathology in couples with unexplained infertility or for any infertility-specific couple relationship patterns [21].

14.6 Specific Diagnostic Aspects

As Wischmann et al. point out [19], it is necessary to consider both unconscious areas of the wish for a child (e.g., fantasies and dreams) and the consciously expressed motives and expectations of the couples. After years of infertility treatment, ambivalent feelings linked to the wish for a child or the medical treatment may barely be perceived by the couple as a consequence of their coping attempts. Often these ambivalences are split up in the couple, which means that one partner represents the "pro" side and the other the "con" (e.g., pro/con child, pro/con gamete donation, pro/con adoption, or pro/con termination of treatment). The doctor can see him-/herself as an "advocate of feelings," including those feelings that the couple has been fending off. This can lead to the couple's greater critical distance in connection with the child wish or the medical treatment offered. The motivation of the desire for a child should not been questioned, but rather the pressure that the couples feel they are under. The doctor may assist in developing new vistas (including a "plan B" if treatment should finally fail) [4, 6, 7].

Furthermore, processes of transference and countertransference should be kept in mind: In analyzing his/her countertransference, the doctor should keep clear his/her own opinion and ethical attitude toward the desire for a child, reproductive medicine, and treatment boundaries. The doctor's own experiences with the wish for a child (unfulfilled in general or in the actual partnership) and especially his/her attitude to reproductive medicine techniques that are not legal in the country (but abroad) can negatively influence the doctor-patient relationship. It is also crucial to watch out for partiality in favor of one or the other partner in order to be aware of gender-specific countertransference tendencies: The doctor should be aligned with both couple members, counseling should be neutral, open, and without preposition.

Usually the doctor needs to ask more detailed questions about the couple's sexuality. This involves inquiring whether coitus is always possible, whether intravaginal ejaculation occurs, and whether the couple experiences any sexual problems. Is the couple well informed about the "fertile window" and about the optimal time of sexual intercourse for enhancing conception chances? Not all couples know that the optimal time for sexual intercourse to conceive a child is 1–2 days *before* ovulation occurs [25].

14.6.1 How Can You Detect Which Coping Strategies Are Used by the Couple?

To identify patients at risk, questionnaires can be used (e.g., SCREENIVF [26] or the COMPI Coping Strategy Scales) or the doctor must ask the specific questions (based on [7]) about the favored coping style of each partner: "Do you turn to work or substitute activity to take your mind off things?" (active-avoidance coping), "Do you talk to someone about your emotions as childless?" (active-confronting coping), "Do you try to forget everything about your childlessness?" (passive-avoiding

coping), or "Do you believe there is a meaning in your difficulties with having children?" (meaning-based coping).

Other specific diagnostic issues can be found in references [3, 6, 19, 27]. Boivin [28] specified the following risk factors for persons who are likely to need intensive counseling: psychopathology (e.g., personality disorder, depression), primary infertility, being a woman, viewing parenting as a central adult life goal, general use of avoidant strategies, poor marital relationship, impoverished social network, situations or people that remind the person of their infertility (e.g., family reunions, pregnant woman), side effects of the medical treatment associated with medication (e.g., mood fluctuation), situations that threaten the goal of pregnancy (e.g., miscarriage, treatment failure) and decision-making times (e.g., start and end of treatment, fetal reduction). In these cases, specific infertility counseling of the couple by a mental health professional or by a psychotherapist might be indispensable [5].

14.7 Specific Therapeutic Aspects

14.7.1 What Kind of Counseling Types Can Be Found in Infertility Counseling?

As shown in the case history, it can be helpful to advise a couple to distinguish between "sex for baby making" and "sex for fun." This means that on fertile days a more target-oriented approach to sexuality is on the agenda, whereas at other times, desire and/or romantic affection are the determining factors in sexual encounters [8].

Learning of relaxation techniques can be recommended and will facilitate successful coping (but will not improve pregnancy rates in the majority of cases) [29].

As Van den Broeck and coworkers point out, the majority of patients tend to be in a passive position of "wait and see and let the doctor act" during infertility treatment. Therefore it is important to empower them to actively join in the decisions regarding their infertility problems (see Case History). This includes helping to explore possible alternatives to biological parenthood and boundaries of ART treatment [6].

14.8 Critical Reflection and Conclusive Remarks

Because of the sensible and intimate nature of fertility consultation, a stable and empathic-based doctor-patient relationship is very important for successful diagnosis and treatment, especially when discussing the "plan B." This relationship can only partly be substituted by reading medical guidebooks or Internet use [29]. The experience of infertility is often experienced as a life crisis by these couples. The emotional impact of this experience can be as strong as suffering from severe illness or the loss of a close relative. As health care professionals we can learn from these couples that nearly every life crisis can be conquered with adequate coping

strategies and with an open and respectful couple communication behavior. Infertile couples should have the opportunity to easily uptake psychological infertility counseling at any stage of the medical treatment process (and also independent of treatment), but the counseling should not be mandatory. The majority of these couples can cope with this situation without the help of a mental health professional. As there is no guarantee for a live-born child after medical infertility treatment, the discussion of a "plan B" should not become a taboo in the doctor-patient relationship.

Tips and Tricks

In counseling it is important for the health care professional:

- To consider both unconscious areas of the wish for a child (e.g., fantasies and dreams) and the consciously expressed motives and expectations of the couples.
- To be aware of processes of transference and countertransference: In analyzing his or her countertransference, the health care professional should keep clear his or her own opinion and ethical attitude toward the desire for a child, reproductive medicine, and treatment boundaries.
- To watch out for partiality in favor of one or the other partner in order to be aware of gender-specific countertransference tendencies: The doctor should be aligned with both couple members, counseling should be neutral, open, and without preposition.
- To ask detailed questions about the couple's sexuality.
- In cases with risk factor (see earlier section on *How Can You Detect Which Coping Strategies Are Used by the Couple?*), specific infertility counseling of the couple by a mental health professional or by a psychotherapist might be indispensable.
- It can be helpful to advise a couple to distinguish between "sex for baby making" and "sex for fun."

Test Your Knowledge and Comprehension

1. In Western countries, the age of the woman giving birth to her first child inclines over the last 10 years.
   (a) True
   (b) False
2. Women always suffer emotionally more from infertility than their male partners.
   (a) True
   (b) False
3. Using online infertility boards or chat rooms is always an adequate substitute for the face-to-face patient-doctor relationship.
   (a) True
   (b) False

4. The majority of infertile couples suffer from temporary sexual dysfunctions during fertility workup or during reproductive medicine treatment.
   (a) True
   (b) False
5. Cigarette smoking does not affect one's fertility negatively.
   (a) True
   (b) False
6. A 1-year waiting time for a pregnancy once in a lifetime might occur in
   (a) No woman with a desire for a child
   (b) Every tenth woman with a desire for a child
   (c) Every third to fourth woman with a desire for a child
   (d) Every woman with a desire for a child
7. Behavior-related infertility occurs in about … of infertile couples:
   (a) 1 %
   (b) 10 %
   (c) 50 %
   (d) 100 %
8. After having been counseled on timed intercourse, the female patient shamedly reports her partner was not able "to do it." What is the doctor's most favorable reaction?
   (a) He or she ignores the patient's information and continues with his routine tasks.
   (b) He or she strongly advises her partner to seek psychiatric consultation.
   (c) He or she points out that during infertility treatment many couples may experience temporarily sexual problems and thus gives relief to the patient.
   (d) He or she terminates infertility treatment because the male partner obviously lacks a serious wish for a child.
9. A primary aim of psychosomatic-oriented infertility counseling should be
   (a) Ignoring infertility-related emotions of the couple
   (b) Helping the couple to find a "plan B"
   (c) Consequently advise not to undergo assisted reproductive treatment
   (d) Solely to explore the "intrapsychic blockades" against getting pregnant
10. Infertility and long-term mental health: Involuntarily childless couples…
   (a) Are usually suicidal
   (b) Have a good prognosis as long as they accept their situation
   (c) Have a bad prognosis if they are socially well integrated
   (d) Always experience a significantly worse life quality compared to parenting couples

Answers

1. True
2. False
3. False
4. True

5. False
6. (c)
7. (b)
8. (c)
9. (b)
10. (b)

References

1. Lazarus RS, Folkmann S. Stress, appraisal, and coping. New York: Springer; 1984.
2. Koropatnick S, Daniluk JC, Pattinson HA. Infertility: a non-event transition. Fertil Steril. 1993;59(1):163–71.
3. Kentenich H, Henning K, Himmel W, Ittner E, Kochen MM, Krause W, et al. Practical therapy in sterility – a manual for gynecologists from a psychosomatic point of view. In: Strauß B, editor. Involuntarily childlessness – psychological assessment, counseling and psychotherapy. Seattle: Hogrefe International; 2002. p. 175–88.
4. Kentenich H, Brähler E, Kowalcek I, Strauß B, Thorn P, Weblus AJ, et al., editors. Leitlinie psychosomatisch orientierte Diagnostik und Therapie bei Fertilitätsstörungen. Gießen: Psychosozial-Verlag; 2014.
5. Peterson B, Boivin J, Norré J, Smith C, Thorn P, Wischmann T. An introduction to infertility counseling: a guide for mental health and medical professionals. J Assist Reprod Genet. 2012;29(3):243–8.
6. Van den Broeck U, Emery M, Wischmann T, Thorn P. Counseling in infertility: individual, couple and group interventions. Patient Educ Couns. 2010;81(3):422–8.
7. Schmidt L. Infertility and assisted reproduction in Denmark. Epidemiology and psychosocial consequences. Lægeforeningens Forlag: Copenhagen; 2006.
8. Wischmann TH. Sexual disorders in infertile couples. J Sex Med. 2010;7(5):1868–76.
9. Wischmann T, Korge K, Scherg H, Strowitzki T, Verres R. A 10-year follow-up study of psychosocial factors affecting couples after infertility treatment. Hum Reprod. 2012;27(11):3226–32.
10. National Institute for Clinical Excellence. Fertility: assessment and treatment for people with fertility problems. Clinical guideline 11. London: National Institute for Clinical Excellence; 2004.
11. Zegers-Hochschild F, Nygren K-G, Adamson GD, de Mouzon J, Lancaster P, Mansour R, et al. The ICMART glossary on ART terminology. Hum Reprod. 2006;21(8):1968–70.
12. Homan GF, Davies M, Norman R. The impact of lifestyle factors on reproductive performance in the general population and those undergoing infertility treatment: a review. Hum Reprod Update. 2007;13(3):209–23.
13. Mills M, Rindfuss RR, McDonald P, te Velde E. Why do people postpone parenthood? Reasons and social policy incentives. Hum Reprod Update. 2011;17(6):848–60.
14. Boivin J, Bunting L, Collins JA, Nygren KG. International estimates of infertility prevalence and treatment-seeking: potential need and demand for infertility medical care. Hum Reprod. 2007;22(6):1506–12.
15. Malizia BA, Hacker MR, Penzias AS. Cumulative live-birth rates after in vitro fertilization. N Engl J Med. 2009;360(3):236–43.
16. Gnoth C, Maxrath B, Skonieczny T, Friol K, Godehardt E, Tigges J. Final ART success rates: a 10 years survey. Hum Reprod. 2011;26(8):2239–46.
17. Cousineau TM, Domar AD. Psychological impact of infertility. Best Pract Res Clin Obstet Gynaecol. 2007;21(2):293–308.

18. Wischmann T, Thorn P. (Male) infertility: what does it mean to men? New evidence from quantitative and qualitative studies. Reprod Biomed Online. 2013;27(3):236–43.
19. Wischmann T, Stammer H, Gerhard I, Verres R. Couple counseling and therapy for the unfulfilled desire for a child – the two-step approach of the "Heidelberg infertility consultation service.". In: Strauß B, editor. Involuntarily childlessness – psychological assessment, counseling and psychotherapy. Seattle: Hogrefe International; 2002. p. 127–49.
20. Meyers M, Weinshel M, Scharf C, Kezur D, Diamond R, Rait DS. An infertility primer for family therapists: II. Working with couples who struggle with infertility. Fam Process. 1995;34:231–40.
21. Wischmann T, Stammer H, Scherg H, Gerhard I, Verres R. Psychosocial characteristics of infertile couples: a study by the "Heidelberg fertility consultation service.". Hum Reprod. 2001;16(8):1753–61.
22. Peterson BD, Pirritano M, Christensen U, Schmidt L. The impact of partner coping in couples experiencing infertility. Hum Reprod. 2008;23(5):1128–37.
23. Schilling K, Toth B, Rösner S, Strowitzki T, Wischmann T. Prevalence of behaviour-related fertility disorders in a clinical sample – results of a pilot study. Arch Gynecol Obstet. 2012;286:1307–14.
24. Wischmann T. Psychogenic infertility – myths and facts. J Assist Reprod Genet. 2003;20(12):485–94.
25. Dunson DB, Colombo B, Baird DD. Changes with age in the level and duration of fertility in the menstrual cycle. Hum Reprod. 2002;17(5):1399–403.
26. Verhaak CM, Lintsen AME, Evers AWM, Braat DDM. Who is at risk of emotional problems and how do you know? Screening of women going for IVF treatment. Hum Reprod. 2010;25:1234–40.
27. Covington SH, Burns LH, editors. Infertility counseling. A comprehensive handbook for clinicians. 2nd ed. Cambridge/London/New York: Cambridge University Press; 2006.
28. Boivin J. Who is likely to need counseling? In: Boivin J, Kentenich H, editors. Guidelines for counseling in infertility. Oxford: University Press; 2002. p. 9–10.
29. Wischmann T. Implications of psychosocial support in infertility – a critical appraisal. J Psychosom Obstet Gynecol. 2008;29(2):83–90.

A Young Woman Facing Cancer Treatment: Shared Decision-Making in Fertility Preservation

15

Lobke Bastings, Catharina Beerendonk, and Christianne Verhaak

15.1 Introduction and Aims

How does one discuss fertility with a young woman recently diagnosed with cancer? What are the treatment possibilities, how does one raise the issue, and how does one support patients in the decision-making process? This chapter introduces the topic of fertility preservation, its techniques, and the counseling aspects. Fertility preservation can be performed in prepubertal girls and women of reproductive age who are diagnosed with cancer or a benign disease and whose future fertility is threatened. Despite or even due to the fact that technical options for fertility preservation are still increasing, decision-making regarding fertility preservation in daily clinical practice is challenging for both patient and caregiver because of the combination of the threat of the cancer, the possible conflict between cancer treatment and treatment for fertility preservation, and the different time frames that are involved. This chapter addresses the treatment possibilities, the emotional impact of decision-making regarding fertility preservation, as well as consequences for counseling in daily clinical practice.

15.2 Definition in Lay Terms

Fertility preservation in women with cancer means that special techniques are applied prior to their cancer treatment in order to maintain future chances for pregnancy.

L. Bastings, PhD, MD • C. Beerendonk, PhD, MD
Department of Obstetrics and Gynecology, Radboud University Medical Center, Nijmegen, The Netherlands
e-mail: Lobke.bastings@radboudumc.nl; Ina.beerendonk@radboudumc.nl

C. Verhaak, PhD (✉)
Department of Medical Psychology, Radboud University Medical Center, Nijmegen, The Netherlands
e-mail: Chris.verhaak@radboudumc.nl

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_15

15.3 Didactic Goals

After this chapter you will:

- Know the most common indications for female fertility preservation
- Have insight in the emotional impact of fertility preservation and the decision-making process that is involved
- Have insight in various options for fertility preservation that is currently available in clinical practice
- Have insight in referral practices for fertility preservation
- Have insight in important aspects of fertility preservation counseling
- Have insight in the role of fertility for the emotional impact of the cancer diagnosis and its treatment for the individual patient
- Have insight in communication strategies to raise the issue of fertility and to inform about the different treatment options
- Be familiar with strategies to support women in the decision-making process

Case History

Emma Azure, a 23-year-old patient with Hodgkin's lymphoma, visits the gynecologist specialized in reproductive medicine together with her boyfriend Peter. After the roller coaster of getting the diagnosis of cancer, realizing the life-threatening aspect at an age where most young adults take their health for granted, Emma is especially shocked when she realizes that the treatment could negatively influence her fertility. She is riven by the confrontation with her cancer and its treatment: the life-threatening character, going bald, how to integrate treatment with her education, and the decisions that had to be made regarding her fertility. Whereas the cancer and its treatment seem to massively impact her near future, the threat to her fertility impacts her total life perspective.

However, Emma does not have a lot of time to consider all this, because given the Hodgkin's disease, she is about to start six cycles of gonadotoxic chemotherapy. For this reason, her future fertility is threatened. Her oncologist discusses this with Emma. She offers her the option for a referral to a fertility specialist. Emma is in great doubt. She herself has had a child wish for as long as she remembered. Peter and Emma, however, only indirectly have discussed a child wish and a possible future together. For Peter, the wish for a child did not bother him earlier. Emma, also after discussing this with her parents, opts for comprehensive consultation regarding fertility preservation options and asks for referral to a specialist in reproductive medicine by her oncological health care provider.

15.4 Facts and Figures: Definitions, Classification, and Prevalence

15.4.1 What Are the Indications for Fertility Preservation?

Premature ovarian insufficiency (POI) or "cessation of menstrual periods before the age of 40 years," may result from cancer therapy [1–3]. Namely, various types of chemotherapy and radiotherapy to the pelvis are gonadotoxic as they impair the ovarian function by damaging the ovarian tissue, follicles, and oocytes [1–3]. As chemotherapy and radiotherapy are also used for the treatment of some severe benign diseases such as hematological or autoimmune diseases, patients with those diseases may also have an indication for fertility preservation [4, 5]. These patients could receive chemotherapy and radiotherapy as a preparation for hematopoietic stem cell transplantation [4, 5]. POI may also result from extensive ovarian surgery or benign (genetic or autoimmune) diseases such as a fragile X premutation or galactosemia [6–8]. For these patients, fertility preservation is also a treatment option when performed before the POI occurred.

15.4.2 How Many Girls and Women Have an Indication for Fertility Preservation?

The exact risk of POI and infertility after cancer therapy for an individual patient depends on various factors. Patients with a diminished ovarian reserve have a higher risk of developing POI, which means that oncological therapy would more easily result in fertility problems in older patients when compared to younger patients, indicating that risks of infertility have to be judged based on individual patient characteristics [9, 10]. Furthermore, specific types of cancer treatment have been associated with a high risk of ovarian damage [9, 10]. These therapies especially include (preparation regimens for) stem cell transplantation, pelvic or total body irradiation, and alkylating chemotherapeutic agents [1–3, 10, 11]. Besides the effects on the ovaries, pelvic irradiation also has detrimental effects on the patient's uterine function [2, 12]. Pregnancies after radiation in doses of more than 40 Gy have not been shown. Pregnancies in women with lower doses of radiation showed more abortions, more premature deliveries, and more delays in growth of the fetus.

15.4.2.1 Cancer in Girls and Young Women

In the United Kingdom, leukemia, brain tumors, lymphomas, renal tumors, and soft tissue sarcoma were the most commonly diagnosed forms of cancer in girls up to the age of 14 years in the years 2009–2011 [13]. A total of 713 girls within this age group were diagnosed with cancer during these 3 years. In women aged 15–24 years, carcinomas, lymphomas, melanomas, brain tumors, and leukemia were most frequently diagnosed, with a total of 1081 women getting cancer in 2009–2011 [13].

Women aged 25–49 were most frequently diagnosed with breast cancer, namely in 45 % of the 21,747 cases (2009–2011) [13].

For up-to-date information on the incidence of cancer in girls and young women, visit http://www.cancerresearchuk.org/cancer-info/cancerstats/incidence/age/

15.4.3 Which Techniques for Fertility Preservation Are Available?

In every woman of reproductive age, before the start of gonadotoxic treatment, an attempt should be made to safeguard a patient's fertility potential. Obviously, whether a patient wishes to proceed with a fertility preservation technique depends on her personal preferences and values, her opinion with regard to the options applicable in her situation, and her risk to become infertile. Various techniques to preserve female fertility—all with their own pros and cons—are currently available in clinical practice (Fig. 15.1).

15.4.3.1 Ovarian Transposition

This technique only prevents damage to the ovaries as a result of pelvic irradiation. Via laparoscopy, the ovaries are transposed outside the radiation field and fixated. In adults, the ovary is successfully protected in 33–92 % of the cases [15]. Ovarian transposition is associated with a risk of about 5 % of benign ovarian cysts, and furthermore, the risk of cancer cells being present in the transposed ovary should be considered [15, 16].

15.4.3.2 Vitrification of Oocytes

After approximately 2 weeks of hormonal stimulation, mature oocytes can be obtained via transvaginal oocyte retrieval with the aim of vitrification. Vitrification is a method in which oocytes are rapidly frozen and stored. After oocyte vitrification, live-birth rates were 5.4 % per vitrified oocyte in subfertile couples [17], with more than 1000 live births being reported worldwide [18–20].

As hormonal stimulation is needed with oocyte vitrification, this technique for fertility preservation is not suitable for prepubertal girls. However, the technique is obviously suitable for patients without a stable partner relationship, since there is no need for a partner present in this technique. Especially in young pubertal girls and adolescents, caution should be taken with the administration of gonadotrophins, as high doses may yield a risk of ovarian hyperstimulation syndrome (OHSS) [21].

15.4.3.3 Cryopreservation of Embryos

For the cryopreservation of embryos, the same steps are taken as for the vitrification of oocytes, namely, ovarian hyperstimulation followed by transvaginal oocyte retrieval. Instead of rapidly freezing the mature oocytes that are obtained, the oocytes are first fertilized. The resulting embryos are frozen and subsequently stored in liquid nitrogen. Both the male and female partner's permission are required for the (ongoing) storage as well as the use of the cryopreserved embryos [22].

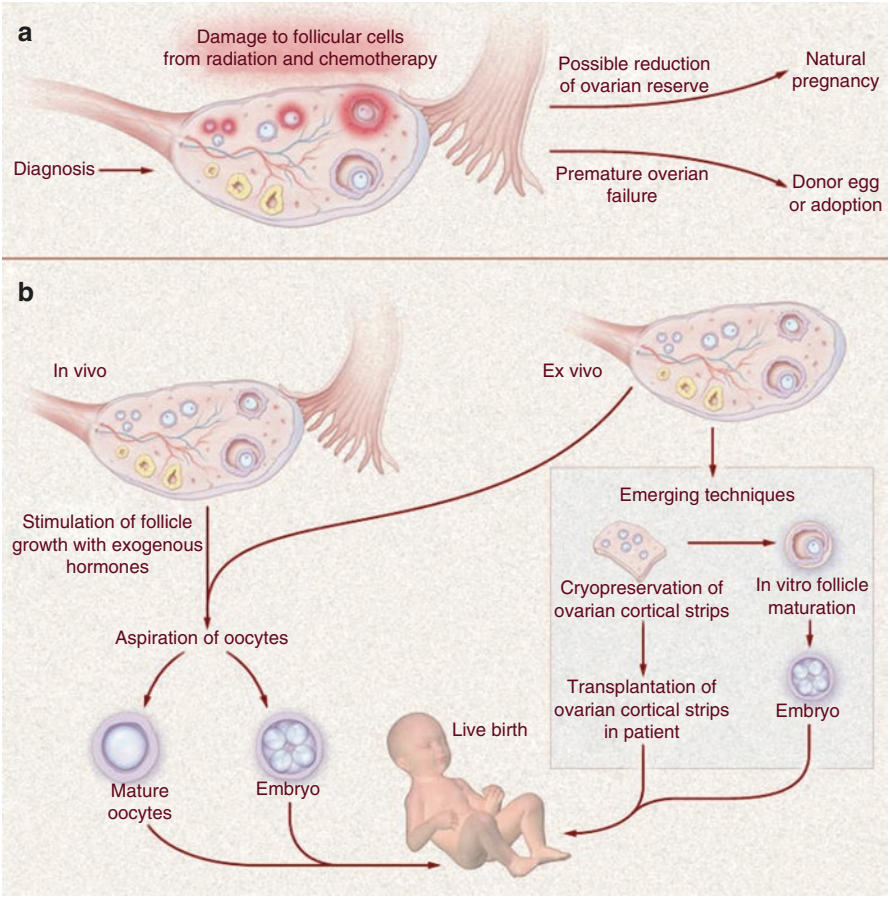


Fig. 15.1 (**a**, **b**) Various techniques to preserve female fertility (used with permission of Massachusetts Medical Society from Jeruss and Woodruff [14])

15.4.3.4 Cryopreservation of Ovarian Tissue

After laparoscopic tissue removal of (part of) one ovary, the ovarian cortex fragments could be prepared and cryopreserved. The aim of this procedure is to thaw and autotransplant the cryopreserved fragments to the patient's abdomen in case of POI and a wish to have a child during cancer survivorship. At the moment, 50 % of the fertilization is spontaneous and the other 50 % needs to take place by in vitro fertilization (IVF) treatment. To date, 37 live births have been reported [23], and the technique is still considered experimental [24]—this, because of safety concerns with regard to the procedure of autotransplantation. In case of cancer survivors, cancer cells could be present in the graft and theoretically induce recurrent malignant disease [25]. Various strategies to reduce or even abandon this risk, including in vitro maturation, the autotransplantation of an artificial ovary, or tumor purging, are currently being investigated [26–31].

In general, one might conclude that there are several fertility preservation techniques that are interesting options for patients to consider. However, success rates, side effects, and possible effects on cancer recurrence are difficult to predict. In addition, even if unambiguous statistics of chances and risks could be provided, it will be difficult for patients as well as for relatives to apply these statistics to their own situation.

15.5 Counseling and Care

15.5.1 How to Counsel Patients?

Obviously, fertility preservation techniques are ideally performed *before* the start of gonadotoxic cancer treatment—at least from a technical perspective. This means that the oncologist has to raise the issue of fertility shortly after the diagnosis. At that same moment, treatment possibilities have to be discussed, which leaves the patient with the task of making decisions regarding her fertility in a very stressful, emotionally, and cognitively overwhelming period.

Next in this chapter, therefore, the psychological impact of both the cancer diagnosis, the threat of infertility, and specific aspects of counseling in these stressful circumstances will be discussed.

Figure 15.2 presents an algorithm that can be helpful in communicating with patients in the development of a treatment plan in partnership with the patient.

15.5.2 What Is the Emotional Impact of Impaired Fertility in Cancer Patients?

15.5.2.1 Emotional Roller Coaster

Patients and their families usually feel overwhelmed by the diagnosis of cancer. They have to try to understand the impact of their diagnosis, they have to consider oncological treatment options, and next to that, they have to think about fertility preservation. The message of a cancer diagnosis itself brings patients and their close relatives into a sort of crisis. Everything in their life seems to be out of balance, and they need time to adapt. In this period of crisis, that normally takes a few weeks, cognitive capacity is limited, and emotions are hard to control. Although this can be regarded as "a psychologically healthy reaction to an unhealthy situation," it makes informed decision-making very difficult. Even under normal, emotionally neutral conditions, considering all the pros and cons of cancer treatment including fertility options in a systematic way is hardly possible, let alone under these circumstances. However, decisions have to be made and usually in the short time frame between diagnosis and the start of the gonadotoxic treatment. This is even more difficult for young patients, who may never have seriously thought about their wish to conceive in the future. The decision they are about to take is irreversible as they are facing gonadotoxic treatment. This situation obliges the

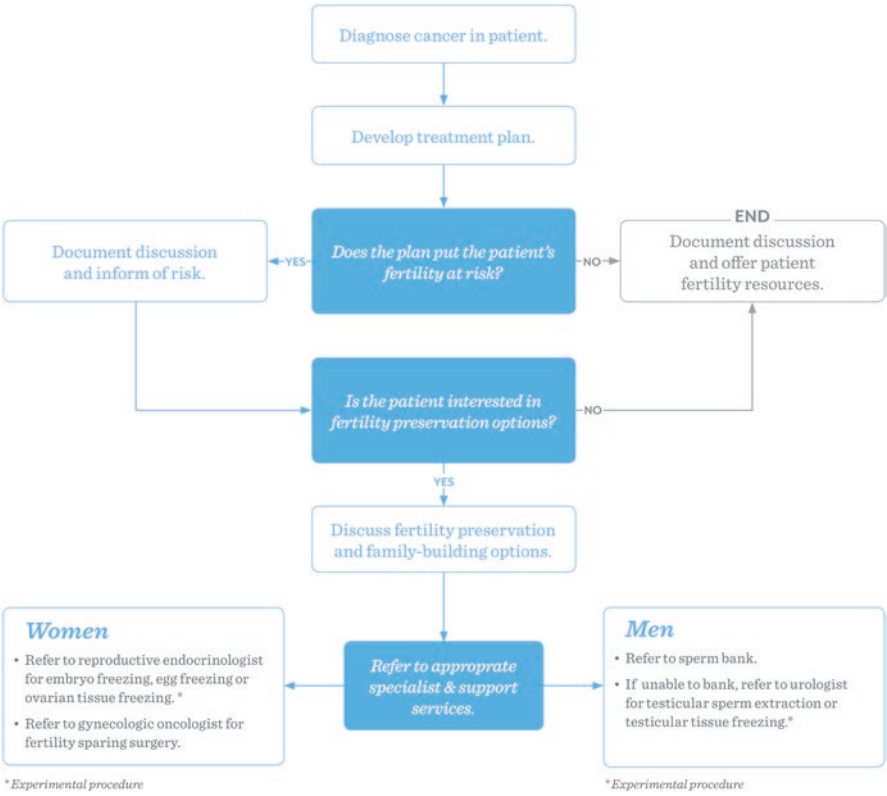


Fig. 15.2 Oncology algorithm for preserving fertility (used with permission of the Livestrong Foundation, Austin, TX, USA, from http://images.livestrong.org/pdfs/livestrong-fertility/LF_OncologyAddressingFertility_Algorithm.pdf. Copyright © Livestrong, a registered trademark of the Livestrong Foundation.)

oncologist or the specialist in reproductive medicine to reduce overwhelming emotions as much as possible and to guide the patient through the decision-making process. For this kind of shared decision-making, clear and well-structured information is the basis of cancer literacy, followed by a process of nondirective or supportive guidance, also known as counseling. For more detailed practical information on counseling as a process, we refer the reader to Chap. 26 on patient education and counseling. In the framework that follows, a brief summary is given of the steps that have to be taken to help patients come to a reasonable decision under stressful circumstances.

Frame: Five steps toward reasonable decisions:

1. *Problem orientation*: One has to identify and describe the nature of the problem or decisional dilemma. In this case, Emma has to balance between her short-time interests as a cancer patient and her future interest as a potential mother. These interests exclude each other and all options have negative side effects. This

means that Emma is "caught between the devil and the deep blue sea" and has to come up with the least worse scenario.
2. *Problem analysis:* In order to gain insight into the problem as a whole, one has to collect information about all potential options. If restrictions are relevant, e.g., due to technical or financial limitations, these have to be made clear at this stage.
3. *Possible solutions*: After a first selection, usually a limited number of options remain to be seriously considered.
4. *Evaluation of a selected number of options*: In this phase, the pros and cons of every option have to identified and summarized, both in terms preferably on a paper or nowadays in a spreadsheet or via an Internet choice assistance. After identification, each pro and con can be given a certain subjective weight. For example, the need to postpone chemotherapy to be able to start ovarian hyperstimulation usually has a high impact on patients because it may directly harm their treatment perspectives.
5. *Choice*: Based on all these weighed arguments, the patient has to come to a decision. This decision does not have to be a perfect or even positive one but has to be "the best possible choice" given the circumstances and arguments available.

15.5.3 Which Other Factors Also Play a Role in Decision-Making on Fertility Preservation?

15.5.3.1 The Threat of Death and the Wish for a Child

In this very stressful situation where the patient has to deal with the diagnosis of a life-threatening disease, she also has to consider these delicate issues regarding her future fertility. In this turmoil, important others also could be involved. In young women without a partner relationship, parents could be their most important relatives supporting them in decision-making. The same could be true in young women who have a boyfriend but no stable relationship yet. Parents usually will be more able to focus on the long-term consequences of the cancer and its treatment, and also of the consequences of the threatening infertility. At the same time, they are personally involved because of their concerns for their child as well as the link with their own future grandchildren. As a parent, being involved in decisions regarding the fertility of your child could be very delicate and complicated.

In other cases, the boyfriend could play an important role. In case of a stable relationship, there could be a difference between couples with an actual child wish, with a future child wish, and couples who have not yet decided about or have not discussed their common child wish yet. Treatment options regarding fertility may put a pressure on the relationship that, at the same time, is a very important source of social support during the stressful period around cancer diagnosis and treatment. That could be true as illustrated in the case of Emma.

In counseling these patients, health care professionals have to discuss which significant others should be involved in discussing treatment options regarding fertility preservation.

15.6 Referral to a Specialist

To help a patient make a high-quality fertility preservation decision, patients need to be referred to a gynecologist specialized in reproductive medicine in a center offering fertility preservation options for comprehensive counseling. Various guidelines recommend the referral of young cancer patients for such a consultation irrespective of their age, their prognosis, and their actual child wish [24, 32].

Studies also show that referral to a specialist in reproductive medicine positively impacts on quality of life and on adjustment to the cancer and its treatment. This referral is implemented in several guidelines, such as those from the American Society of Clinical Oncology [33], the guidelines of the American Agency for Healthcare Research and Quality [34], as well as the UK National Institute for Health and Care Excellence (NICE) guidelines [35]. Besides that, even to be able to discuss issues regarding fertility seems to support patients in their adjustment to the cancer.

Nevertheless, referral percentages are still low and a significant proportion of the cancer survivors cannot recall counseling on fertility preservation after cancer diagnosis [36–41]. Disparities in the referral of cancer patients to a specialist in reproductive medicine have been described for sociodemographic factors, ethnicity, and patients' clinical characteristics [38, 39, 42, 43]. These disparities seem to be related to lack of knowledge about the possibility of threatening fertility. More highly educated patients could have access to knowledge on the possibility of fertility preservation more easily. In addition, in many countries, fertility preservation costs money that will continue to be an expense for many years. Another issue is the difficulties patients experience in actively putting the issue of the fertility preservation on the agenda of consultation. This indicates that it is important for doctors to actively bring fertility preservation into the agenda of the consultation. Reluctance from professionals to raise the issue of fertility preservation could be related to lack of knowledge of treatment possibilities but also with urgency felt regarding the oncological treatment. In addition, clinicians need to be aware of biases in their estimations of the wish for fertility preservation in patients involved. Even patients with a poor prognosis have indicated they feel supported by a discussion about their fertility. Only raising the issue and discussing it with the patient can make sure if a referral to a fertility specialist is warranted.

Case History – Continued

Despite the additional burden of having to decide on even more treatment options, Emma Azure is strangely enough looking forward to meeting the fertility counselor. She feels some sort of hope because thinking about her future fertility makes her realize that there is a life after cancer.

After providing some basic information about the educational process, the fertility counselor starts with asking Emma and Peter some questions. She

asks about their ideas about fertility in general and their feelings about making this kind of important decision right now in particular. Then the three of them go through the preservation treatment options one by one. After having given the technical explanation, using several graphical aids, the counselor ends each treatment option with a short summary of pros and cons. She asks Emma and Peter not to decide yet but to discuss all this information together thoroughly and if they want, with family and friends first. However, because of the upcoming treatment, they have to come to a decision in a few days.

In the beginning, Emma and Peter spend most of their time and effort discussing the possibility of cryopreserving embryos, as this is the most established fertility preservation option. However, while discussing this option over and over again, it becomes more and more clear that this will mean that, in case of premature ovarian failure, Emma will no longer have the option to have a biological child if the partner-relationship would crumble, because that would mean that they have to destroy the embryos. At the other end, it is also hard for Emma to decide on postponing her chemotherapy to be able to start ovarian hyperstimulation. She is afraid that it would negatively impact her treatment perspectives. This means that the number of embryos that could be cryopreserved or the number of oocytes that could be vitrified is restricted to the harvest of one treatment cycle.

As a faster alternative, however still experimental, the cryopreservation of ovarian tissue—retrieved via laparoscopy—was discussed. After a few days in which Emma and Peter discuss all options together, Emma opts for ovarian tissue cryopreservation.

15.6.1 What Are the Most Important Medical Pros and Cons of the Current Fertility Preservation Options?

15.6.1.1 Counseling by the Fertility Specialist

During fertility preservation consultation with a specialist in reproductive medicine, patients first need to be informed about their estimated risk of future fertility problems as a result of POI.

Furthermore, the fertility preservation techniques that are considered applicable in a patient's individual situation should be discussed. These risks and treatment options could be difficult to understand for patients not used to discussing chances and statistics. In addition, future fertility and future child wish are often abstract issues for the future. Providing written information next to what is discussed in the consultation could help patients to rehear information again at home. It also gives them the opportunity to share information with important others. In addition, it compensates for problems remembering information provided during consultations, especially in these stressful circumstances.

Given the nature of the fertility preservation decision, decisional conflict (i.e., difficulties with decision-making) has been described for the fertility preservation

decision [44–46]. Decisional conflict is related to uncertainty in choosing options for treatment and possible outcomes. Patients tend to experience more decisional conflict when they feel insufficiently informed, when high-stakes choices are involved with important gains and losses, or when they have to make decisions that could conflict with their personal values. Presumably, decisional conflict is also related to regret about the decision at a later time point, as has even been found in a prospective study with a short follow-up [45]. Regret regarding previous decisions, or lack of opportunity to be involved in decision-making, could hamper the adjustment process to consequences of the disease and its treatment. Risk factors for decisional regret have been shown to be related to patients' knowledge about the topic and opportunities to ask questions during consultation [44, 45, 47]. This means that being able to discuss fertility preservation options with a doctor supports the adjustment process. This is in line with other studies indicating that shared decision-making, also in situations with high threat, support adjustment to the threat even if it does not change the actual decisions. In this perspective, it is impressive that qualitative studies show that even in patients with a very poor prognosis, discussing fertility preservation options are highly valued by patients and seem to support their feeling of control in a highly uncontrollable situation.

To optimize fertility preservation counseling, various strategies have been proposed. As a patient's lack of knowledge on fertility preservation has been associated with more decisional conflict, some of these strategies are aimed at improving a patient's knowledge in order to facilitate the decision-making process. Examples are to provide written information material provided before and/or after consultation [48, 49] and a decision aid [45, 50].

Literature on the best way of counseling in fertility preservation is still scarce. However, websites such as www.oncofertility.org [51] also provide information on counseling issues for health care professionals. In addition, guidelines and the studies that are available, show that addressing the issue of fertility preservation is important, regardless of age, social situation, and prognosis. Still, health care professionals have difficulties in discussing fertility preservation with their patients. The following barriers are described.

15.6.1.2 Knowledge of Doctors

Oncologists indicate not feeling confident in their knowledge about the treatment options for fertility preservation. Education and easy access to inter-colleague consultations could support the provision of actual knowledge of treatment options for different kinds of patients.

15.6.1.3 Confidence in Discussing These Issues with Patients

Clinicians also indicate not feeling confident about discussing fertility, especially with young patients or with patients with a poor prognosis. Training in communication could support clinicians in dealing with these delicate issues in their consultation. Online training courses are available (see, e.g., www.oncofertility.org [51]). In addition, protocols supporting addressing the issue of fertility preservation, together with the discussion of cancer treatment options, could support clinicians in raising

the issue. Retrospective studies on patient experiences consistently support a patient's need to be informed as early as possible, despite their prognosis, their age, and their personal situation.

15.6.1.4 Providing Information

Information has shown to be an important source of gaining control in threatening situations. Websites and decision aids have been highly appreciated by patients. Information could prepare them to ask questions of their doctor, could structure their decisional insecurity, and could help them involve relatives in the decision-making process.

15.6.1.5 Providing Opportunity for Referral

When patients were asked, they preferred the opportunity of a referral to a specialist in reproductive medicine to discuss and support their options regarding fertility preservation [44, 48, 49].

In addition, the opportunity to visit a psychosocial counselor has been suggested [50]. Oncologists' restricted knowledge about fertility preservation techniques or other reasons of discomfort with discussing fertility preservation may form barriers for discussing the topic with patients or their parents [52, 53]. Especially in case of pediatric patients, the decision-making and informed consent for fertility preservation may be complicated, since the parents carry the major responsibility for the decision whether or not to proceed with fertility preservation [54]. In order to improve referral rates for fertility preservation counseling, some interventions aim to focus on improved counseling by oncological health care providers, as these professionals are the ones to refer a patient for comprehensive counseling as soon as possible after cancer diagnosis. Next to that, seminars and other training events about the topic are organized to provide psycho-education for the oncologists and fertility specialists aimed to improve the consultation with the cancer patient and to reduce discomfort in both professional and patient [36, 55, 56]. Furthermore, the availability of a telephone number for expert advice on fertility preservation, such as initiated by the Oncofertility Consortium, may be helpful.

Case History – Continued

In the case of Emma Azure, one ovary is removed by laparoscopic surgery. A total of 11 strips of the ovarian cortex of this ovary are cryopreserved, whereas the other ovary is left untouched. She then starts with her chemotherapy. During the following years, Emma has a total of three relapses, treated with chemotherapy, radiotherapy, and stem cell transplantation. Being in remission for 3.5 years, she revisits the gynecologist because of amenorrhea while she wishes to conceive. Emma then is 29 years old and has met a new partner since the first counseling on fertility preservation. Hormonal examination shows that she is diagnosed with premature ovarian insufficiency. She chooses to opt for an autotransplantation of her cryopreserved tissue.

15.7 Critical Reflection and Conclusive Remarks

In conclusion, various strategies to preserve the future fertility of girls and young women whose fertility is threatened by a severe disease or (cancer) therapy are now available. Clinically available fertility preservation techniques include ovarian transposition (in case of radiotherapy), the vitrification of oocytes, the cryopreservation of embryos, and the cryopreservation of ovarian tissue. Despite the availability of these options and recommendations of international guidelines to refer young, newly diagnosed cancer patients for fertility preservation consultation with a specialist in reproductive medicine, not all patients receive counseling on this topic.

Decision-making on fertility preservation is complex given the nature of the decision, the restricted time for decision-making, and the burdensome period of a patient's life in which the decision has to be made. Several strategies have been proposed to facilitate the referral for fertility preservation counseling and the process of decision-making in order to prevent patient's regret on the longer term.

Cancer and patient organizations produced many tools on the Internet that could support patients in their decision-making.

In general, patients appreciate their health care professionals guiding them through the jungle of information that is available on the Internet. These links could help. It is important, however, that information is in line with what is provided by the medical team that is adequately equipped to meet the questions and needs of this patient in crisis.

Tips and Tricks

Health care providers for girls and women in their fertile period who are diagnosed with cancer can make use of the following useful Websites:

- http://oncofertility.northwestern.edu/ and http://oncofertility.northwestern.edu/ODT-web-portal (Fig. 15.3a): A website with very comprehensive information for health care professionals and patients providing decision-making tools, links to scientific publications, as well as information for patients, clinical guidelines, decision trees, and virtual teaching programs.
  Information for Patients

- http://www.cancer.net/navigating-cancer-care/videos/young-adults-cancer (Fig. 15.3b)
- http://www.livestrong.org/we-can-help/fertility-services/fertility-women/#tab2 (Fig. 15.3c)

  Guidelines

- American Society of Clinical Oncology – http://www.cancer.net/research-and-advocacy/asco-care-and-treatment-recommendations-patients/fertility-preservation
- US Department of Health – http://www.guideline.gov/content.aspx?id=47119

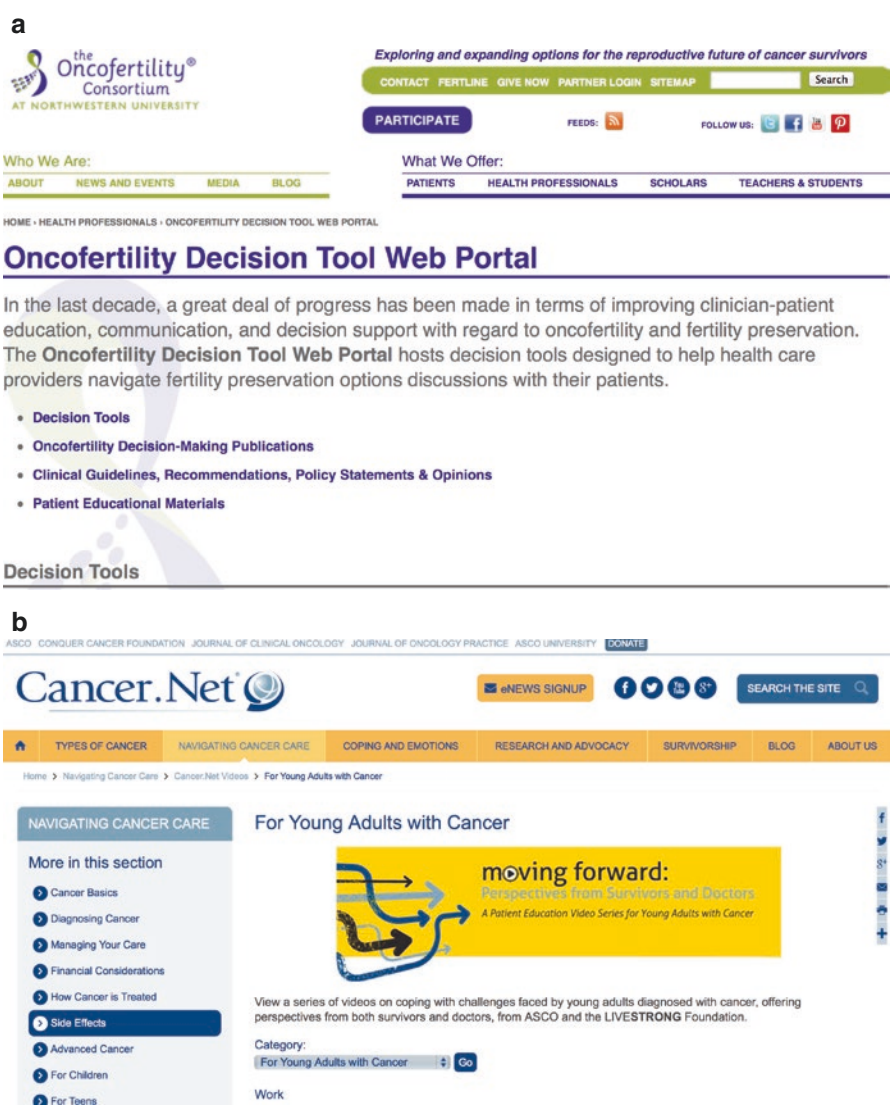


Fig. 15.3 Educational websites for medical professionals and patients. (**a**) http://oncofertility.northwestern.edu/ODT-web-portal (used with permission from The Oncofertility Consortium, Chicago, IL, USA); (**b**) http://www.cancer.net/research -and-advocacy/asco-care-and-treatment-recommendations-patients/fertility-preservation (used with permission of the American Society of Clinical Oncology, Alexandria, VA, USA; Copyright © American Society of Clinical Oncology. All Rights Reserved); (**c**) http://www.livestrong.org/we-can-help/fertility-services/fertility-women/ (Used with permission of The Livestrong Foundation, Austin, TX, USA. Copyright © Livestrong, a registered trademark of The Livestrong Foundation)

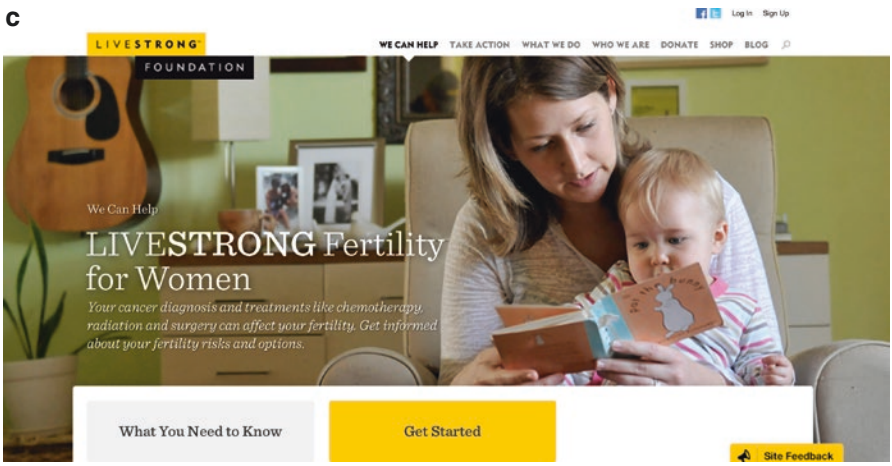


Fig. 15.3 (continued)

- NICE guidelines for children and young adults with cancer – https://www.nice.org.uk/guidance/qs55

Test Your Knowledge and Comprehension

1. Gonadotoxic therapy for cancer is the most common indication for fertility preservation.
   (a) True
   (b) False
2. A variety of options for fertility preservation are currently being available for prepubertal girls.
   (a) True
   (b) False
3. Guidelines recommend the referral of girls and young women who require gonadotoxic therapy to a specialist in reproductive medicine for fertility preservation counseling.
   (a) True
   (b) False
4. Difficulties experienced by patients during fertility preservation decision-making have been associated with patients' negative experiences with fertility preservation counseling.
   (a) True
   (b) False

5. Reproductive concerns may influence the psychological well-being of cancer survivors.
   (a) True
   (b) False
6. Which diseases may be an indication for female fertility preservation?
   (a) Cancer and benign autoimmune diseases
   (b) Benign hematological diseases
   (c) Extensive ovarian surgery
   (d) All of the above
7. To a patient who needs to start with chemotherapy immediately, the following fertility preservation technique could be offered
   (a) In vitro fertilization with the cryopreservation of all embryos
   (b) Vitrification of oocytes
   (c) Cryopreservation of ovarian tissue
   (d) Transposition of the ovaries
8. Disparities in the referral of cancer patients to a specialist in reproductive medicine have been described for
   (a) A patient's socioeconomic characteristics
   (b) A patient's ethnicity
   (c) A patient's clinical characteristics
   (d) All of the above
9. In case of gonadotoxic therapy for cancer, patients should be referred for fertility preservation counseling:
   (a) Directly after cancer diagnosis if it is likely that gonadotoxic therapy will be needed
   (b) As soon as it is clear that gonadotoxic therapy will be started
   (c) After the start of gonadotoxic therapy
10. Which interventions have been suggested to facilitate counseling and decision-making on fertility preservation?
   (a) Written information material and a decision aid
   (b) Having the opportunity to visit a psychosocial counselor
   (c) Training for (oncological) health care providers and a telephone number for expert advice to (oncological) health care providers
   (d) All of the above

Answers

1. True
2. False
3. True
4. True
5. True
6. (d)
7. (c)
8. (d)
9. (a)
10. (d)

References

1. Borgmann-Staudt A, Rendtorff R, Reinmuth S, Hohmann C, Keil T, Schuster FR, Holter W, Ehlert K, et al. Fertility after allogeneic haematopoietic stem cell transplantation in childhood and adolescence. Bone Marrow Transplant. 2012;47(2):271–6.
2. Lobo RA. Potential options for preservation of fertility in women. N Engl J Med. 2005;353(1):64–73.
3. Morgan S, Anderson RA, Gourley C, Wallace WH, Spears N. How do chemotherapeutic agents damage the ovary? Hum Reprod Update. 2012;18(5):525–35.
4. Farge D, Labopin M, Tyndall A, Fassas A, Mancardi GL, Van Laar J, Ouyang J, Kozak T, et al. Autologous hematopoietic stem cell transplantation for autoimmune diseases: an observational study on 12 years' experience from the European Group for Blood and Marrow Transplantation Working Party on Autoimmune Diseases. Haematologica. 2010;95(2):284–92.
5. Dalle JH. Hematopoietic stem cell transplantation in SCD. C R Biol. 2013;336(3):148–51.
6. el Abdel-Hady S, Abdel-Hady Hemida R, Gamal A, El-Shamey M. Fertility sparing surgery for ovarian tumors in children and young adults. Arch Gynecol Obstet. 2012;285(2):469–71.
7. Michelotti B, Segura BJ, Sau I, Perez-Bertolez S, Prince JM, Kane TD. Surgical management of ovarian disease in infants, children, and adolescents: a 15-year review. J Laparoendosc Adv Surg Tech A. 2010;20(3):261–4.
8. van Erven B, Gubbels CS, van Golde RJ, Dunselman GA, Derhaag JG, de Wert G, Geraedts JP, Bosch AM, et al. Fertility preservation in female classic galactosemia patients. Orphanet J Rare Dis. 2013;8:107.
9. Chiarelli AM, Marrett LD, Darlington G. Early menopause and infertility in females after treatment for childhood cancer diagnosed in 1964–1988 in Ontario. Canada Am J Epidemiol. 1999;150(3):245–54.
10. Meirow D, Biederman H, Anderson RA, Wallace WH. Toxicity of chemotherapy and radiation on female reproduction. Clin Obstet Gynecol. 2010;53(4):727–39.
11. Wallace WH, Thomson AB, Kelsey TW. The radiosensitivity of the human oocyte. Hum Reprod. 2003;18(1):117–21.
12. Urbano MT, Tait DM. Can the irradiated uterus sustain a pregnancy? A literature review. Clin Oncol (R Coll Radiol). 2004;16(1):24–8.
13. Childhood cancer incidence statistics. Cancer Research UK. Available from http://www.cancerresearchuk.org/cancer-info/cancerstats/childhoodcancer/incidence/.
14. Jeruss JS, Woodruff TK. Preservation of fertility in patients with cancer. N Engl J Med. 2009;360(9):902–11.
15. Irtan S, Orbach D, Helfre S, Sarnacki S. Ovarian transposition in prepubescent and adolescent girls with cancer. Lancet Oncol. 2013;14(13):e601–8.
16. Zhao C, Wang JL, Wang SJ, Zhao LJ, Wei LH. Analysis of the risk factors for the recurrence of cervical cancer following ovarian transposition. Eur J Gynaecol Oncol. 2013;34(2):124–7.
17. Rienzi L, Cobo A, Paffoni A, Scarduelli C, Capalbo A, Vajta G, Remohi J, Ragni G, Ubaldi FM. Consistent and predictable delivery rates after oocyte vitrification: an observational longitudinal cohort multicentric study. Hum Reprod. 2012;27(6):1606–12.
18. Chian RC, Huang JY, Tan SL, Lucena E, Saa A, Rojas A, Ruvalcaba Castellon LA, Garcia Amador MI, Montoya Sarmiento JE. Obstetric and perinatal outcome in 200 infants conceived from vitrified oocytes. Reprod Biomed Online. 2008;16(5):608–10.
19. Cobo A, de los Santos MJ, Castello D, Gamiz P, Campos P, Remohi J. Outcomes of vitrified early cleavage-stage and blastocyst-stage embryos in a cryopreservation program: evaluation of 3,150 warming cycles. . 2012;98(5). 1138–46, e1.
20. Noyes N, Porcu E, Borini A. Over 900 oocyte cryopreservation babies born with no apparent increase in congenital anomalies. Reprod Biomed Online. 2009;18(6):769–76.
21. Jadoul P, Dolmans MM, Donnez J. Fertility preservation in girls during childhood: is it feasible, efficient and safe and to whom should it be proposed? Hum Reprod Update. 2010;16(6):617–30.

22. Anderson RA, Wallace WH. Fertility preservation in girls and young women. Clin Endocrinol (Oxf). 2011;75(4):409–19.
23. Lecture handouts ESHRE Campus 2014. ESHRE Campus symposium organised by the Special Interest Groups Ethics & Law, Psychology & Counselling and Safety & Quality in ART, the Paramedical Group and the TF Fertility Preservation in Severe Diseases. Amsterdam, The Netherlands. 14–15 March 2014. https://www.eshre.eu/Publications/Textbooks-and-lecture-handouts/Lecture-handouts/Lecture-handouts-ESHRE-Campus-2014.aspx.
24. Loren AW, Mangu PB, Beck LN, Brennan L, Magdalinski AJ, Partridge AH, Quinn G, Wallace WH, Oktay K. Fertility preservation for patients with cancer: American Society of Clinical Oncology clinical practice guideline update. J Clin Oncol. 2013;31(19):2500–10.
25. Bastings L, Beerendonk CCM, Westphal JR, Braat DDM, Peek R. Cryopreservation and autotransplantation of ovarian tissue in cancer patients: is it safe? J Adolesc Young Adult Oncol. 2013;2(1):31–4.
26. Dunlop CE, Telfer EE, Anderson RA. Ovarian stem cells—potential roles in infertility treatment and fertility preservation. Maturitas. 2013;76(3):279–83.
27. Luyckx V, Dolmans MM, Vanacker J, Legat C, Fortuno Moya C, Donnez J, Amorim CA. A new step toward the artificial ovary: survival and proliferation of isolated murine follicles after autologous transplantation in a fibrin scaffold. Fertil Steril. 2014;101(4):1149–56.
28. Schroder CP, Timmer-Bosscha H, Wijchman JG, de Leij LF, Hollema H, Heineman MJ, de Vries EG. An in vitro model for purging of tumour cells from ovarian tissue. Hum Reprod. 2004;19(5):1069–75.
29. Smitz J, Dolmans MM, Donnez J, Fortune JE, Hovatta O, Jewgenow K, Picton HM, Plancha C, et al. Current achievements and future research directions in ovarian tissue culture, in vitro follicle development and transplantation: implications for fertility preservation. Hum Reprod Update. 2010;16(4):395–414.
30. Telfer EE, Zelinski MB. Ovarian follicle culture: advances and challenges for human and nonhuman primates. Fertil Steril. 2013;99(6):1523–33.
31. Vanacker J, Luyckx V, Dolmans MM, Des Rieux A, Jaeger J, Van Langendonckt A, Donnez J, Amorim CA. Transplantation of an alginate-matrigel matrix containing isolated ovarian cells: first step in developing a biodegradable scaffold to transplant isolated preantral follicles and ovarian cells. Biomaterials. 2012;33(26):6079–85.
32. COSA Clinical Oncological Society of Australia. Fertility preservation for AYAs diagnosed with cancer: Guidance for health professionals. http://wiki.cancer.org.au/australia/COSA:AYA_cancer_fertility_preservation.
33. American Society of Clinical Oncology. http://www.cancer.net/research-and-advocacy/asco-care-and-treatment-recommendations-patients/fertility-preservation.
34. American Agency for Healthcare Research and Quality. http://www.guideline.gov/content.aspx?id=47119.
35. National Institute for Health and Care Excellence. https://www.nice.org.uk/guidance/qs55.
36. Anderson RA, Weddell A, Spoudeas HA, Douglas C, Shalet SM, Levitt G, Wallace WH. Do doctors discuss fertility issues before they treat young patients with cancer? Hum Reprod. 2008;23(10):2246–51.
37. Forman EJ, Anders CK, Behera MA. A nationwide survey of oncologists regarding treatment-related infertility and fertility preservation in female cancer patients. Fertil Steril. 2010;94(5):1652–6.
38. Goodman LR, Balthazar U, Kim J, Mersereau JE. Trends of socioeconomic disparities in referral patterns for fertility preservation consultation. Hum Reprod. 2012;27(7):2076–81.
39. Kohler TS, Kondapalli LA, Shah A, Chan S, Woodruff TK, Brannigan RE. Results from the survey for preservation of adolescent reproduction (SPARE) study: gender disparity in delivery of fertility preservation message to adolescents with cancer. J Assist Reprod Genet. 2011;28(3):269–77.
40. Tschudin S, Bitzer J. Psychological aspects of fertility preservation in men and women affected by cancer and other life-threatening diseases. Hum Reprod Update. 2009;15(5):587–97.
41. Bastings L, Baysal O, Beerendonk C, Braat D, Nelen W. Referral for fertility preservation counselling in female cancer patients. Human Reprod. 2014;29(10):2228–37.

42. Letourneau JM, Smith JF, Ebbel EE, Craig A, Katz PP, Cedars MI, Rosen MP. Racial, socioeconomic, and demographic disparities in access to fertility preservation in young women diagnosed with cancer. Cancer. 2012;118(18):4579–88.
43. Loren AW, Brazauskas R, Chow EJ, Gilleece M, Halter J, Jacobsohn DA, Joshi S, Pidala J, et al. Physician perceptions and practice patterns regarding fertility preservation in hematopoietic cell transplant recipients. Bone Marrow Transplant. 2013;48(8):1091–7.
44. Kim J, Deal AM, Balthazar U, Kondapalli LA, Gracia C, Mersereau JE. Fertility preservation consultation for women with cancer: are we helping patients make high-quality decisions? Reprod Biomed Online. 2013;27(1):96–103.
45. Peate M, Meiser B, Cheah BC, Saunders C, Butow P, Thewes B, Hart R, Phillips KA, et al. Making hard choices easier: a prospective, multicentre study to assess the efficacy of a fertility-related decision aid in young women with early-stage breast cancer. Br J Cancer. 2012;106(6):1053–61.
46. Peate M, Meiser B, Friedlander M, Zorbas H, Rovelli S, Sansom-Daly U, Sangster J, Hadzi-Pavlovic D, Hickey M. It's now or never: fertility-related knowledge, decision-making preferences, and treatment intentions in young women with breast cancer—an Australian fertility decision aid collaborative group study. J Clin Oncol. 2011;29(13):1670–7.
47. Patel A, Sreedevi M, Malapati R, Sutaria R, Schoenhage MB, Patel AR, Radeke EK, Zaren HA. Reproductive health assessment for women with cancer: a pilot study. Am J Obstet Gynecol. 2009;201(2). 191, e1–4.
48. Garvelink MM, Ter Kuile MM, Bakker RM, Geense WJ, Jenninga E, Louwe LA, Hilders CG, Stiggelbout AM. Women's experiences with information provision and deciding about fertility preservation in the Netherlands: 'satisfaction in general, but unmet needs'. Health Expect. 2015;18(5):956–68.
49. Thewes B, Meiser B, Rickard J, Friedlander M. The fertility and menopause-related information needs of younger women with a diagnosis of breast cancer: a qualitative study. Psychooncology. 2003;12:500–11.
50. Hill KA, Nadler T, Mandel R, Burlein-Hall S, Librach C, Glass K, Warner E. Experience of young women diagnosed with breast cancer who undergo fertility preservation consultation. Clin Breast Cancer. 2012;12(2):127–32.
51. Yale Oncofertility Center. www.oncofertility.org.
52. Garvelink MM, ter Kuile MM, Fischer MJ, Louwe LA, Hilders CG, Kroep JR, Stiggelbout AM. Development of a decision aid about fertility preservation for women with breast cancer in The Netherlands. J Psychosom Obstet Gynaecol. 2013;34(4):170–8.
53. Quinn GP, Vadaparampil ST, King L, Miree CA, Wilson C, Raj O, Watson J, Lopez A, Albrecht TL. Impact of physicians' personal discomfort and patient prognosis on discussion of fertility preservation with young cancer patients. Patient Educ Couns. 2009;77(3):338–43.
54. Nisker J, Baylis F, McLeod C. Choice in fertility preservation in girls and adolescent women with cancer. Cancer. 2006;107(7 Suppl):1686–9.
55. Adams E, Hill E, Watson E. Fertility preservation in cancer survivors: a national survey of oncologists' current knowledge, practice and attitudes. Br J Cancer. 2013;108(8):1602–15.
56. Vadaparampil S, Quinn G, King L, Wilson C, Nieder M. Barriers to fertility preservation among pediatric oncologists. Patient Educ Couns. 2008;72(3):402–10.

A Couple Who Considers Artificial Reproductive Techniques: Psychosocially Informed Care in Reproductive Medicine

16

Heather Rowe, Jane Fisher, and Karin Hammarberg

16.1 Introduction and Aims

16.1.1 What Is Infertility and How Common Is It?

Infertility is a heterogeneous group of conditions of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse. If having a child is a highly desired life goal, the experience and diagnosis of infertility can have profound adverse psychological consequences. There is debate about whether infertility-related psychological distress is more accurately conceptualized as psychopathological or as an intense psychological reaction to abnormal personal circumstances. Infertility affects about one in ten couples worldwide, although there is no evidence about population prevalence available from most low- and middle-income countries.

16.1.2 What Is Assisted Reproductive Technology and How Commonly Used Is It?

Assisted reproductive technology (ART) is defined as all treatments or procedures that include the in vitro handling of both human oocytes and sperm, or embryos, for the purpose of establishing a pregnancy [1]. This includes, but is not limited to, in vitro fertilization and embryo transfer, gamete intrafallopian transfer, zygote

H. Rowe, BSc (Hons), PhD (✉) • J. Fisher, BSc (Hons), PhD, MAPS
K. Hammarberg, RN, BSc, PhD
Jean Hailes Research Unit, School of Public Health and Preventive Medicine, Monash University, Melbourne, Australia
e-mail: Heather.rowe@monash.edu.au; Jane.fisher@monash.edu.au; Karin.hammarberg@monash.edu.au

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_16

intrafallopian transfer, tubal embryo transfer, gamete and embryo cryopreservation, oocyte and embryo donation, and gestational surrogacy. ART does not include artificial insemination using sperm from either a woman's partner or a sperm donor.

In countries where ART attracts government and health insurance subsidy, up to 4 % of births are a result of ART. This proportion increases with greater subsidy and better access to services. ART it not universally available and, if available, the cost is prohibitive to most couples in resource-constrained countries. Simplified and less costly protocols are being developed to increase access to ART.

Treatments with ART are physically demanding, at least for the woman, and accompanied by successive feelings of hope and despair, which is exacerbated when several treatment cycles are undertaken. Psychological distress is compounded by uncertainty about treatment success and the low chance of a live birth. This chapter addresses how health-care professionals can give psychosocially informed care. This requires a set of acquired skills that promotes patients' wellbeing and includes empathy, honesty, respect, effective communication, nonjudgmental language, patient involvement, and emotional support.

16.2 Definition in Lay Terms

Infertility means a failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse.

Assisted reproductive technology (ART) refers to all treatments or procedures that include the handling of both human oocytes and sperm, or embryos, *outside the human body* for the purpose of establishing a pregnancy.

16.3 Didactic Goals

After reading this chapter you will:

- know that infertility and its treatment place demands on individuals' psychological and social resources.
- appreciate that all infertility and ART clinicians need to be responsive to the increased psychological and social needs of their patients.
- recognize the stages of ART that are associated with increased vulnerability to psychological distress.
- identify the features of psychosocially informed care: empathy, a sound therapeutic alliance, respect, effective communication, patient involvement, and emotional support [2].
- understand that psychosocially informed care requires a set of acquired skills that are sensitive to and respond to patients' increased psychosocial needs.

Case History

Wendy Orchid is 35 years old and John is 39. They have been trying to conceive for a year and are worried that something is wrong.

They see their primary care physician, Lester Viridian, for advice. He is sympathetic and gives them a brief overview of how they will work together to investigate what may be causing the infertility and how this will determine the treatment options. He explains that the infertility investigation and treatment can be emotionally, physically, and financially demanding. He encourages them to be open with each other about how they feel and to seek support. They hear that they are not alone—around 10 % of couples experience fertility difficulties. He explains that, whether the problem is female- or male-related, infertility is a couple's problem. Both women and men are likely to believe that the woman is responsible, even if etiology is unexplained or involves combined male and female factors. Most of the investigations and treatments involve the woman.

He explains that John will have a semen analysis and Wendy will need blood tests and a procedure, such as hysterosalpingography and/or laparoscopy, to investigate whether her fallopian tubes are open. Together, they will evaluate the implications of the results. If the test results reveal that assisted reproductive technology (ART) treatment could help, they will be referred to a fertility specialist, but meanwhile, they can make up their minds together about whether or not to proceed.

Although they may be very hard to change, individual behaviors can influence the chance of conceiving spontaneously or with ART. Lester directs them to information about preconception health and how to optimize fertility (www.yourfertility.org.au). John is smoking 15 cigarettes per day and Wendy is in the overweight range (body mass index [BMI] = 26), so Lester recommends specific evidence-informed strategies for quitting smoking and losing weight.

16.4 Facts and Figures: Psychosocial Aspects of Infertility and Assisted Reproductive Technology

16.4.1 What Are the Potential Psychological Consequences of Infertility and Assisted Reproductive Technology?

Everyone experiencing infertility and ART has heightened needs for psychological support, but few will require specialist assistance to meet these needs. Symptoms of anxiety and depression are often elevated in people experiencing infertility, but rates of psychopathology are similar to the general population. Some people may experience despair and the loss of existential meaning at the prospect of a future without biological progeny. Unlike other adverse life events, infertility is regarded as

uniquely distressing because it can last for many years, there is uncertainty about whether it will be resolved, and, for many, it will not be concluded by the birth of a baby. An "infertility strain profile" is characterized by increased anxiety, irritability, profound sadness, self-blame, lowered energy levels, social isolation, and heightened interpersonal sensitivity [3]. Almost all people presenting for treatment are having some of these experiences that might best be conceptualized as a normal emotional response to a painful predicament.

16.4.2 What Is the Nature of Psychological Distress Among Couples Seeking Assisted Reproductive Technology?

Guilt is especially prominent among women, linked in particular to fears that earlier sexual experiences, sexually transmitted infections, abortion, the use of contraceptives, or delaying conception while pursuing other goals has compromised fertility. The lack of agency and frustration associated with being unable to control conception and physiological functioning can lead to anger, which may be directed toward the infertile partner, friends and associates who have been able to conceive easily, and people who offer unsolicited advice. Reaction to infertility is also conceptualized as "disenfranchised grief." The many intangible potential losses include sexual spontaneity; the experiences of pregnancy, childbirth, and breastfeeding; the children and grandchildren who will not exist; genetic continuity; parenthood and the activities and relationships it entails; and an element of adult and gender identity that will never be realized and can be substituted with an infertile identity.

16.4.3 What Is the Evidence for "Psychogenic Infertility"?

Infertility, particularly of unknown etiology, and among women, was once widely attributed to personality characteristics or psychiatric conditions, so-called "psychogenic infertility." This led to misattribution of the cause of infertility and blaming of victims. A systematic review found no significant differences in rates of psychiatric illness, other psychopathology or personality factors between presumed fertile groups and those seeking infertility treatment, or between infertile groups and population norms, or between groups with infertility of different etiology and duration [4].

16.4.4 How Do Women and Men Typically Differ in Their Psychological Responses to Infertility and Assisted Reproductive Technology?

Infertility and its treatment are often socially isolating experiences. Spontaneous disclosure of emotional needs and explicit support-seeking are uncommon, particularly among men affected by infertility. They are more likely to confide in and desire information and emotional support from infertility clinicians rather than from friends or mental health professionals.

Women experience more emotional distress associated with infertility than men, except in cases of male factor infertility where the degree of distress is similar. Even when male factors are implicated, women experience more guilt and self-blame than their male partners, which may be because most of the investigations and treatments focus on the female partner.

Most men aspire to parenthood and can experience chronic grief if this goal is not realized. Infertility-specific anxiety is elevated in men at the initiation of diagnostic investigations, confirmation of diagnosis, and during treatment, but the overall prevalence of clinically significant symptoms of depression and anxiety is no higher than in the general population [5]. Some men appear able to compartmentalize their emotions and to continue to participate in their lives without being preoccupied or disabled by anxiety or to suspend their emotional needs in service of their partner's increased need for support. Both women and men can fear losing significant relationships, in particular with the partner, and some may offer to allow their spouse to partner with someone else in order to have a child.

16.4.5 What Are Some of the Consequences of Psychological Distress in Women and Men Seeking Assisted Reproductive Technology?

People respond to disturbing life events in individual ways. Studies of women show that those who participate actively in seeking information and making treatment decisions have lower levels of depression and attract more social support than those who submit passively to medical recommendations. Individuals with high self-esteem and dispositional optimism are protected against severe depression. The reciprocal is also true: better mood is associated with solution-focused problem-solving and increased emotional support [6].

People who use avoidant coping and deny the emotional impact of infertility may seek multiple medical opinions in order to find an optimistic assessment. They are at higher risk of becoming more severely depressed or anxious and may also be vulnerable to exploitation by extravagant claims for treatments, including for complementary therapies for which there is scant scientific evidence. Fertility difficulties challenge personal identity and disrupt an individual's achievement of their planned life goals. It can exert a pervasive negative effect on quality of life, compromising planning and commitment to other life activities.

16.4.6 How Can the Clinician Promote Psychological Wellbeing in Couples Seeking Assisted Reproductive Technology?

Comprehensive psychosocially informed care in couples seeking ART involves:

- Ensuring that the couple has adequate knowledge of the fertile period in the menstrual cycle and the need to have sexual intercourse then
- Assisting the couple to make a realistic appraisal of the chance of treatment success

- Not colluding with unrealistic hopes for success
- Acknowledging that it is not a straightforward decision for the clinician or the couple and assisting the couple to decide when to continue and when to cease treatment
- Being available to provide emotional support in the interval between embryo transfer and pregnancy testing and at other critical times during treatment
- Countering common concerns that infertility is related to anxiety or stress and challenging the view that if they could relax, conception would occur spontaneously
- Challenging the inaccurate belief that unsuccessful ART cycles are because of something that a person did or did not do
- Actively eliciting disclosure of psychological needs

Comprehensive psychosocially informed clinical care within infertility services is of particular importance to the promotion of emotional wellbeing. The psychological consequences of diagnosis and treatment for infertility are reduced if clinicians can build a therapeutic alliance within which a couple can be assisted to understand and respond to an unanticipated adverse life experience for which there is generally not a simple solution. This alliance will grow if the clinician is perceived as knowledgeable, technically skilled, warm, unhurried, trustworthy, and nonjudgmental.

16.4.7 How Would You Explain the Chance of Success of Assisted Reproductive Technology to an Individual Couple?

- The woman's age is the most important factor determining ART success. Women in their early thirties are about five times more likely than women in their early forties to have a baby with ART.
- Carefully selected language should be used to display empathy and understanding in order to minimize guilt.
- Couple characteristics that influence chance of ART success including age, reproductive and health history, tobacco use, and BMI should be considered [7].
- Definitions of success vary between clinics. For example, defining success as "clinical pregnancy per embryo transfer" will yield a much higher percentage than "live births per started treatment cycle."
- Multiple birth and the associated poorer perinatal outcomes are more common after ART than spontaneous conception, because of the practice in many clinics of transferring more than 1 embryo.
- The birth of a singleton is the most appropriate measure of ART success, and the best way of achieving this is by transferring only 1 embryo per cycle [8].

Case History: Continued

Three weeks later Wendy and John Orchid have an appointment with Selena Plum, a fertility specialist at an ART clinic. They discuss the test results. John has a low sperm count and Wendy has mild endometriosis. Because they are both subfertile, the chance of spontaneous conception is low and ART treatment is indicated.

Selena outlines the physical, psychological, and financial implications of ART. A multidisciplinary expert team including doctors, embryologists, counselors, and nurses cares for couples who undergo treatment. A nurse is responsible for the day-to-day care and coordination including:

- Daily hormone injections to stimulate the growth and maturation of 10–12 oocytes (eggs)
- Monitoring of ovarian stimulation with blood tests and vaginal ultrasounds to determine the optimal time to retrieve the oocytes
- Hospital admission for ultrasound-guided oocyte retrieval
- The production of a sperm sample to be added to the oocytes
- Embryo transfer
- A 2-week wait to find out whether pregnancy has occurred

Selena explains that in each step there is a risk of treatment failure: the hormone stimulation may not yield the desired number of oocytes or may produce an excessive, potentially dangerous response; the oocytes may not fertilize; and the embryo may not implant. Several attempts are often needed to give couples a reasonable chance of having a baby, and she suggests that Wendy and John think of ART as a series of treatments rather than a "one-off." She reassures them that the clinic staff are aware of and can help them manage the hopes and disappointments of treatment.

To help Wendy and John make an informed decision about whether or not to pursue ART, Selena emphasizes the importance of understanding how the statistics about treatment success apply to an individual couple's circumstances. She uses simple diagrams she has created to explain the different ways of expressing the probability of having a baby [9]. Selena also gives them information about the possible adverse health effects and the financial costs of ART.

Wendy says that she has been told by a well-meaning relative that she should give up her career and relax more so that she can improve her chances of becoming a mother. Selena reassures her that there is no scientific evidence that "stress" reduces chance of conception [10]. This is a relief to Wendy.

John and Wendy express concern about having a baby with a birth abnormality but Selena reassures them that, although birth defects are slightly more common after ART than after spontaneous conception, they are still very rare [11]. Selena also mentions that the age of the woman is the most important factor determining the chance of having a baby with ART, but having a high BMI and smoking also reduce chance of ART success. Selena uses carefully chosen nonjudgmental language to display empathy and acknowledge that making changes can be difficult to do but urges the couple to adopt healthy behaviors in preparation for treatment.

Wendy and John feel well informed and decide to give themselves some more time to try to conceive spontaneously and achieve the best possible health. John is finally able to give up smoking and Wendy sets a goal to lose 5 k in weight. Six months later, they have not conceived and decide to proceed with ART treatment. Because of John's low sperm count, the embryologist performs the intracytoplasmic sperm injection (ICSI) procedure where one sperm is manually injected into each oocyte using highly specialized equipment. After three unsuccessful ART treatment cycles and an early miscarriage, Wendy and John feel despondent and uncertain about the future.

Selena talks to them about how couples often find it difficult to stop treatment and gives Wendy and John an opportunity to reflect on whether this is so for them, and if so, why. She tells them that making this decision is complex and that reasons why couples discontinue ART include the psychological burden of continuous cycles of emotional "highs" and "lows," uncertainty about the outcome of treatment, and cost [12]. She discusses with them the importance of taking control and setting a limit to the number of treatments and how making alternative plans for the future can help the decision to end treatment. She also tells them the evidence that almost all couples who remain childless after infertility treatment go on to have fulfilling lives [13]. She encourages them to talk to each other and asks them to come and see her again.

Over the next several months Wendy and John oscillate between the wish to try ART again and the fear of more treatment failure. They see Selena who informs them that the chance of ART success diminishes with each failed treatment and this helps them decide to end treatment. The sadness of being childless stays with Wendy and John, but over time they are able to focus on other rewarding life goals. Thinking back on the experience, they have no regrets because they explored all available possibilities for having a baby. They both agree that although unsuccessful, the ART treatment and the supportive care they received helped them to make infertility a part of their life story as a couple.

16.5 Specific Therapeutic Aspects and Tips and Tricks

16.5.1 What Are Some Useful Techniques for Building a Therapeutic Alliance with Couples Experiencing Infertility?

These techniques illustrate a psychosocially well-theorized, gender-informed, eclectic approach:

- Using open-ended questions (e.g., Please tell me about…? How did you feel when…?).
- Addressing feelings and using reflection first and then deeper questions later. Avoid asking "Why…?" and ask instead "What makes…?" or "What is the greatest loss?" or "What has struck you the most?"
- Enquiring explicitly using the statement and question method, for example, "I have met many men experiencing infertility, and they often feel sad, worried, embarrassed, or lonely" followed by "Have you had any feelings of this kind?" or "How you are feeling?" Always respecting the couple's level of willingness to disclose their feelings.
- Asking each member of the couple, "Who have you talked to about the fertility difficulties?" and "What do you imagine other people's reactions to your situation might be?"
- Addressing questions to each member of the couple separately, not allowing one to answer on behalf of the other.
- Providing couples with clear and unambiguous information about the likelihood of having a baby. This should be defined as percentage of live births per started treatment cycle.
- After providing clinical information, for example, about the infertility problem, a proposed treatment, or the outcome of a cycle, checking comprehension by asking the couple to summarize their understanding of what has just been discussed.
- Using plain language and not assuming that more highly educated people already understand technical terms or discipline-specific terminology.
- Using person-first language, for example, "the woman/man/person with…" rather than "the infertile woman/man/person."
- Emphasizing "treatment failure" not personal failure in the event of an unsuccessful cycle.
- Aiming to assist the couple, if treatment is unsuccessful, to work toward adaptation to the loss of the hoped-for baby, using a structured approach combining emotional support with opportunities for the couple to confront and explore their feelings.
- Working toward the goal of the final phase of the clinical work, which is to leave the couple feeling that treatment has been a worthwhile experience for them whatever the outcome.

16.5.2 What Can Clinicians Do to Manage Their Own Personal Reactions?

Clinical practice with couples experiencing infertility and ART treatment is intrinsically challenging because:

- The likelihood of a successful outcome is low.
- The clinician is treating a couple not just an individual.
- Treatment is expensive.
- Patients may express difficult emotions, including anger and frustration directed at the clinician.
- Of the imperative to assist couples to balance their competing needs to preserve hope with a realistic appraisal of treatment success.

A high degree of self-awareness about a clinician's personal reactions to treatment failure, their motives for offering further treatment cycles, and the influence of personal reproductive experiences on clinical care is essential for preserving professional boundaries and objectivity. Managing the inevitable challenges will be facilitated by knowing when to refer and avoiding working in isolation. Multidisciplinary team care provides support and mentorship for clinicians and is associated with better decision-making and patient outcomes [14].

The multidisciplinary team:

- Includes gynecologists, psychologists, nurses, and embryologists and meets regularly at scheduled times for complex case review.
- Is chaired actively to allow all members to speak.
- Is collaborative and confirms that a single clinician need not embody all the necessary skills.

16.6 Critical Reflection and Concluding Remarks

Good clinical practice for infertility and ART clinicians involves much more than the essential biomedical and technical competence. Psychosocially informed care requires a set of acquired skills that promotes patients' wellbeing and includes empathy, honesty, respect, effective communication, nonjudgmental language, patient involvement, and emotional support. Infertility and ART clinical care necessitates a high degree of self-awareness and can be psychologically challenging work. Multidisciplinary team approaches to clinical practice promote clinicians' wellbeing.

Test Your Knowledge and Comprehension

1. Stressful environments cause difficulties with conception.
   (a) True
   (b) False
2. The clinician should maintain the couple's hope for a successful outcome regardless of how many treatment cycles have been undertaken.
   (a) True
   (b) False
3. Lifestyle factors are the most important cause of infertility and ART success.
   (a) True
   (b) False
4. Women who have an active style of managing difficulties experience lower levels of depression and engage more social support than women who accept recommendations passively.
   (a) True
   (b) False
5. Assisting couples to make an active decision about when to cease treatment is an important aspect of ART treatment.
   (a) True
   (b) False
6. Which technique is not useful for building a therapeutic alliance with a couple undergoing ART?
   (a) Using open-ended questions
   (b) Encouraging members of the couple to answer on behalf of each other
   (c) Using plain, nontechnical language
   (d) Emphasizing treatment failure not personal failure
7. What is the most appropriate way to present ART success?
   (a) % pregnancies per embryo transfers
   (b) % pregnancies per started stimulated cycles
   (c) % live births per embryo transfers
   (d) % live births per started stimulated cycles
8. What is the most important determinant of ART success?
   (a) The reputation of the clinic
   (b) The cause of infertility
   (c) The woman's age
   (d) The number of previous IVF attempts
9. What is the most stressful time in an ART treatment cycle?
   (a) Starting treatment
   (b) Having injections and blood tests
   (c) The interference of treatment with daily life activities
   (d) The 2-week wait after embryo transfer

10. Infertility is not associated with
    (a) Increased risk of psychopathology
    (b) Feelings of guilt
    (c) Fear of losing significant relationships
    (d) Social isolation

Answers

1. False
2. False
3. False
4. True
5. True
6. (b)
7. (d)
8. (c)
9. (d)
10. (a)

References

1. Zegers-Hochschild F, Adamson D, De Mouzon J, Ishihara O, Mansour R, Nygren K, et al. The international committee for monitoring assisted reproductive technology (icmart) and the world health organization (who) revised glossary on art terminology, 2009. Hum Reprod. 2009;24(11):2683–7.
2. Dancet EAF, Van Empel IW, Rober P, Nelen WL, Kremer JAM, D'Hooghe TM. Patient-centred infertility care: a qualitative study to listen to the patient's voice. Hum Reprod. 2011;26(4):827–33.
3. Berg BJ, Wilson JF. Psychiatric morbidity in the infertile population: a reconceptualization. Fertil Steril. 1990;53(4):654–61.
4. Greil A, Slauson-Blevins K, McQuillan J. The experience of infertility: a review of recent literature. Sociol Health Illn. 2010;32(1):140–62.
5. Fisher J, Hammarberg K. Psychological and social aspects of infertility in men: an overview of the evidence and implications for psychologically informed clinical care and future research. Asian J Androl. 2012;14:121–9.
6. Rockliff HE, Lightman SL, Rhidian E, Buchanan H, Gordon U, Vedhara K. A systematic review of psychosocial factors associated with emotional adjustment in in vitro fertilization patients. Hum Reprod Update. 2014;20(4):594–613.
7. Anderson K, Nisenblat V, Norman RJ. Lifestyle factors in people seeking infertility treatment: a review. Aust N Z J Obstet Gynaecol. 2010;50:8–20.
8. Min JK, Breheny SA, MacLachlan V, Healy DL. New debate: what is the most relevant standard of success in assisted reproduction? The singleton, term gestation, live birth rate per cycle initiated: the best endpoint for assisted reproduction. Hum Reprod. 2004;19(1):3–7.
9. Lautenbach DM, Christensen KD, Sparks JA, Green RC. Communicating genetic risk information for common disorders in the era of genomic medicine. Annu Rev Genomics Hum Genet. 2013;14(1):491–513.

10. Boivin J, Griffiths E, Venetis CA. Emotional distress in infertile women and failure of assisted reproductive technologies: meta-analysis of prospective psychosocial studies. BMJ. 2011;342:d223.
11. Hansen M, Kurinczuk JJ, Milne E, de Klerk N, Bower C. Assisted reproductive technology and birth defects: a systematic review and meta-analysis. Hum Reprod Update. 2013;19(4):330–53.
12. Verberg MF, Eijkemans MJC, Heijnen EM, Broekmans FJ, De Klerk C, Fauser BC, et al. Why do couples drop-out from ivf treatment? A prospective cohort study. Hum Reprod. 2008;23(9):2050–5.
13. Verhaak CM, Smeenk JMJ, Evers AW, Kremer JAM, Kraaimaat FW, Braat DD. Women's emotional adjustment to ivf: a systematic review of 25 years of research. Hum Reprod Update. 2007;13(1):27–36.
14. Taylor C, Munro AJ, Glynne-Jones R, Griffith C, Trevatt P, Richards M, et al. Multidisciplinary team working in cancer: what is the evidence? BMJ. 2010;340:c951.

A Woman Who Never Could Have Coitus: Treatment of Lifelong Vaginismus

17

Moniek M. ter Kuile and P.T.M. Weijenborg

17.1 Introduction and Aims

Lifelong vaginismus is diagnosed when a woman has never been able to have intercourse. The prevalence rates vary between 0.4 and 6.0 % in a general population. Research on the etiology of vaginismus is scarce, and no definitive cause has been identified. The aim of this chapter is to provide insight into the recent diagnostics and treatment of lifelong vaginismus. A fear-avoidance model for vaginismus is described that can give the professional (gynecologists, psychologists, physical therapist) and the women herself pointers to understand a woman's physical and emotional response(s) to (attempts at) penetration.

17.2 Definition in Lay Terms

Vaginismus is commonly described as a persistent difficulty in allowing vaginal entry of a penis or other "objects" (e.g., tampons, fingers, speculum), despite the woman's expressed wish to do so.

17.3 Didactic Goals

After reading this chapter you:

- Are able to recognize lifelong vaginismus as a sexual problem
- Are familiar with the fear-avoidance model of vaginismus

M.M. ter Kuile, PhD (✉) • P.T.M. Weijenborg, MD, PhD
Department of Gynecology, Leiden University Medical Centre, Leiden, The Netherlands
e-mail: M.m.ter_Kuile@lumc.nl; p.t.m.weijenborg@lumc.nl

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_17

- Are familiar with the most recent insights in diagnostics in lifelong vaginismus
- Are familiar with the most recent insights in treatment interventions in lifelong vaginismus

Case History

Jane Periwinkle, 32 years old, 5 years married to Peter, is referred by her general practitioner with the complaint that sexual intercourse has never been possible; attempts resulted in pain. She and her partner are very hopeful to overcome this problem in order to be able to conceive children.

Questions Belonging to the Case History

1. Give three possible explanations why sexual intercourse has never been possible?
2. As a doctor (general practitioner/gynecologist), would you perform an internal gynecological examination to exclude physical pathology?
3. If this couple is only interested to overcome this problem in order to conceive children, what would you advise them?
4. If this couple wants to overcome this problem in order to have sexual intercourse, what would you advise them?

17.4 Facts and Figures: Definitions, Classification, and Prevalence

Vaginismus is defined in the *Diagnostic and Statistical Manual of Mental Disorders*, fourth edition, text revision (*DSM-IV-TR*), as an involuntary contraction of the musculature of the outer third of the vagina interfering with intercourse, causing distress and interpersonal difficulty [1]. This definition has received considerable criticism. For example, the focus on vaginal spasm as the key diagnostic criterion has never been empirically supported [2]. In response to the lack of empirical support for the *DSM-IV* diagnostic criteria and the persistent difficulties in clearly differentiating vaginismus from dyspareunia, these two sexual pain disorders in the *DSM-IV-TR* have been merged into a new *DSM-5* "genito-pelvic pain/penetration disorder" (GPPPD) [3]. The diagnostic criteria of the DSM-5 refers to four commonly comorbid symptom dimensions: (1) difficulties with having intercourse, (2) marked genito-pelvic pain, (3) marked fear of pain or vaginal penetration, and (4) marked tension of the pelvic floor muscles. Lifelong or primary vaginismus occurs when a woman has never been able to have intercourse. In acquired or secondary vaginismus, a woman loses the ability to have intercourse after a non-symptomatic period of time mostly as a consequence of vulvovaginal pain during intercourse. In this chapter, however, the focus lies on women with lifelong vaginismus. Epidemiological studies often subsume vaginismus in more generalized questions about pain with

intercourse resulting in only a few accurate prevalence estimates. The best estimates of reported rates vary between 0.4 and 6.0 % in a general population [4–7]. In the more traditional Islamic populations in Turkey, vaginismus is the most important reason for seeking help (58–76 %) [8–11]. In Western and Southern Europe, these figures vary between 14 and 25 % [12, 13]. Cultural influences, such as strict religious and social rules concerning sexuality, virginity, (demonstration of virginity at) the first coitus during the wedding night, and/or fertility could possibly be associated with vaginismus.

17.5 Etiology and Pathogenesis

Although lifelong vaginismus has been a well-known concept for a long time, up till now no specific cause for this problem is known. Somatic, pelvic floor, sexological, and psychological factors are intertwined but are discussed here for didactical reasons as separate entities.

17.5.1 Somatic Factors

There is rarely a physical explanation for lifelong vaginismus (0–5 %) and can include congenital hymeneal or vaginal abnormalities (e.g., hymen semilunaris altus or septum vaginalis) [2, 14, 15]. Many women diagnosed with vaginismus also experience vulvar pain on touch (40 %–100 %) [2, 14–16]. This vulvar pain is typically diagnosed as provoked vestibulodynia (PVD) [17] (see Chap. 18).

17.5.2 Pelvic Floor Muscle Involvement

Because of the 150-year consensus concerning the nature of vaginismus, most clinical reports and etiological studies take for granted that women diagnosed with vaginismus exhibit vaginal muscle spasms upon attempted vaginal penetration [18]. This remarkable consensus is based primarily on expert clinical opinion and is preserved in the DSM-IV-TR. However, recent studies showed that the spasm criterium is neither reliable nor valid [2].

Pelvic floor muscle activity can be assessed with a surface electromyography (EMG), vaginal probe, or needle EMG, and pelvic floor muscle palpation by trained physical therapists.

Women suffering from vaginismus would be expected to demonstrate higher levels vaginal electromyography (EMG) in response to external threat stimuli, such as threat-inducing films.

Until now there are no additions that women with vaginismus differ from women without vaginismus in terms of the degree of pelvic floor muscle tension as a response to a physically and sexually threatening stimulus. Consequently, it has been suggested that increased pelvic muscle tension and/or contraction is more a

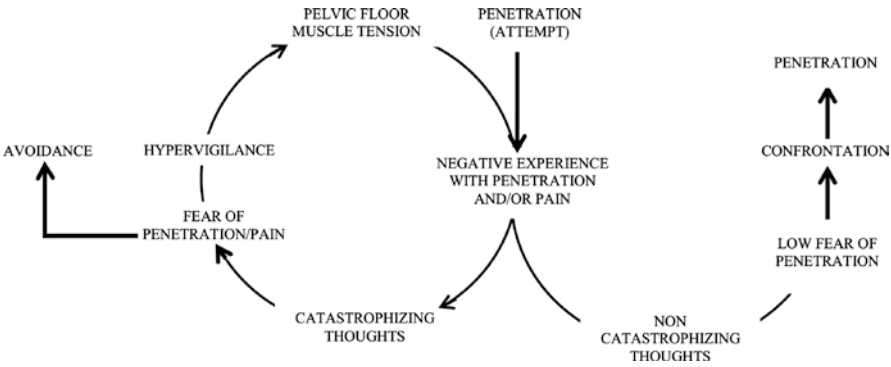


Fig. 17.1 Fear-avoidance model of vaginismus (FAM-V) (Used with permission of Guilford Press from ter Kuile and Reissing [28])

"general" protective mechanism in response to potential threat for all women [19] and women with vaginismus show this specific defense reflex in response to potential vaginal penetration [20].

17.5.3 Sexual and Psychological Factors

Conservative and religious attitudes, lack of sex education, sexual abuse, and relationship factors have all been reported as potential causal variables; however, none have been confirmed empirically (using cross-sectional study design) [21]. Vaginismus is classified as a sexual dysfunction; however, little information is available on sexual function and response in sufferers. While some women report few sexual problems if vaginal penetration is not anticipated or attempted, others find their sexual functioning significantly compromised [21]. Women with vaginismus appear to respond differently to erotic stimuli; they report more thoughts about negative consequences of intercourse and demonstrate increased negative affective appraisal of vaginal penetration. For example, they have been found to have elevated fears of injury, losing control, as well as negative self-and genital image, and worries about genital incompatibility [22, 23]. Other studies have identified that feelings of sexual disgust appear to be more prominent in women with lifelong vaginismus [24–26].

17.5.4 Fear-Avoidance Model of Vaginismus (FAM-V)

On the basis of the fear-avoidance model of Vlaeyen and Linton (2000) [27], a fear-avoidance model was proposed for vaginismus (Fig. 17.1) [28]. This model provides an explanation of why vaginal penetration problems develop in a minority of women who experience discomfort or pain with attempted vaginal penetration. The basic tenet of the model is that catastrophic thinking about vaginal penetration and/or a catastrophic interpretation of a negative experience with penetration (e.g., pain, genital incompatibility) elicits vaginal penetration-related fears. To cope with fear, a woman may avoid all activities related to vaginal penetration, or she may be

Table 17.1 Anamnesis questions

What can and what cannot be inserted into the vagina?
Can the woman insert a tampon or 1 or 2 of her own fingers or of her partner's fingers or penis?
Does the woman have any experience with gynecological examination, in particular a speculum examination? If so: was this possible?
Has it always been this way or has this come about over time?
Vulvar pain
Is there vulvar pain when inserting a tampon or 1 or 2 of her own fingers or of her partner's fingers or his penis?
What is the nature of the pain?
What is the course of the pain?
Is there also vulvar pain when urinating after (attempted) intercourse?
Does vulvar pain exist not associated with sexual activity?
What is, according to the woman, the cause of the inability to have intercourse: the pain? It does not fit?
What are the consequences of the problem in the sexual situation?
Does the woman recognize that she is more tense/more anxious in general and specifically in the pelvic floor area? Does she anticipate the pain by becoming more tensed?
Does the woman recognize that she is less sexually excited during lovemaking, particularly less moist/lubricated?
Does the woman recognize that she has gradually less or no desire in sexual contact, intercourse? Does she avoid every (sexual) contact?
Are there other pelvic floor hypertonic symptoms, such as frequent urination and/or constipation?
Are there other gynecological complaints such as excessive vaginal discharge?
Does the woman have negative/traumatic sexual experiences?
What are the consequences of the problem for the woman herself in the psychological sense, such as experiencing shame and having a feeling of guilt toward the partner?
What is the impact of the problem for the relationship with her partner, such as tensions in the relationship? Why is (are) the woman (and her partner) seeking help now? To improve the sexual relationship and function better or a child wish?

hypervigilant for stimuli that are related to her specific fearful thoughts (e.g., pain, genital incompatibility). The latter can result in an exaggerated attention to physical sensations and increased fear that facilitates the experience of pain during attempted vaginal penetration. These attempts are met with defensive pelvic muscle contractions. Increased muscle tone results in further pain or failed attempts. The experience of the inability to "achieve" penetration in turn confirms negative expectations, thereby further exacerbating and perpetuating the vicious cycle of vaginismus.

17.6 Specific Diagnostic Aspects

17.6.1 History Taking

The diagnosis is made on the basis of the anamnesis. Questioning related to the problem goes through various steps (Table 17.1). The clinical presentation of and the request for help made by women with vaginismus are very diverse: she can be young (around 20 years of age) or somewhat older (around 30 years old); she may

be able to function sexually very well without intercourse or on the other hand avoid every sexual situation; she may not be able to insert anything into her vagina, or be able to insert tampons or allow a speculum examination, while insertion of the penis is impossible; and finally she may wish to improve her sexual functioning or she may wish to become pregnant in "a natural way."

Moreover, it is not always easy through the anamnesis to distinguish between "vaginismus" and "dyspareunia." In both groups, there can be vulvar pain when the penis is inserted or attempts at insertion of the penis are made. When intercourse has never been successful, the woman is diagnosed with "lifelong vaginismus." When intercourse has been possible but became painful at the start or over the course of time and eventually is no longer possible, this is acquired "secondary" vaginismus.

Case History: Continued

Jane Periwinkle, like most other woman with lifelong vaginismus, has never been able to insert a finger or tampon into her vagina or have a pelvic exam with finger or speculum insertion. Jane initially indicates that she desired nothing more than being able to experience intercourse, but her inability to insert a tampon led her to believe that her vagina could not possibly accommodate a penis. She and her partner are very anxious that "physical causes" were making vaginal penetration impossible.

Jane's partner colludes with her in avoiding intercourse. He has observed her difficulties and shared her fears about physiological pathology. He cares for his partner and wants to avoid the negative emotional fallout. They have been married for 5 years but could barely remember attempts at intercourse. However, Jane and Peter do not avoid sexual intimacy with the explicit agreement that vaginal penetration will not be attempted. She reports no history of sexual abuse. This is their first attempt at formal treatment and both are very hopeful to overcome the problem in order to be able to conceive children in a natural way.

17.6.2 Physical Examination

An (external) gynecological examination is carried out on women with lifelong vaginismus to assess, on the one hand, any congenital abnormalities of the hymen or vagina and, on the other hand, to inform the woman about her genitals, about the location of the pain that she may be experiencing during an attempt at intercourse, and about what can happen when her pelvic floor muscles tighten voluntarily or involuntarily. The examination thus has an educational purpose. Patient preparation is central to an educational pelvic examination (EPE) to avoid further distress (for details about patient preparation, see also Chap. 30). To facilitate the EPE, the patient is informed of what to expect and reassured that no vaginal insertion (of a finger or speculum) will be attempted. She is invited to be an active participant (e.g.,

holding a mirror to observe exam, ask questions) and reminded that she can terminate the exam whenever she wishes. Instructions on coping with fear/anxiety can be very helpful (e.g., breathing techniques).

The examination consists of inspection of the external genitals, the vaginal introitus, and the hymeneal ring and palpation of the vaginal vestibule. In a large group of women (40–100 %) with lifelong vaginismus, findings as are described in the diagnosis "provoked vestibulodynia" (PVD) (see Chap. 18) can be found. In that case, the woman indicates having pain when the vaginal vestibulum is touched with a moistened cotton wool swab, the so-called "touch test" or "Q-tip test," in which sometimes vestibular erythema is also visible. The pain is regularly recognized by the woman as the pain that she feels during (attempted) intercourse.

17.6.2.1 Evaluation of Vaginistic Response or Pelvic Floor Hypertonicity

It is logical that the woman tightens her pelvic floor muscles as a response to pain. This behavior is frequently seen on performing the Q-tip test. Sometimes a traditional or classic vaginistic response can be observed with tightening of the pelvic floor muscles, adduction of the thighs, curling of the toes/feet and lower back, and sometimes autonomous tension responses. Because intravaginal palpation is not possible or desirable, pelvic floor hypertonicity or the constant tensing of the pelvic floor muscles can be assumed when the woman has difficulties lying on the edge of the examination couch with her pelvis relaxed or remaining relaxed during the examination and palpation.

17.6.2.2 Do Not Do

Speculum examination and bimanual internal examination must be avoided. This will frequently also be impossible, or if one perseveres in doing so will be accompanied by pain and the occurrence of a vaginistic response.

Case History: Continued

Jane Periwinkle's physical examination is limited to a visual inspection of her external genitals, and no pathology is noted. She is quite anxious in anticipation; she displays an elevated degree of pelvic reactivity during the EPE but put at ease by the process of the EPE. She reports pain on the Q-tip test at 5 and 7 o'clock. She recognizes "the pain" during the Q-tip test as the pain she has felt during the unsuccessful penetration attempts she has carried out a long time ago.

17.6.3 Discussion of Findings

After the physical examination, it is logical to discuss the findings and to explain the complaint in a way that is comprehensible for the woman and her partner. It can help to make a schematic drawing of the vulva on which the urethra, vaginal introitus, the

pain spots, and location of the pelvic floor muscles can be drawn while talking. It is not possible to say what a possible cause might be, but one can explain how physical and psychological factors could influence sexual functioning and the inability to have intercourse. The FAM-V model can be useful in this context (Fig. 17.1). The FAM-V model can give the woman pointers to understand her own physical and emotional response(s) to (attempts at) penetration. She often recognizes various elements that are maintaining the vicious circle in which she is caught up.

Case History: Continued
The FAM-V model is discussed, taking into account Jane Periwinkle's fearful cognitions "it does not fit" and her behavioral response (elevated degree of pelvic reactivity during the EPE), to explain her response to attempts at penetration. Jane and Peter recognize the various elements of the FAM-V model. And both think that the explanation that it is all "normal" will help to overcome the fearful cognition "there is something wrong."

17.6.4 Treatment Plan

On the basis of the information obtained from the anamnesis and the physical examination, a purely medical approach is not appropriate. In the further course of the consultation, the different components of treatment can be discussed. When the wish for a child is prominent, an explanation can be given about self-insemination do-it-yourself (DIY insemination with own sperm). For women with vaginismus who wish to have intercourse, a sexological coaching session is appropriate. Clinical psychologists/sexologists, who are trained in the basic principles of exposure, are best equipped to accompany the couple during exposure treatment. There is, above all, a role for the pelvic floor physiotherapist in addition to medical and psychological expertise specifically when a woman prefers this approach.

17.7 Specific Therapeutic Aspects

17.7.1 Medical Treatment

Different forms of treatment have been used to address the somatic correlates of vaginismus, for example, surgical removal of the hymen or widening of the introitus [29], injections of botulinum toxin in the pelvic musculature [30], or application of topical anesthetic creams [31]. No evidence of the effectiveness of one of these treatments is available from controlled studies [21, 32].

17.7.2 Physical Therapy

Although physical therapy is often used in clinical practice, evidences from prospective and controlled studies is lacking [32].

17.7.3 Psychological Treatment

The widespread application of the anxiety-reduction approach of gradual exposure reflects the consensus among theoreticians and clinicians about the important role of anxiety in vaginismus [32]. Since Masters and Johnson (1970) [33], most therapies for vaginismus have used vaginal "dilatation" in which initially the woman becomes accustomed to self-touch to the vaginal introitus and insertion of her own finger or dilators through the introitus and pass way into her vagina, and then places the first of a series of inserts of gradually increasing diameter into her vagina. In reality, of course, there is no actual dilation but rather a gradual reduction of fear. According to the FAM-V model, the penetration-related fears are maintained in women with vaginismus because avoidance prevents disconfirmation of the catastrophic beliefs. By directly reducing avoidance and increasing successful penetration behaviors, fears are disconfirmed; catastrophization is reduced and eventually eliminated.

Gradual exposure is nearly always combined with relaxation instruction, which in the literature is described as systematic desensitization. These core elements are often included within the context of a broader approach involving cognitive restructuring, education, sex therapy, and homework assignments. Although there have been many reports in the literature about the various versions of the treatment inventions described for vaginismus, only a few randomized and controlled effect studies have been conducted until now. The success (intercourse is possible) of these few studies varied greatly: 14–96 % [32]. The treatment success of recent, exposure-type treatments [34] is significantly greater than that of therapies that combine multiple treatment techniques [35].

Case History: Continued
Jane and Peter Periwinkle are referred to a sexologist/psychologist, recommended to start with stepwise exposure treatment.

17.8 Critical Reflection and Conclusive Remarks

When intercourse is not possible and has never been successful, despite the expressed wish of the woman to do so, this is regarded as lifelong vaginismus. Studies have shown that fearful penetration cognitions and avoiding behavior appear to play an important role in this problem.

If a woman with lifelong vaginismus consults a gynecologist, a focused anamnesis is the appropriate instrument for making the diagnosis. The physical examination is a first step in the treatment. Inspection of the external genitals during which, in particular, the vaginal vestibulum, the introitus, and the proximal part of the vagina can be assessed provides sufficient information about the existence of coitus-obstructing somatic factors. Moreover, the examination has a significant educational character. A speculum examination and bimanual internal examination are absolutely not advised.

After the physical examination, the gynecologist informs the woman and her partner about the findings. Here too, information can be given about the prevailing ideas about vaginismus on the basis of the fear and avoidance model for vaginismus. Many couples acknowledge and recognize that they over time had started avoiding "wanting to have intercourse" and they are living with various anxious/negative ideas about this. Also the components of the current treatment can be discussed. Following this, the couple can be referred for subsequent treatment. The chance of success with exposure treatment is very high. When the wish for a child is prominent, an explanation can be given about self-insemination do-it-yourself (DIY insemination with own sperm). The wish for a child is sometimes the only reason to consult a gynecologist, and then referral for subsequent treatment is not necessary.

Tips and Tricks

- The diagnosis of vaginismus is made on the basis of the anamnesis.
- Speculum examination and bimanual internal examination must be avoided.
- An (external) gynecological examination is carried out on women with lifelong vaginismus as an educative pelvic examination (EPE) in order to assess, on the one hand, any congenital abnormalities of the hymen or vagina and, on the other hand, to inform the woman about her genitals, about the location of the pain that she may be experiencing during an attempt at intercourse, and about what can happen when her pelvic floor muscles tighten voluntarily or involuntarily.
- On the basis of the information obtained from the anamnesis and the physical examination, a purely medical approach is not appropriate.
- The FAM-V model (Fig. 17.1) can give the woman pointers to understand her own physical and emotional response(s) to (attempts at) penetration.
- The chance of success with exposure treatment is very high.
- When the wish for a child is prominent, an explanation can be given about self-insemination do-it-yourself (DIY insemination with own sperm).

Test Your Knowledge and Comprehension

1. With the persistent difficulties in clearly differentiating vaginismus from dyspareunia, these two sexual pain disorders in the DSM-IV-TR have been merged into a new DSM-5 "genito-pelvic pain/penetration disorder" (GPPPD). Give at least three symptoms that are often reported in women with lifelong vaginismus and women with dyspareunia.
2. Is a history of sexual abuse a contra indication for a stepwise penetration exposure treatment? Motivate your answer with arguments.
3. Describe the FAM-V model, step by step for Jane and Peter, taking into account, i.e., Jane's fearful cognitions and her behavioral response during the physical examination to explain her response to attempts at penetration.

4. Jane and Peter are referred to a psychologist/sexologist. Jane and Peter want more information about the psychological treatment interventions that can be expected. Describe a stepwise exposure treatment plan for the couple.
5. The sexologist/psychologist also invited Peter to participate in the stepwise exposure treatment. Give three (possible) reasons that the therapist invited Peter to participate in the exposure treatment. Motivate you answer with arguments.
6. Physical explanation (i.e., congenital hymeneal or vaginal abnormalities) for lifelong vaginismus is found frequently (20–40 %).
   (a) True
   (b) False
7. A very few women diagnosed with lifelong vaginismus also experience vulvar pain on touch (0–5 %).
   (a) True
   (b) False
8. The diagnosis of lifelong vaginismus is made on the basis of the anamnesis.
   (a) True
   (b) False
9. Speculum examination and bimanual internal examination must be avoided in women with lifelong vaginismus.
   (a) True
   (b) False
10. If a couple wants to overcome lifelong vaginismus only to conceive children, then an explanation can be given about in vitro fertilization (IVF).
    (a) True
    (b) False
11. In most of the stepwise exposure treatments, it is the woman who is inserting fingers/dilators herself and not the therapist.
    (a) True
    (b) False

Answers

1. For answers, see Chap. 18.

2 through 5 are open book answers based on Chap. 17.

6. False
7. False
8. True
9. True
10. False
11. True

References

1. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. (4th ed, and Text revision). Washington, DC: Author; 2000.
2. Reissing ED, Binik YM, Khalife S, Cohen D, Amsel R. Vaginal spasm, pain, and behavior: an empirical investigation of the diagnosis of vaginismus. Arch Sex Behav. 2004;33(1):5–17.
3. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. Arlington: Author; 2013.
4. Christensen BS, Gronbaek M, Osler M, Pedersen BV, Graugaard C, Frisch M. Sexual dysfunctions and difficulties in Denmark: prevalence and associated sociodemographic factors. Arch Sex Behav. 2011;40(1):121–32.
5. Fugl-Meyer AR, Fugl-Meyer KS. Sexual disabilities, problems and satisfaction in 18–74 year old Swedes. Scan J Sexol. 1999;2:79–105.
6. Kadri N, Mchichini AKH, Mchakra T. Sexual dysfunction in women: population based epidemiological study. Arch Women Ment Health. 2002;5:59–63.
7. Oberg K, Fugl-Meyer KS. On Swedish women's distressing sexual dysfunctions: some concomitant conditions and life satisfaction. J Sex Med. 2005;2(2):169–80.
8. Dogan S. Vaginismus and accompanying sexual dysfunctions in a Turkish clinical sample. J Sex Med. 2009;6(1):184–92.
9. Oniz A, Keskinoglu P, Bezircioglu I. The prevalence and causes of sexual problems among premenopausal Turkish women. J Sex Med. 2007;4(6):1575–81.
10. Ozdemir O, Simsek F, Ozkardes S, Incesu C, Karakoc B. The unconsummated marriage: its frequency and clinical characteristics in a sexual dysfunction clinic. J Sex Marital Ther. 2008;34(3):268–79.
11. Yasan A, Gurgen F. Marital satisfaction, sexual problems, and the possible difficulties on sex therapy in traditional Islamic culture. J Sex Marital Ther. 2009;35(1):68–75.
12. Catalan J, Hawton K, Day A. Couples referred to a sexual dysfunction clinic psychological and physical morbidity. Br J Psychiat. 1990;156:61–4.
13. Nobre PJ, Pinto-Gouveia J, Gomes FA. Prevalence and comorbidity of sexual dysfunctions in a Portuguese clinical sample. J Sex Marital Ther. 2006;32(2):173–82.
14. de Kruiff ME, ter Kuile MM, Weijenborg PTM, van Lankveld JJDM. Vaginismus and dyspareunia: is there a difference in clinical presentation? J Psychosom Obstet Gynecol. 2000;21(3):149–55.
15. ter Kuile MM, van Lankveld JJDM, Vlieland CV, Willekes C, Weijenborg PTM. Vulvar vestibulitis syndrome: an important factor in the evaluation of lifelong vaginismus? J Psychosom Obstet Gynecol. 2005;26(4):245–9.
16. Basson R. Lifelong vaginismus: a clinical study of 60 consecutive cases. J SOGC. 1996;18:551–61.
17. Moyal-Barracco M, Lynch PJ. 2003 ISSVD terminology and classification vulvodynia: a historical perspective. J Reprod Med. 2004;49(10):772–7.
18. Binik YM, The DSM. Diagnostic criteria for vaginismus. Arch Sex Behav. 2010;39(2):278–91.
19. van der Velde J, Laan E, Everaerd W. Vaginismus, a component of a general defensive reaction. An investigation of pelvic floor muscle activity during exposure to emotion-inducing film excerpts in women with and without vaginismus. Int Urogynecol J Pel. 2001;12(5):328–31.
20. Shafik A, El-Sibai F. Study of the pelvic floor muscles in vaginismus: a concept of pathogenesis. Eur J Obstet Gynecol Reprod Bio. 2002;105(1):67–70.
21. van Lankveld JJDM, Granot M, Weijmar Schultz WCM, Binik YM, Wesselmann U, Pukall CF, Bohm-Starke N, Achtrari C. Women's sexual pain disorders. J Sex Med. 2010;7:615–31.
22. Klaassen M, ter Kuile MM. The development and initial validation of the Vaginal Penetration Cognition Questionnaire (VPCQ) in a sample of women with vaginismus and dyspareunie. J Sex Med. 2009;6:1617–27.
23. Reissing ED. Consultation and treatment history and causal attributions in an online sample of women with lifelong and acquired vaginismus. J Sex Med. 2012;9:251–8.

24. Borg C, de Jong PJ, Schultz WW. Vaginismus and dyspareunia: automatic vs. deliberate disgust responsivity. J Sex Med. 2010;7(6):2149–57.
25. Cherner RA, Reissing FD. A psychophysiological investigation of sexual response in women with lifelong vaginismus. J Sex Med. 2013;10(5):1291–303.
26. de Jong PJ, van Overveld M, Schultz W, Peters ML, Buwalda FM. Disgust and contamination sensitivity in vaginismus and dyspareunia. Arch Sex Behav. 2009;38(2):244–52.
27. Vlaeyen JWS, Linton SJ. Fear-avoidance and its consequences in chronic musculoskeletal pain: a state of the art. Pain. 2000;85(3):317–32.
28. ter Kuile MM, Reissing ED. Chapter 8. Lifelong vaginismus. In: Binik YM, Hall K, editors. Principles and practice of sex therapy. 5th ed. New York: Guilford press; 2014. p. 177–92.
29. Addar MH. The unconsummated marriage: causes and management. Clin Exp Obstet Gynecol. 2004;16:279–81.
30. Pacik P. Vaginismus: treatment with intravaginal Botox and Dilation under anesthesia. A prospective study of 70 consecutive patients. J Sex Med. 2011;8:64.
31. Praharaj SK, Verma P, Arora M. Topical lignocaine for vaginismus: a case report. Int J Imp Res. 2006;18(6):568–9.
32. Melnik T, Hawton K, McGuire H. Interventions for vaginismus. Cochrane Database Syst Rev. 2012;12:CD001760.
33. Masters WH, Johnson VE. Human sexual inadequacy. Boston: Little Brown; 1970.
34. ter Kuile MM, Melles R, Groot HE, Tuijnman-Raasveld CC, van Lankveld JJDM. Therapist-aided exposure for women with lifelong vaginismus: a randomized waiting-list controlled trial of efficacy. J Consult Clin Psychol. 2013;81(6):1127–36.
35. van Lankveld JJDM, ter Kuile MM, de Groot HE, Melles R, Nefs J, Zandbergen M. Cognitive-behavioral therapy for women with lifelong vaginismus: a randomized waiting-list controlled trial of efficacy. J Consult Clin Psychol. 2006;74:168–78.

A Woman with Coital Pain: New Perspectives on Provoked Vestibulodynia

18

Symen K. Spoelstra and Harry B.M. van de Wiel

18.1 Introduction and Aims

Provoked vestibulodynia (PVD) is characterized by pain at the vulvar introitus, in particular the vulvar vestibule, provoked by touch, pressure, and vaginal penetration. Although distinct and interesting hypotheses have been put forward, the pathogenesis of PVD still remains largely unknown. In general, the etiology is considered to be multifactorial. Problems arise in PVD when normal protective functions "overreact": when normal behavior or a psychophysiological state is *too extreme*, *too prolonged*, or *too intense*. This attention to contextual appropriateness is one of the key principles of psychosomatic obstetrics and gynecology. It is therefore the major reason why PVD symptoms should always be put into a biopsychosocial perspective.

18.2 Definition in Lay Terms

Provoked vestibulodynia (PVD) is characterized by pain at the vulvar entrance, in particular the vulvar vestibule, provoked by touch, pressure, and vaginal penetration.

S.K. Spoelstra, MD (✉)
Department of Obstetrics and Gynecology, University Medical Center Groningen, Groningen, The Netherlands
e-mail: korspoelstra@gmail.com

H.B.M. van de Wiel, PhD
Wenckebach Institute, University of Groningen, University Medical Center Groningen, Groningen, The Netherlands
e-mail: har.wiel@planet.nl

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_18

18.3 Didactic Goals

After reading this chapter, you will:

- Be able to recognize PVD as a *sexual* as well as a *chronic pain* problem
- Know that its onset often has the character of an acute *disease* but that this disease easily turns into a chronic pain *syndrome* through the particular psychological makeup of the patient or couple
- Be aware of the most recent insights into diagnostic and therapeutic options in PVD
- Know that a multidimensional treatment provides the best options for long-term success
- Know that the key element of this treatment is to end the vicious circle of pain and fear
- Be able to inform patients and partners about diagnostics and therapeutics, including complications or disturbances that may occur throughout the treatment process
- Know that even after what can be considered as successful treatment, the motto at the resumption of intercourse remains: "Handle with care!"

Case History
Bianca Olive, a 30-year-old woman, para 2, enters your consultation room alone. She is referred by her general practitioner (GP) for gynecological examination. Her main problem is pain during sexual intercourse, which started after the birth of her second child, about 2 years ago. At that time she also suffered from some vaginal discharge. Her GP treated her with antimycotic vaginal suppositories against vaginal infection. The treatment alleviated her complaints for a few weeks but then the pain returned. She describes the pain as a very intense burning pain starting from the moment of penetration. The pain is always present during sexual intercourse and it can even hold on for hours afterward. She is using OAC (ethinyl estradiol 30 ug/levonorgestrel 150 ug), no other medication or drugs. Bianca has no history of illnesses or sexual or physical abuse.

18.4 Facts and Figures: Epidemiology, Classification, and Differential Diagnosis

18.4.1 Epidemiology

The prevalence of PVD is unclear and depends on a number intermediating variables, such as age, cultural background or ethnicity, and setting:

- *Age*: with regard to the prevalence of dyspareunia, there appears to be a bimodal age distribution that varies from 14 to 34 % in younger (premenopausal) women

and from 6.5 to 45 % in older women [1]. In premenopausal women, PVD is the most frequent cause of chronic painful sexual intercourse [2].

- *Cultural background/ethnicity*: the prevalence of dyspareunia in Northern European countries seems low, whereas in the USA, relatively high prevalence figures have been reported. Historically, PVD was primarily considered to be a disorder that only affects white Caucasian (young nulliparous) women [3]. However, it has become increasingly clear that the lifetime prevalence of PVD is the same regardless of ethnicity [4].
- *Setting*: a prevalence of 3–18 % has been reported in the general population, 3–46 % in general practice populations, and 10–20 % at outpatient gynecology clinics [5].

Besides these more general mediators, *time frame* (as specified by researchers), *comorbidity*, and the *physician's initiative* in bringing up the topic seem to play important roles in determining the prevalence [1].

18.4.2 Classification

For several decades, there has been debate about the classification and terminology of vulvar pain in general. Its origin lies merely in the many different dimensions that are used to underpin the classification process, such as *quality*, *quantity*, *localization*, *origin*, and *duration* of the pain or (more generally speaking) discomfort:

- *Quality*: where the International Society for the Study of Vulvovaginal Diseases (ISSVD) refers to the pain as burning, others describe the pain as sharp (knifelike).
- *Quantity*: the degree of vulvar pain experienced varies per patient. PVD is characterized by hyperalgesia, i.e., increased response to a painful stimulus, and allodynia – the experience of pain in response to a normally not painful stimulus.
- *Localization*: depending on the anatomical site of the pain, vulvodynia can be divided into a generalized and a localized subtype. The *generalized* form is far less common and has been understudied. The more customary *localized* subtype chiefly occurs in the vulvar vestibule. The locus of the allodynia is limited to specific areas and is symmetrical in the majority of women. It occurs particularly at the 5 o'clock and 7 o'clock positions exteriorly to the hymenal ring [3]. In a very small percentage of women, the hypersensitivity is localized in the anterior part of the vulva. These cases in particular are usually therapy resistant.
- *Origin*: vulvar pain can be divided into provoked, unprovoked, and mixed. The most common presenting symptom of *provoked vestibulodynia* is severe vulvar pain during sexual intercourse. In extreme cases, sexual intercourse is virtually impossible. However, the pain also can occur during other forms of penetration, such as the insertion of a finger, vibrator, tampon, or speculum. Furthermore, the pain can occur during nonsexual activities, such as cycling or horse riding.

- *Duration*: PVD can be divided into a primary form and a secondary form. In the primary form, the pain has been present since starting intercourse or tampon use, whereas in the secondary form, there has been a period of pain-free intercourse or tampon insertion prior to the onset of symptoms. After intercourse, the pain may last for several hours to several days and mainly occurs during micturition.

There is long-term ongoing debate about whether vaginismus can be differentiated from dyspareunia/PVD categorically, dimensionally, or not at all [6]. In 2013, the diagnosis of genito-pelvic pain/penetration disorder (GPPPD) was introduced in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5), to replace the diagnoses of dyspareunia and vaginismus [7]. GPPPD is defined as:

A. Persistent or recurrent difficulties with one (or more) of the following:
   - Vaginal penetration during intercourse
   - Marked vulvovaginal/pelvic pain during vaginal intercourse/penetration attempts
   - Marked fear/anxiety about vulvovaginal or pelvic pain in anticipation of, during, or as a result of vaginal penetration
   - Marked tensing or tightening of the pelvic floor muscles during attempted vaginal penetration

B. The symptoms in criterion A have persisted for a minimum duration of approximately 6 months.

C. The symptoms in criterion A cause clinically significant distress in the individual.

D. The sexual dysfunction is not better explained by a nonsexual mental disorder or as a consequence of a severe relationship distress (e.g., partner violence) or other significant stressors, and it is not attributable to the effects of a substance/medication or other medical conditions.

There is a lifelong and acquired subtype of GPPPD. Furthermore, based on the degree of distress in criterion A, GPPPD is categorized into mild, moderate, and severe. Up to date, the validity and reliability of the GPPPD diagnosis has not yet been established. Regardless of the new DSM diagnosis, the debate on the classification of dyspareunia and vaginismus still continues [6].

18.4.3 Differential Diagnosis

The diagnosis of PVD is based on exclusion, which is largely established through client history. The most important differential diagnoses are:

- Recurrent vulvovaginal candidosis:
  - In a proportion of women, PVD simply starts with recurrent vulvovaginal infections. It is likely that PVD develops because these women continue to have sexual intercourse with the accompanying pain, despite having an infection.

- "Ordinary" dyspareunia:
  - If there is insufficient sexual arousal, then there will be insufficient lubrication. Penetration may become painful and lead to "the anticipation of pain," also in the absence of chronic inflammation. The difference between "ordinary" dyspareunia and PVD is found in the number of times that there is sufficient sexual arousal, without the experience of pain. Moreover, sometimes in women with PVD, penetration may succeed without pain. That's because in women with sufficient arousal (and orgasm), the pain threshold temporarily increases. However, in these cases the pain continues thereafter. (See Chap. 20 for discussion on insufficient sexual arousal.)
- Vaginismus and other overactive pelvic floor dysfunctions:
  - Although vaginismus can be accompanied by pain, its main characteristic is involuntary contraction of the vaginal sphincter, which makes penetration impossible. (See Chap. 17 for discussion of vaginismus.)
- The presence of anogenital dermatoses:
  - Chronic disorders of the female genital skin may interfere with sexual contact, because they cause pain. Examples are lichen sclerosus, Zoon's vulvitis, mucosal lichen planus, etc. Diagnostic uncertainty can be ruled out by vulvoscopy or by taking a biopsy and performing histological examination. (See Chap. 19 for discussion of the sexual consequences of lichen sclerosus.)

18.5 Etiology and Pathogenesis

Before discussing the etiology of PVD, some critical comments must be made from a biopsychosocial perspective about syndrome diagnoses in general. This perspective is summarized under the label "functional complaints."

18.5.1 Functional Complaints

Although this is often forgotten in health care, the two main characteristics of syndromes such as PVD – i.e., pain and fear – are extremely important aids to human survival. In the case of threat or actual danger, high levels of fear and/or pain are "healthy reactions to an unhealthy situation." The same holds true for somatic stress reactions, such as increases in muscle tension, heart rate, blood pressure, etc. With (the threat of) sexual harassment and violence, the vaginal sphincter should contract, and the genital area should become hypersensitive, including an inflammatory reaction, to protect against and inhibit hostile invasion or reduce the negative consequences should this occur. In essence, these are normal psychophysiological reactions. Therefore, the question of pathology does not lie in the phenomenon itself, but in its *appropriateness*, i.e., the match between action and reaction. Problems arise when normal protective functions "overreact": when normal behavior or a psychophysiological state is *too extreme*, *too prolonged*, or *too intense*. This attention to contextual appropriateness is one of the key principles of psychosomatic

obstetrics and gynecology. It is therefore the main reason why symptoms should always be put into a biopsychosocial perspective.

18.5.2 Etiology

Although distinct and interesting hypotheses have been put forward, the pathogenesis of PVD still remains largely unknown. In general, the etiology is considered to be multifactorial. PVD is generally considered to be a *chronic pain syndrome*, because clusters of characteristics, especially symptoms and risk factors, often coincide, such as:

- The typical vicious circle of chronic pain and psychosomatic complaints
- Comorbidity with other pain syndromes, such as fibromyalgia and the irritable bowel syndrome
- Comorbidity with pelvic floor dysfunction

Other observations have also been made that give PVD a more chronic pain disease-like character, such as:

- The presence of a peripheral and central neuropathic process [8, 9]
- Accompanying pathology in terms of increases in mast cells and nerve tissue in the vestibulum [10, 11]
- Histology of the vestibule showed markedly increased mast cells as well as pain nociceptors [12], such that touch was perceived as painful
- Lower pain thresholds in nongenital parts of the body [13], which supports the notion that PVD is characterized by central pain center dysfunction

An explanation for the "hybrid" character of PVD – i.e., disease combined with syndrome – might be found in its chronological development. What often starts as an ordinary acute disease (vaginal infection) or normal reaction to an averse stimulus (having intercourse without sexual arousal) gradually turns into a chronic pain syndrome. It is believed that psychological and social variables play an important role in why this occurs and why no normal adaptation takes place.

18.5.3 Psychological Factors

Many studies have been performed on the relationship between PVD and psychological characteristics of the patient and/or couple. Dimensions have been distinguished such as intrapersonal variables, interpersonal variables, social variables, and variables related with sexual behavior. Some of the studies focused on the psychosomatic perspective, i.e., the psychological makeup as the cause of the complaints or the contributing factor. Other studies concentrated on the somatopsychological perspective, i.e., the effects of PVD on the psychosocial functioning of the patient and/or couple. Although conclusions were often drawn about

cause–effect, most epidemiological studies were performed without any clear starting hypotheses, which makes causal inferences highly speculative.

18.5.3.1 Intrapersonal Variables

Psychological morbidity is significantly higher in PVD-affected women than in asymptomatic women. Many studies reported high levels of anxiety, depressive symptoms, somatization disorders, and hypochondrial symptoms. However, no convincing evidence is found of a psychological cause for the vestibular pain [14]. Epidemiological studies reported higher prevalences of comorbid anxiety disorders and depression in women with vulvodynia compared to healthy control groups [15]. With regard to obsessive–compulsive behavior, inconsistent results were found [16]. Additionally, PVD-affected women are more prone to specific personality traits, such as shyness, perfectionism, harm avoidance, increased tendency to catastrophize, hysterical personality, reward dependency, low self-esteem, and fear of negative evaluation than asymptomatic women [1, 5].

18.5.3.2 Interpersonal Variables

Women with PVD were found to have more negative feelings toward sexual-partner contact, but their marital satisfaction with the nonsexual aspects of the relationship was similar to that in normative groups. Nevertheless higher pain ratings in women with PVD were associated with lower marital adjustment and higher levels of harm avoidance and reward dependence [1].

18.5.3.3 Sexual Behavior

Women with PVD demonstrated impaired sexual functioning, namely, lower levels of sexual desire, arousal, frequency of intercourse, lower sexual pleasure, and erotophobia [15, 17]. They experienced more difficulties with sexual arousal and lubrication during partnered sexual activities than during masturbation [1]. Childhood physical abuse and sexual abuse were found to be potential risk factors for the development of PVD [17].

18.5.4 Vicious Circle

Pain is a complex sensation that encompasses sensory, affective, and cognitive features. Similar to many other chronic (pain) syndromes, PVD starts like or as an ordinary disease, e.g., a vaginal infection, cystitis, etc. Whereas normally recovery occurs, symptoms fade away or are treated successfully; in chronic syndromes, a vicious circle develops. In the case of pain during sexual intercourse, this circle may have several different components, such as:

- PAIN → Fear → PAIN
- PAIN → No genital sexual response (blood flow, transudation, etc.) → PAIN
- PAIN → Pelvic floor muscle hypertonia → PAIN
- PAIN → Inflammation → PAIN
- PAIN → Elevated nerve density → PAIN

Once the circle has developed, in no time these strings of components become a toxic cocktail of stress reactions: PAIN → stress reactions → PAIN.

In order to complete the circle, there must be a stimulus that provokes the pain response. This means that the consequences of PVD must be intrusive. Fortunately, the psychosocial impact of chronic pain has been well documented, and the burden is indeed devastating. Feelings of hopelessness, depression, and anxiety are common [18]. Chronic pain can be debilitating and demoralizing. Pain associated with sexuality can decrease self-esteem and disrupt relationships [19]. Coital pain is not the patient's only problem. Some women who considered themselves cured of coital pain reported fear of intercourse due to the long-term experience of painful intercourse [20]. This information about the consequences of PVD enables us, while making use of the biomedical perspective, to combine medical knowledge with insights into psychological finality. This combination model not only makes PVD easy to grasp for health-care providers but also for patients and partners. A key factor in this model is the role of the *vicious circles*. As mentioned previously, in chronic pain syndromes, none of the so-called risk factors, or the general stress reaction patterns, are pathological in themselves. On the contrary, each phenomenon is a sound reaction to danger or threat. The question is why normal adaptation does not take place, when the context makes it clear to the woman that she is not being "threatened."

Relevant questions in the light of PVD are as follows: When is "attempting to have intercourse" part of normal adaptive behavior, and when is it a neurotic habit and thereby a serious sign of threat? What does it mean when some women try to break through the pain while having intercourse? And if you want to break through the pain as a form of desensitization, why choose the most difficult and complex way of doing so, by having intercourse?

It is therefore important to obtain a clear view of the interaction between all those involved, preferably when faced with problems that require collaboration. In other cases, the present may be safe, but memories of the past are so intrusive that they interfere with current functional behavior. Especially sexual encounters, with their focus on emotional openness and closeness, are vulnerable to this type of interference from the past, as, for example, research into cancer survivorship has shown [21]. So even when there is no clear-cut post-traumatic stress disorder, sensitization may take the place of adaptation. In order to grasp this sort of understandable but still problematic coping behavior, thorough exploration of the personal (sexual) history of the patient and/or the couple is needed.

Case History: Continued

Bianca Olive is devastated. Until now, nothing has alleviated her complaints. Instead, they have worsened. She fears that her relationship will end due to the painful sexual encounters. She admits that, once in a while, she let her husband penetrate, while she tries to hide her pain from him. Recently, it was too painful and they stopped all sexual activity. Even intimacy is difficult for her now, afraid as she is, that intimacy "turns into sexual intercourse."

18.6 Specific Diagnostic Aspects

18.6.1 Aims and Strategies

Owing to the lack of any clear etiology, the vicious circle of pain, and the prospect that the complaints are functional, it is not surprising that PVD is difficult to treat or, in other words, PVD is highly therapy resistant. This has consequences on the treatment aims and strategies that can be used to fulfill the aims:

- *Aims*: it is wise to not strive for immediate success in terms of pleasurable sexual intercourse, but to focus instead on breaking the vicious circle of pain.
- *Strategies*: given the multitude and heterogeneous character of the intermediating variables (the elements in the vicious circle), many options are available. This plurality enables us to tailor the treatment to the individual characteristics and needs of the patient and/or couple (Table 18.1). In order to be able to do so, a number of preconditions must be met, such as the presence of a multidisciplinary team.

18.6.2 Psychosocial Aspects/Biopsychosocial Approach

Research into the treatment of PVD still pays too little attention to the biopsychosocial model. From this perspective, all the phases of the treatment process are interdependent. It is only for didactical reasons that we discuss the phases separately, according to the following standard categorization [22]:

- Problem and patient orientation
- Diagnostic phase
- Indication and differential diagnosis
- Informed consent and shared decision-making

It is important to note that these stages are interdependent – like buttoning up a white lab coat: If you start at the wrong buttonhole or miss one, the coat will not fit properly!

After the aforementioned phases, the therapeutic phase and the follow-up and evaluation phase will follow (described later in the section on *Specific Diagnostic Aspects*).

18.6.2.1 Problem and Patient Orientation

The acquaintance phase is especially important when dealing with patients who are coping with chronic illness. These patients are often at the end of their tether, because they have been looking for treatment for many years. In women with PVD, a quest of 5 years or more is no exception [19], and the mean number of physicians consulted prior to diagnosis is three [4]. PVD patients are likely to be feeling ashamed about having to reveal their very intimate problems to yet another

Table 18.1 Multidimensional and multidisciplinary approach of PVD

Careful history taking (in a safe atmosphere/setting)
An educative gyneco-sexological examination that the patient is able to follow with a hand mirror (and when applicable with the partner present)
Providing information about provoked vestibulodynia (PVD), its natural course, treatment options, and a treatment plan
Involvement of the patient and partner in the decision process about potential treatment options
Prescription of an inert cream (simple eye ointment or petroleum jelly 20 % in cetomacrogol) to protect the vestibular area and to urge the woman to touch the painful area (mucosal desensitization) (local corticosteroids are contraindicated)
Vaginal EMG biofeedback, pelvic floor physiotherapy *(by a registered pelvic floor physical therapist)* with the aim of alleviating pelvic floor hypertonia
Homework assignments that comprised self-exploration of the genitals and biofeedback by means of digital control, or with the aid of vaginal dilators and lubricants, together with a temporary coitus prohibition
A hygienic protocol, e.g., no vaginal douching, no press-on panty liners
Normalizing, reframing, and encouraging sexual activity without penetration to avoid development of feelings of guilt
If appropriate, individual sexological counseling that aims to improve the woman's self-image, body image, and autonomy, with the aid of a registered *psychologist/sexologist*
If appropriate, sexological partner-relation therapy that primarily aims to improve physical and noncoital sexual contact, with the aid of a *registered psychologist/sexologist*
If appropriate, nerve stimulation by means of transcutaneous electrical nerve stimulation
If appropriate in some cases of persistent PVD, surgical intervention (vestibulectomy) as an additional form of treatment to facilitate breaking the vicious circle of irritation, pelvic floor muscle hypertonia, and sexual maladaptive behavior (end-of-line treatment)

health-care provider. During history taking, it is important to decrease the woman's anxiety level by selecting a low-pressure setting, somewhere in private, with the woman fully clothed and not sitting on an examination table [19]. An important first step toward recovery is for patients to understand and accept their diagnosis. Providing clear and concise information is essential (psychoeducation). Over the years, women with PVD are likely to have received misinformation or ambivalent information from the different health-care providers [23].

PVD has a highly negative impact on quality of life. Patients are often young women at the start of their sexual life, when the couples' problem-solving skills (as a duo) still need time to develop. A negative male attitude toward PVD was found to be a significant predictor of decreased dyadic adjustment and sexual satisfaction, as well as increased psychological distress, although it failed to predict sexual functioning. These findings indicate that partners should be involved in the treatment of PVD [24]. It is likely that facilitative male partner responses will improve sexual functioning, whereas solicitous and negative responses may be detrimental. Psychological interventions that target partner responses can help to improve the sexual functioning of the affected couple [25, 26]. However, it is suggested that PVD is not necessarily associated with general relationship maladjustment of the woman and her partner [27].

Especially the lack of a clear or acceptable cause is experienced as an extra burden. All in all, this supplementary stress makes the patient (hyper)sensitive to the

course of events during the first encounter. A reassuring but sensitive approach combined with ample communication about the current emotions and feelings often helps a lot. Whereas in acute situations, swift medical action can be a blessing; in these cases, it is essential to take your time. *Festina lente* (make haste slowly)!

18.6.2.2 Diagnostic Phase

As there are no clear causal pathways in the case of syndrome diagnoses, the diagnosis of PVD is mostly determined by exclusion. Even then PVD is difficult to recognize, because if the women is sufficiently sexually aroused, intercourse can still be pleasurable, even in the presence of PVD. In some cases, the pain manifests itself *after* sexual intercourse.

Case History: Continued

After she has given her consent, Bianca Olive is gynecologically examined, while she watches herself with a hand mirror. Her vulvar skin is reddish. There is no visible vaginal discharge. Upon request, it is difficult for her to relax her pelvic floor muscles. There are two bright red spots at 5 and 7 o'clock visible in the vulvar introitus, which are extremely painful when touching them with a wet cotton swab. Careful examination, after explicit permission of Bianca, with one gloved, lubricated finger, reveals firmly tightened levator muscles, eliciting the pain she recognizes when starting penetration.

18.6.2.3 Indication and Differential Diagnosis

Because there is no clear etiology and there are so many targets (i.e., risk factors to deal with), in the eyes of beginners or outsiders, the indication process and the differential diagnosis appear to be "trial and error driven." However, in the hands of an experienced clinician, the complaints and behavior of the patient become usually quite easily meaningful, and thereby a diagnostic and therapeutic pathway emerges for all involved. However, between sharing a rationale and complying with a treatment regime often lies a great distance – at least for the patient. This makes patient education more than a moral but a legal obligation. In case of PVD, it is a sine qua non.

18.6.2.4 Informed Consent and Shared Decision-Making

In many countries, informed consent is already a legal condition to start treatment, while shared decision-making is rapidly gaining ground as a moral condition. However, research has shown that in practice, neither of these conditions are adequately met [28]. This can even be a problem when treating illness with a clear biomedical cause. We know that adherence to lifestyle changes is extremely low in most chronic illnesses such as rheumatic arthritis, multiple sclerosis, etc., but in the case of chronic sexual problems, it is almost nil. We therefore pay ample attention to both conditions as follows:

18.6.3 Informed Consent

In medical practice, understanding why things happen does not guarantee therapeutic success. Moreover, even when success is possible, the way to achieve it is not always the solution the patient is seeking. In some situations, as we already pointed out when discussing the etiology of PVD, a reaction or symptom can have a protective function. In such cases, it is very difficult to eradicate, because the problem is also a solution. It is precisely this functional characteristic that raises the (ethical) question of whether health professionals should try to resolve the problem. Especially when there is no clear biomedical pathology, it is important to discuss and deliberate explicitly with the patient about the aims of the treatment process and the potential positive and negative consequences. In the case of PVD, the following possible aims could be discussed:

- Promoting quality of life in general
- Promoting quality of sexual life in particular, with or without intercourse
- Reducing morbidity and complaints
- Attempting to make intercourse non-harmful and as pleasurable as possible

Sometimes a patient's grasping of the situation, or gaining a clearer understanding, resolves the problem or the request for help. If the request for help persists, the elements that make up the vicious circle need to be clearly explained, and special attention must be paid to the need for full symptom prevention.

18.6.4 Shared Decision-Making

It should be clear to all those involved that the only way to resolve this sexual variant of the old "chicken and the egg dilemma" is to establish a different means of "sexual self-management." The object of this self-management should not be the act of sexual intercourse, but full symptom prevention. The term "self-management" in itself stresses that this can only be achieved with the active involvement and participation of the patient and/or couple. Just like many other lifestyle issues, such as eating, drinking, physical activity, etc., sexual habits are difficult to change. Besides informed consent and sexual literacy, shared decision-making is a sine qua non for the treatment of PVD. Therefore, preferably during the whole process, but at least when you have established the diagnosis of PVD, explain to the patient what you are going to do and repeatedly ask for her consent. Keep in mind that in psychological terms, these patients are at risk anyway. They may also have been "mistreated" medically and been traumatized for years. If a gynecological examination is needed, do it in an educational way, and give maximum control to the patient. Ask her whether she wants her partner, if present, to be involved; ask her if she would like to use a hand mirror to see what is happening. Listen to her answers carefully, and look closely at how the patient and her partner interact as a couple. Having to make changes to their sexual lifestyle will put extra stress on the relationship. Therefore,

careful observation might provide important information about the need to reconsider some treatment aims or procedures. In the end, it should be clear exactly which aims have been set, for which reasons and which procedures are needed. The patient should not only be informed but should also be the one who has made the decision to start treatment. This means that the patient and/or couple should be sexually literate in general, but particularly about the most important therapeutic options regarding PVD.

18.7 Specific Therapeutic Aspects

18.7.1 Therapeutic Phase

In terms of the actual treatment, it is of eminent importance to keep in mind that the primary aim is not the reuptake of intercourse, but full symptom prevention: breaking the vicious circle! As stated previously (see the section on *Aims and Strategies*), several different, but not mutually exclusive, strategies can be used.

18.7.2 Follow-Up and Evaluation Phase

The importance of follow-up and evaluation lies in the opportunity to make adjustments to the current case and to learn from it, in order to improve the approach to future cases (reflection). Given the complex nature of PVD, a number of possible pitfalls can be distinguished and thereby points for evaluative reflection.

18.7.2.1 Examples of Patient-Related Topics for Reflection

- Some patients are unwilling to adopt a psychosocial stance and insist on receiving somatic treatment. If this occurs, it is important to realize that it is *unbearable* for many patients that their PVD complaints are rooted in more fundamental psychological or interpersonal (sexual) problems. This means that our good news, i.e., that we have solved the puzzle, is perceived by the patient as bad news. When discussing future action, the rules of a bad news consultation should be followed. Do not try persuasion, but ask questions about the patient's emotions and what the message means to her.
- Make a decision in the multidisciplinary meeting regarding who will be the one to talk with the patient.
- Sometimes young patients are accompanied by one of their parents, or a dominant partner, whose ideas and behavior interfere with the treatment process. It is important to address these types of disturbance first, before actual treatment can start. An elegant strategy is to relate PVD to the theme of autonomy versus dependency.
- Some patients feel very embarrassed about discussing intimate details with a health-care professional. Having sexual problems and being forced to talk about them is a way of expressing who they really are as a person. Unmasking

themselves – and often their partner as well – makes people extremely vulnerable. It is easy to implicitly presume that the partner is the ideal co-therapist or that he will at least provide social support for the patient. However, for him, treatment also means being exposed, and moreover, it is the start of an intimate triangular relationship. Owing to the fact that health-care professionals in sexology often deliberately act as "the ideal partner," their therapeutic behavior alone may induce intense feelings of jealousy, anger, etc. Beware of this transference, also on the part of the partner, and if it happens, eradicate the disturbances first before starting actual treatment.

18.8 Critical Reflection and Conclusive Remarks

When dealing with syndrome diagnoses such as PVD, it is always the match between the patient and the professional that in the end determines failure or success. This does not mean that it is unimportant to follow a clear road from hello to goodbye. On the contrary, but as a health professional, one has to be able to discover or, better, to co-create with the patient the pathway that serves her best. Moreover, many patients look back at the treatment process as "a difficult yet rewarding process of personal and relational growth."

Case History: Continued

After getting dressed and at the desk, Bianca Olive learns about the vicious cycle she has entered. She acknowledges that it has been a long time since she had experienced sexual excitement and lubrication – afraid of the coming pain. She understands that she needs to quit the attempts for penetration until she has more control of her pelvic floor musculature. She will bring her husband for the follow-up visit, in order to talk about the mechanism of the complaints. In the meantime she will start pelvic floor physical therapy and apply emollients to smoothen her irritated skin. She is willing to find out alternative sexual stimulation. Some leaflets and websites are provided to her, so she can orientate herself on which aspects might stimulate her in an erotic sense if desired. During the standard telephone follow-up evaluation 6 months later, Bianca says that she now realizes how sexually ignorant she and her partner were at the beginning of the therapy. Together they are now exploring a whole new dimension in their relationship that goes beyond having intercourse.

Tips and Tricks

1. During the problem and patient orientation phase:
   - Realize that when dealing with syndrome diagnoses such as PVD, a patient–physician relationship of excellent quality is of utmost importance. Therefore, keep in mind that "There is no second chance to make a first impression" and "The medium is the message."

2. During the diagnostic phase:
   - Combine empathy with moral neutrality; try to put apparently problematic phenomena, such as pain and fear, into a functional perspective without "blaming the victim."
   - In the case of a vicious circle, shift the focus from the normal elimination of causes to breaking the circle.
   - Before you share your ideas about the ultimate diagnosis and treatment options with the patient, inform the patient that you will discuss and check them within the multidisciplinary team. Listen carefully to all the arguments, because they will probably reoccur in your discussions with the patient.
   - Be aware of the possible influences of sexual traumata. Ask proactively about previous sexual traumata!
3. When talking things over with the patient:
   - Be careful using terms with "psy" in them (psychic, psychogenic, psychosomatic, or even psychologist), because they mean bad news to most patients who are suffering from a syndrome diagnosis.
   - Do not impose your solutions; offer them as neutral options.
4. During the therapeutic phase:
   - PVD is a multifactorial disorder that should be treated in a multidimensional way in accordance with etiological factors, the risk profile, and context.
   - If you try to follow a stepped care model, beware: the more you become involved in the treatment process, the greater the intimacy and the stronger the bonding. Do not wait too long before referring the patient on.
   - When referring, make it clear that you are not doing it due to the complexity or magnitude of the complaints but due to the limitations of your professional repertoire.
5. During the follow-up and evaluation phase:
   - Even with timely referral, intimacy will have developed during the treatment process; therefore, attention should be paid to the way the patient, the couple, and/or the professional "return to normal."
   - When looking back on successful treatment, parallel lines can be drawn between effective coping with PVD and other often coexisting problems, such as fibromyalgia, etc.

Test Your Knowledge and Comprehension

1. The lifetime prevalence of PVD is the same regardless of ethnicity.
   (a) True
   (b) False
2. In women, with sufficient arousal (and orgasm), the pain threshold temporarily increases.
   (a) True
   (b) False
3. Evidence is found of a primary psychological cause for PVD.
   (a) True
   (b) False

4. In women with PVD, the marital satisfaction with the nonsexual aspects of the relationship is similar to that in normative groups.
   (a) True
   (b) False
5. Childhood sexual abuse is found to be a potential risk factor for the development of PVD.
   (a) True
   (b) False
6. Which of the following statements referring to allodynia in women with PVD is *not* true? The allodynia areas:
   (a) Chiefly occur in the vulvar vestibule
   (b) Are limited to specific areas
   (c) Always coincide with local redness
   (d) Are symmetrical in the majority of women
7. Choose the option that is contraindicated in the treatment of PVD.
   (a) Local corticosteroids
   (b) Penetration prohibition
   (c) Pelvic floor physiotherapy
   (d) Multidisciplinary approach
8. The primary aim of the treatment of PVD is:
   (a) The reuptake of intercourse
   (b) Full symptom prevention
   (c) Recovery of sexual response
   (d) Removal of negative feelings toward sexual-partner contact
9. What is the most essential condition for the treatment of PVD?
   (a) Sharing a rationale
   (b) Shared decision-making
   (c) Complying to treatment
   (d) Patient education
10. What is the mean number of physicians consulted prior to the PVD diagnosis?
    (a) 1
    (b) 2
    (c) 3
    (d) 4

Answers

1. True
2. True
3. False
4. True
5. True
6. (c)
7. (a)
8. (b)
9. (d)
10. (c)

Acknowledgments We would like to thank Prof. Dr. W.C.M. Weijmar Schultz, emeritus professor of Psychosomatic Obstetrics and Gynecology, for his comments on this chapter.

References

1. Van Lankveld JJ, Granot M, Weijmar Schultz WC, Binik YM, Wesselmann U, Pukall CF, Bohm-Starke N, Achtrari C. Women's sexual pain disorders. J Sex Med. 2010;7:615–31.
2. Meana M, Binik YM, Khalifé S, Cohen D. Dyspareunia: sexual dysfunction or pain syndrome? J Nerv Ment Dis. 1997;185:561–9.
3. Bohm-Starke N. Medical and physical predictors of localized provoked vulvodynia. Acta Obstet Gynecol Scand. 2010;89:1504–10.
4. Harlow BL, Stewart EG. A population-based assessment of chronic unexplained vulvar pain: have we underestimated the prevalence of vulvodynia? J Am Med Women's Assoc. 2003;58:82–8.
5. Weijmar Schultz W, Basson R, Binik Y, Eschenbach D, Wesselmann U, Van Lankveld J. Women's sexual pain and its management. J Sex Med. 2005;2:301–16.
6. Reissing ED, Borg C, Spoelstra SK, Ter Kuile MM, Both S, de Jong PJ, van Lankveld JJ, Melles RJ, Weijenborg PT, Weijmar Schultz WC. "Throwing the baby out with the bathwater": the demise of vaginismus in favor of genito-pelvic pain/penetration disorder. Arch Sex Behav. 2014;43:1209–13.
7. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. Washington, DC: APA; 2013.
8. Pukall CF, Strigo IA, Binik YM, Amsel R, Khalifé S, Bushnell MC. Neural correlates of painful genital touch in women with vulvar vestibulitis syndrome. Pain. 2005;115:118–27.
9. Schweinhardt P, Kuchinad A, Pukall CF, Bushnell MC. Increased gray matter density in young women with chronic vulvar pain. Pain. 2008;140:411–9.
10. Bornstein J, Goldschmid N, Sabo E. Hyperinnervation and mast cell activation may be used as histopathologic diagnostic criteria for vulvar vestibulitis. Gynecol Obstet Invest. 2004;58:171–8.
11. Bohm-Starke N, Hilliges M, Falconer C, Rylander E. Increased intraepithelial innervation in women with vulvar vestibulitis syndrome. Gynecol Obstet Invest. 1998;46:256–60.
12. Chadha S, Gianotten WL, Drogendijk AC, Weijmar Schultz WC, Blindeman LA, van der Meijden WI. Histopathologic features of vulvar vestibulitis. Int J Gynecol Pathol. 1998;17:7–11.
13. Pukall CF, Baron M, Amsel R, Khalifé S, Binik YM. Tender point examination in women with vulvar vestibulitis syndrome. Clin J Pain. 2006;22:601–9.
14. Nunns D, Mandal D, Byrne M, McLelland J, Rani R, Cullimore J, Bansal D, Brackenbury F, Kirtschig G, Wier M, British Society for the Study of Vulval Disease (BSSVD) Guideline Group. Guidelines for the management of vulvodynia. Br J Dermatol. 2010;162:1180–5.
15. Desrochers G, Bergeron S, Khalifé S, Dupuis MJ, Jodoin M. Fear avoidance and self-efficacy in relation to pain and sexual impairment in women with provoked vestibulodynia. Clin J Pain. 2009;25:520–7.
16. Van Lankveld JJ, Weijenborg PT, Ter Kuile MM. Psychologic profiles of and sexual function in women with vulvar vestibulitis and their partners. Obstet Gynecol. 1996;88:65–70.
17. Durocher's G, Bergeron S, Landry T, Jodoin M. Do psychosexual factors play a role in the etiology of provoked vestibulodynia? A critical review. J Sex Marital Ther. 2008;34:198–226.
18. Goldstein AT, Burrows L. Vulvodynia. J Sex Med. 2008;5:5–14.
19. Stone-Godena T. Vulvar pain syndromes: vestibulodynia. J Midwifery Womens Health. 2006;51:502–9.
20. Bohm-Starke N, Rylander E. Surgery for localized, provoked vestibulodynia: a long-term follow-up study. J Reprod Med. 2008;53:83–9.
21. Weijmar Schultz WCM, van de Wiel HBM. Sexual functioning after gynaecological cancer treatment. Groningen: Thesis University of Groningen; 1991.

22. Grundmeijer HG, Reenders K, Rutten GE. The medical process from problem to solution. Maarssen: Elsevier; 1999.
23. Brotto LA, Sadownik L, Thomson S. Impact of educational seminars on women with provoked vestibulodynia. J Obstet Gynaecol Can. 2010;32:132–8.
24. Jodoin M, Bergeron S, Khalifé S, Dupuis MJ, Desrochers G, Leclerc B. Male partners of women with provoked vestibulodynia: attributions for pain and their implications for dyadic adjustment, sexual satisfaction, and psychological distress. J Sex Med. 2008;5:2862–70.
25. Rosen NO, Bergeron S, Sadikaj G, Glowacka M, Delisle I, Baxter ML. Impact of male partner responses on sexual function in women with vulvodynia and their partners: a dyadic daily experience study. Health Psychol. 2014;33:823–31.
26. Rosen NO, Bergeron S, Sadikaj G, Glowacka M, Baxter ML, Delisle I. Relationship satisfaction moderates the associations between male partner responses and depression in women with vulvodynia: a dyadic daily experience study. Pain. 2014;155:1374–83.
27. Smith KB, Pukall CF. A systematic review of relationship adjustment and sexual satisfaction among women with provoked vestibulodynia. J Sex Res. 2011;48:166–91.
28. Leclercq WKG, Keulers BJ, Houterman S, Veerman M, Legemaate J, Scheltinga MR. A survey of the current practice of the informed consent process in general surgery in the Netherlands Patient. Saf Surg. 2013;7:4.

A Woman with Changing Vulvar Anatomy: Sexuality in Women with Lichen Sclerosus

19

Moniek M. ter Kuile and Katja N. Gaarenstroom

19.1 Introduction and Aims

Lichen sclerosus (LS) is a chronic inflammatory skin disease and mainly occurs in the anogenital area. Occasionally patients also have extragenital skin abnormalities. It primarily occurs in postmenopausal women. Itching is the main symptom. However, a burning sensation, dyspareunia, and dysuria are frequently reported symptoms.

Postinflammatory scarring may cause fusion of the labia minora, narrowing the vaginal introitus and burying the clitoris. This chapter mainly focuses on the sexual aspects in women that suffer from lichen sclerosus and how the healthcare provider can adequately diagnose and treat this condition.

19.2 Definition in Lay Terms

Lichen sclerosus is a chronic skin disease of the vulvar and perineal region characterized by whiteness of the skin, slowly disappearing of the inner labia, and tightening of the vaginal opening. Itching is the main symptom, but symptoms such as a burning sensation and pain with sexual intercourse and with micturition are also reported.

19.3 Didactic Goals

After reading this chapter, you will be familiar with:

M.M. ter Kuile, PhD (✉) • K.N. Gaarenstroom, MD, PhD
Department of Gynecology, Leiden University Medical Centre, Leiden, The Netherlands
e-mail: M.m.ter_Kuile@lumc.nl; K.n.gaarenstroom@lumc.nl

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_19

- The definition of lichen sclerosus (LS)
- The clinical features of LS
- Effects and impact of LS for genital and sexual functioning
- The results of treatment modalities in women with LS
- Lifestyle recommendations for women with LS

Case History

Anne Salmon, 55 years old, married to John, has regularly suffered from pain during intercourse for the past 6 years. The complaints started following a period of vulvovaginal yeast infections about 6 years ago. Since then she suffers from vulvovaginal itch with regular intervals, which she thinks is related to chronic yeast infections. These infections were self-treated "successfully" with over-the-counter topical medications. She tells that the pain during intercourse also seems to increase during a period of yeast infections. However, these infections were not confirmed by cultures.

Anne consulted her general practitioner, a gynecologist, urologist, and dermatologist. Two years ago, the dermatologist told her that she had lichen sclerosus (LS); the diagnosis was confirmed by biopsy. She got a "strong" corticosteroid ointment for a period of 2 months and a low dose for the rest of the time. After using the strong corticosteroids, the itching was much less for a period. However, she never used the low doses of the corticosteroid cream because she was afraid it would make her skin thinner. She asked for a second opinion because of the regular pain during intercourse and regular periods of itching and burning sensations.

19.4 Facts and Figures: Definition, Classification, and Prevalence

19.4.1 What Is Known About the Clinical Features of Lichen Sclerosus in Women?

Lichen sclerosus (LS) is a chronic inflammatory condition of the skin that causes distress symptoms and discomfort. LS can occur at any age, but it has two main peaks in incidence: The first occurs before puberty in childhood; the second peak is after menopause. The observation that lichen sclerosus is more common in low-estrogen physiologic states (prepuberty and postmenopause) has led to the speculation that hormonal influences may play a role in the etiology of lichen sclerosus. However, until now there are no indications that estrogen or progesterone affects the disease process of LS [1, 2]. Especially in children, the signs and symptoms of LS like anogenital itch are sometimes falsely associated with sexual abuse [3].

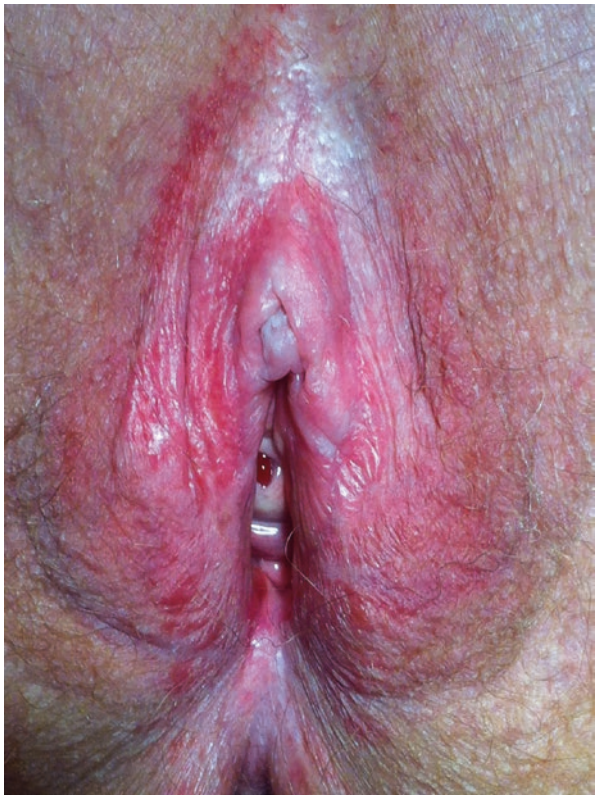


Fig. 19.1 The vulva with longer existing lichen sclerosus. The labia minora have almost completely disappeared. Hyperkeratotic area of the clitoris. Narrowing of the introitus. Excoriations on the vulva and red skin surrounding the introitus, as a consequence of scratching, also signs of lichenification (lichen simplex chronicus) as a result of scratching. Sometimes a superimposed yeast infection may be present, also presenting as red areas and symptoms of scratching

Prevalence rates are difficult to establish, as the condition is asymptomatic and underreported for a large group. In general gynecological practice, the rate of histologically proven LS varied between 1.7 and 7.1 % [4, 5]. More than one-third of all cases (39 %) were asymptomatic [4]. LS may affect any site, but it mainly occurs in the anogenital area (the genital area and around the anus), where it causes itching and pain. Scarring leads to the destruction of the anogenital structures, such as fusion of the vulvar lips (labia), narrowing of the vaginal opening, and burying of the clitoral glans (Figs. 19.1 and 19.2).

19.4.2 What Is Known About the Course of Lichen Sclerosus in Women?

LS is a chronic condition and cure cannot be expected [6]. With medical treatment (see later in this chapter), the symptoms of the condition can be reduced and handled [1, 7–13].

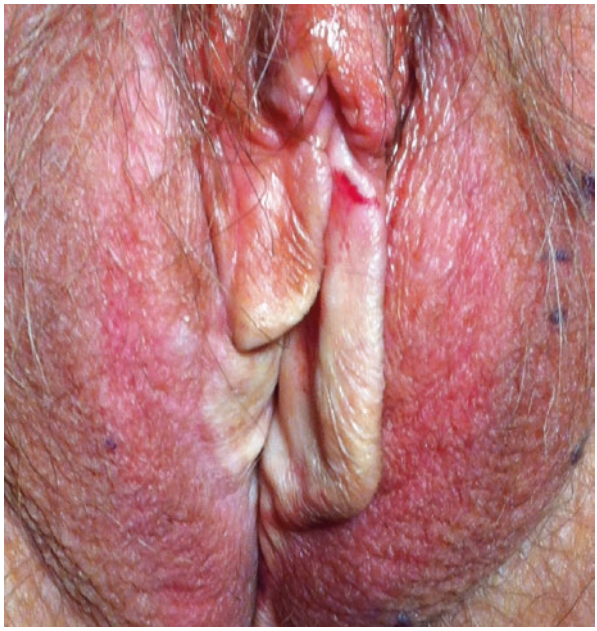


Fig. 19.2 Lichen sclerosus of the vulva. The labia minora have partly disappeared and have a white atrophic aspect. A small hemorrhage or fissure on the labium minor is on the left side. The skin of the vulva is red, with signs of lichenification, which may be a result of scratching or superponed yeast infection

19.5 Etiology and Pathogenesis

19.5.1 What Is Known About the Etiology/Pathogenesis of Lichen Sclerosus?

The etiology of LS is unknown, but there is a strong association with autoimmune diseases. Thyroid disease, alopecia areata, vitiligo, and pernicious anemia are the most commonly seen. Genetic factors are implicated, and cases of familial lichen sclerosus have been reported [14]. An infective etiology has been postulated, but there are no clear data to show that lichen sclerosus is related to an infectious disease [15]. Women with genital LS can develop squamous cell carcinoma (SCC) of the vulva, although the risk seems to be very small (5 %) [16].

19.5.2 What Are the Effects and Impact of Lichen Sclerosus on Quality of Life and Sexuality in Women?

LS can have a huge impact on a woman's quality of life [17–19]: for example, some have persistent itching and pain (despite medication) and in some women LS interferes with function (particularly sexual functioning) also despite successful control of the itching. Many affected women feel embarrassed and do not talk about these problems. We will discuss the itching and pain complaint in more detail.

19.5.2.1 Itch and Scratching

The prominence of "itching" as a symptom of LS quite often leads to patients being treated incorrectly for a yeast infection. In those women with itch, this is often worse at night and may be sufficiently severe to disturb sleep. Some women with vulvar LS have histologic evidence of epidermal thickening at the time of diagnosis. The thickening is believed to be related to superimposed lichen simplex chronicus (LSC). LSC is the lichenification that occurs as a result of scratching. Affected women report that "itching is much more distressing than the experience of pain."

19.5.2.2 Pain

In those with *pain during intercourse*, the pain can be a consequence of (1) the erosions and fissures but can also be a direct consequence of (2) anatomical changes in the vulvar area, i.e., narrowing of the introitus and fusion of the labia minora, or (3) as a consequence of fear of pain. In the last case, the fear of pain during intercourse may result in decreased sexual arousal during sexual activity and thus in vaginal dryness and/or increased pelvic floor muscle tone (as a protective reaction to anticipated or actual pain). The combination of vaginal dryness and increased pelvic floor muscle tone cause friction between the penis and vulvar skin, which may result in pain and even tissue damage. Skin damage itself may result in pain or may further increase already existing pain. In some patients with LS, a provoked vestibulodynia (PVD) also is seen (see Chap. 18). Often it is not one factor that causes the pain, but a combination of the different factors as discussed earlier.

19.6 Specific Diagnostic Aspects

19.6.1 History Taking

The most common location of LS is the anogenital region. The clinical picture of LS is variable: complaint-free periods alternate with exacerbations. The course of the disease is chronic. Vulvar and/or perineal itching is the main symptom, but the absence of itching does not exclude LS. Furthermore, a burning sensation, dyspareunia, and dysuria are frequently reported symptoms. So history taking also includes specific questions related to sexual function (Table 19.1) [7].

Case History: Continued

Anne Salmon reports to have irregular pain during intercourse (half of the time). The pain is located at the entrance of the vagina and is described as a burning pain. During the periods of dyspareunia, she recognizes that her lubrication was diminished and that she is tensing her pelvic floor muscles in response to the pain. She has no problems with orgasm, except during the periods when penetration was so painful. Despite the pain she suffers

sometimes, she forces herself to have intercourse because she finds it difficult to discuss the problem with her husband. During the periods of what she calls the "chronic yeast infections," she is scratching a lot, mostly during the night. Furthermore, she reports that she is using regular vaginal douches (as she feels so dirty).

Table 19.1 Clinical features of LS and diagnosis

Clinical features
Symptoms
Itch/irritation
Pain (burning)
Dyspareunia
Urinary symptoms
Constipation, can occur if there is perianal involvement
Can be asymptomatic
Physical signs
Patchy pale, white atrophic areas affecting the vulva
Purpura (ecchymosis) is common
Erosions, but blistering is very rare
Fissuring
Hyperkeratosis can occur caused by itching
Changes may be localized or in a "figure of eight" distribution including the perianal area
Loss of architecture may be manifest as loss of the labia minora and/or midline fusion. The clitoral hood may be sealed over the clitoris so that it is buried
Effects of LS
Development of clitoral pseudocyst
Development of squamous cell carcinoma estimated to be 3–5 % (actual risk uncertain but small)
Sexual dysfunction
Dysesthesia
Diagnosis
Characteristic clinical appearance
Histology of vulval biopsy[a]: thinned epidermis with subepidermal hyalinization and deeper inflammatory infiltrate. In early disease histology can be difficult

Used with permission from British Association for Sexual Health and HIV (BASHH). UK National Guideline on the Management of Vulval Conditions. 2014. http://www.bashh.org/documents/2014_vulval_guidelines%20Final.pdf

[a]A biopsy is recommended in the case of (a) diagnostic uncertainty or when there is a need to confirm the clinical diagnosis, (b) there are atypical features or coexistent vulval intraepithelial neoplasia (VIN), and (c) squamous cell carcinoma (SCC) is suspected

19.6.2 Physical Examination

In women, the entire vulva can be affected, but also the perineum (like a figure of eight). On inspection LS is characterized by hypopigmentation, fissures, hyperkeratotic areas, and ecchymoses. Small hemorrhages can occur spontaneously as a

consequence of scratching. When scratching has taken place, excoriations are frequently seen in addition to small hemorrhages. When LS is present on the vulva and the anus, fissures can occur. With long-standing LS, an atrophic (parchment-like) and/or sclerotic picture can predominate. During the course of LS, the labia minora can disappear completely. Also fusion of the labia around the clitoris can lead to a hidden clitoral glans (fusion of the preputium) and narrowing of the vaginal introitus is seen. The vaginal mucosa is *not* involved in LS.

Extragenital lesions, characterized by hypopigmented maculae or papules/plaques that are accompanied by atrophy and or hyperkeratosis, can be found in 15–20 % of cases, particularly on the torso, upper legs, neck, and wrists. In rare cases, LS has been described as occurring on the head. Extragenital lesions are not generally linked with itching. In part, because of the sometimes look-a-like clinical picture, genital LS is considered a disorder in the same spectrum as lichen planus (LP). One important distinction is the involvement of the vaginal epithelium with LP, while, with LS, the vaginal epithelium is not affected. In addition, LP can occur mucosally (orally and vaginally), while LS does not affect the oral mucosa. Furthermore, the main symptom of LP is pain and not itch [20].

Case History: Continued
On inspection, fissures on the vulva and anus, hypopigmentation, atrophy of the labia minora, and some narrowing of the vaginal introitus are seen. Furthermore, some epidermal thickening of the labia majora and small hemorrhages are seen, which could be the consequence of regular scratching.

19.6.3 Diagnosis

The diagnosis of anogenital LS can generally be easily made on the basis of medical history and physical examination if it involves a classic presentation (see earlier section on *Facts and Figures*). A punch biopsy is recommended in the case of (1) diagnostic uncertainty or when there is a need to confirm the clinical diagnosis, (2) suspicion of neoplasia, and (3) inadequate response to cortisone creams.

Case History: Continued
The diagnosis of LS is made on the basis of medical history and physical examination. The hypothesis is that the itching is a symptom of LS and not a symptom of a chronic yeast infection (as the patient believed). The pain during intercourse seems to be related to more than one factor: (1) the fusing of the labia and narrowing of the introitus, (2) lesions related to the scratching, (3) decreased sexual arousal due to (imminent threat of) pain experience, and (4) increased pelvic muscle tension in response to the pain.

19.7 Specific Therapeutic Aspects

19.7.1 Which Treatment Options Are Evidence-Based in Women with Lichen Sclerosus?

There is no known cure for LS; however, part of the symptoms can be treated well. These include the relief of subjective symptoms (itching and pain) [12]. Some clinical signs may be reversed (i.e., the effects of chronic scratching LSC), but any scarring that has occurred will remain [21, 22]. It is possible that treatment may prevent malignant transformation, but there is no evidence for this hypothesis. The most frequent interventions for LS and its consequences on sexual functioning and how to cope with these consequences are briefly described next.

19.7.1.1 Psychoeducation

Psychoeducation starts with good information about LS, in which it is important to recognize and treat the complaints on time. Furthermore, it is important that the physician explains what the consequences are of LS on the genitals and on the sexual relationship and how to cope with these consequences (see below). It might be helpful and supporting to point toward self-help groups or web sites with patient information about LS.

19.7.1.2 Medication

Topical cortisone creams (containing clobetasol propionate class IV corticosteroids and mometasone furoate class III corticosteroids) are effective in the treatment of genital LS [9]. The response to itching is rapid and usually complete. Depending on the severity of the disorder, a particular application regime is prescribed. One example is once a night for 4 weeks (clobetasol propionate 0.05 %), then on alternate nights for 4 weeks, and then twice weekly for a further 4 weeks, before review. If symptoms recur when the frequency of application is reduced, the patient is instructed to use the treatment more often until the symptoms resolve. They then can try to reduce the frequency again [12]. Itching is the most important clinical parameter in this matter. This example is expert-based because there is currently no good scientific evidence available [9]. Almost all patients with LS need ongoing treatment with cortisone creams at different time intervals or sometimes on a regular basis for 1–5 days per week, in order to prevent itching and further scarring. Most patients with ongoing disease seem to require 30–60 g of clobetasol propionate 0.05 % ointment annually [12]. A disadvantage of chronic use of cortisone creams is further thinning (atrophy) of the skin. However, if creams are used intermittently, this seems to pose no problem. Regular checkups are advised depending on the severity of the symptoms, in order to minimize the symptoms and possibly detect vulvar cancer at an early stage [1, 7–13]. Sometimes hydroxyzine (an antihistaminic agent) may be prescribed before sleeping to reduce the itch, especially during the night.

The following therapies are not indicated as a treatment of LS: local testosterone, local progesterone, tretinoin, cryosurgery, and photodynamic therapy or laser vaporization. Surgery should be used exclusively for malignancy and postinflammatory sequelae [12].

19.7.1.3 Care and Lifestyle Recommendations

Along with medication, various lifestyle recommendations are given orally and preferably on paper. It is advisable to use an emollient ointment (several times per day) in the case of LS to prevent dehydration of the skin; dry skin itches faster and scratching can lead to new LS lesions (Koebner phenomenon). Some patients scratch themselves until they are bleeding as a reflex to the itching. Practical lifestyle recommendations to reduce the damage caused by scratching to a minimum include cutting the nails very short. If there is itching, it is important that patients learn to make an incompatible response such as balling one's hands into fists and consciously seeking diversion attention during the most difficult moments and putting gloves on for sleeping. Sometimes it seems valuable to refer a patient to a psychologist to learn to cope with chronic itch.

Furthermore LS makes the anogenital skin vulnerable. For this reason it is wise to avoid external/mechanical irritation (e.g., by using a modified bicycle saddle instead, i.e., silicone saddle with or without a longitudinal hole), clothing that is very tight fitting, soap (or vaginal showers), and wearing cotton breathable (not synthetic) underwear.

19.7.2 What Are Treatment Options for Sexual Complaints in Women with Lichen Sclerosus?

- The labia minora can become fused, as a result of which the introitus narrows, and intercourse can become difficult or impossible.
  - Recommend, if necessary, a different position for intercourse or the possibilities for sex without intercourse. When there is persistent dyspareunia resulting from fissures in the posterior commissure, surgery may be an option in exceptional cases (see below). The use of an emollient ointment around the introitus before penetration may relieve pain or dryness [11].
- The clitoral glans can become hidden because of fusion of the labia minora; this generally does not result in any direct problem with achieving orgasm. Possibly there may be, indirectly because of anxiety and/or pain, less subjective sexual arousal, resulting in possible problems with orgasm.
  - If desired, a vibrator can heighten the clitoral stimulation. When there is insufficient lubrication, a (hypoallergenic) lubricant can be used (water or silicon based) [11].
- The pelvic floor muscles can tense reflexively as a response to (fear of) pain, as a result of which intercourse becomes (even more) difficult or impossible.
  - Discuss the importance of relaxing the vaginal pelvic floor muscles. The patient and partner must be informed about the possibility of coaching by a registered pelvic floor physiotherapist in order to improve the sensation, the coordination, and relaxation of the pelvic floor muscles [11].
- Arousal/lubrication can diminish reflexively as a response to (fear for) pain as a result of which intercourse becomes (even more) difficult or impossible.
  - Discuss the importance of good sexual arousal. When there is insufficient lubrication, a (hypoallergenic) lubricant can be used [11].

- Sexual desire can reduce and in the end a sexual aversion (resistance to sex) can arise. Not only the patient but also the partner can start avoiding intercourse, e.g., from fear of hurting his partner.
  - Patient and partner must be informed about the possibility of coaching by a sexologist to improve their sexual relationship. Generally the sexologist gives information, advice, specific suggestions, and as necessary a more intensive cognitive behavioral therapy-based treatment [11].

19.7.2.1 Surgery

LS can cause the vestibulum to become so narrowed that intercourse is very painful or even impossible. A surgical intervention to the rearmost or the foremost part of the vestibulum may ensure that there is once again more space, so that intercourse becomes possible again in some cases. However, because LS is a chronic inflammatory skin disease, the final result is not predictable and surgery is not commonly recommended. Furthermore, the covering of the clitoris by the fused labia minora does not necessarily obstruct orgasm. If, however, there is a pronounced wish for the clitoris to be released or if infections frequently occur under an almost completely hidden clitoris, that may be an indication for surgical treatment. In the past, LS was treated with surgery to remove the vulvar skin, but this is contraindicated, as it does not resolve the LS, and should only be performed for postinflammatory sequelae exceptionally [12].

19.7.2.2 Sexologist

When there are persistent sexual complaints, the patient is referred to a sexologist when necessary.

19.7.2.3 Pelvic Floor Physiotherapist

When reactive pelvic floor muscle tension is suspected, the patient can be referred for further diagnosis and possible treatment to a pelvic floor physical therapist.

Case History: Continued

Information was given about LS and various lifestyle recommendations were given. Within the following weeks, it became clear (by testing) that the itch was not related to a chronic yeast infection as the patient believed. Treatment was started with cortisone cream and the response was very rapid and complete. Anne stopped scratching herself.

As she still complained about (irregular) pain during intercourse, she and her husband were seen by a sexologist. Attention was paid to the decreased sexual arousal and pelvic muscle tension during intercourse due to the threat of pain experience in more detail. Furthermore, the role of intercourse was discussed within their sexual relationship. It was for the couple an enormous relief that “the problem” was discussed in more detail. Anne’s condition remained under control by the gynecologist.

19.8 Critical Reflection and Conclusive Remarks

The clinical course of LS is a chronic disease that mostly affects the vulvar skin and is possibly related to autoimmune diseases, but in fact with unknown etiology. There is no known cure for LS; however, there are good outcomes of treating LS with topical cortisone creams combined with daily use of emollients. Because of the symptoms such as itching, (burning) pain, and the genital scarring, there is a considerable effect on the quality of life and, more specifically, a burden on the sexual experience and the sexual relationship. Additional problems such as secondary infection (yeast infections), contact eczema, vulvodynia (chronic pain in the vulva), meatal stenosis, and psychosexual problems must be recognized as such and treated. There is a small risk of the occurrence of squamous cell carcinoma. Follow-up is advised depending on the severity of the symptoms and anatomical changes of the skin.

Tips and Tricks

Note that every woman with LS may have sexual complaints. Many women will not tell you that spontaneously. Below, we summarize the most important tips and tricks for everyday practice:

- Recommend, if necessary, a different position for intercourse or the possibilities for sex without intercourse. When there is persistent dyspareunia resulting from fissures in the posterior commissure, surgery may be an option in exceptional cases (see below). The use of an emollient ointment around the introitus before penetration may relieve pain or dryness.
- If desired, a vibrator can heighten the clitoral stimulation. When there is insufficient lubrication, a (hypoallergenic) lubricant can be used (water or silicon based).
- Discuss the importance of relaxing the vaginal pelvic floor muscles. The patient and partner must be informed about the possibility of coaching by a registered pelvic floor physiotherapist in order to improve the sensation, the coordination, and relaxation of the pelvic floor muscles.
- Discuss the importance of good sexual arousal. When there is insufficient lubrication, a (hypoallergenic) lubricant can be used.
- Patient and partner must be informed about the possibility of coaching by a sexologist to improve their sexual relationship. Generally, the sexologist gives information, advice, specific suggestions, and as necessary a more intensive cognitive behavioral therapy-based treatment.

Test Your Knowledge and Comprehension

1. Sometimes it is difficult to differentiate lichen sclerosus (LS) from lichen planus (LP) or lichen simplex chronicus (LSC). Give the two main symptoms on how to differentiate these three diagnoses.

2. Anne is scratching often. How could she prevent scratching? What should you advise here?
3. Anne visits you for the complaint of pain during intercourse. Please describe what your opinion is about the pain and how the pain can be treated.
4. Would you refer Anne to a sexologist? Motivate your answer with arguments.
5. Would you refer Anne to a pelvic floor physiotherapist? Motivate your answer.
6. Itching is one of the main symptoms of the LS.
   (a) True
   (b) False
7. LS is sometimes difficult to distinguish from lichen planus (LP). Particularly in the very early stages, LS and LP strongly resemble each other both clinically and histologically. One important distinction is the involvement of the vaginal epithelium with LS, while with LP, the vaginal epithelium is not affected.
   (a) True
   (b) False
8. The clitoris can become hidden because of fusion of the labia minora; this generally results in problems with achieving orgasm.
   (a) True
   (b) False
9. One out of five women with LS will develop squamous cell carcinoma (SCC).
   (a) True
   (b) False
10. Topical cortisone creams are effective in the treatment of genital LS.
    (a) True
    (b) False
11. It is advisable to use an emollient ointment to prevent dehydration of the skin.
    (a) True
    (b) False

Answers

1 through 5 are open book answers based on Chap. 19.

6. True
7. False
8. False
9. False
10. True
11. True

References

1. Jones RW, Scurry J, Neill S, MacLean AB. Guidelines for the follow-up of women with vulvar lichen sclerosus in specialist clinics. Am J Obstet Gynecol. 2014;198(5):496e1–3.
2. Smith YR, Haefner HK. Vulvar lichen sclerosus: pathophysiology and treatment. Am J Clin Dermatol. 2004;5(2):105–25.
3. Wood PL, Bevan T. Lesson of the week: child sexual abuse enquiries and unrecognised vulval lichen sclerosus et atrophicus. Br Med J. 1999;319(7214):899–900.

4. Goldstein AT, Marinoff SC, Christopher K, Srodon M. Prevalence of vulvar lichen sclerosus in a general gynecology practice. J Reprod Med. 2005;50(7):477–80.
5. Eberz B, Berghold A, Regauer S. High prevalence of concomitant anogenital lichen sclerosus and extragenital psoriasis in adult women. Obstet Gynecol. 2008;111(5):1143–7.
6. Powell JJ, Wojnarowska F. Lichen sclerosus. Lancet. 1999;353(9166):1777–83.
7. British Association for Sexual Health and HIV (BASHH). UK National Guideline on the Management of Vulval Conditions. 2014. http://www.bashh.org/documents/2014_vulval_guidelines%20Final.pdf.
8. Bradford J, Fischer G. Long-term management of vulval lichen sclerosus in adult women. Aust N Z J Obstet Gynaecol. 2010;50(2):148–52.
9. Chi CC, Kirtschig G, Baldo M, Brackenbury F, Lewis F, Wojnarowska F. Topical interventions for genital lichen sclerosus. Cochrane Database Syst Rev. 2011;(12).
10. Fistarol SK, Itin PH. Diagnosis and treatment of lichen sclerosus an update. Am J Clin Dermatol. 2013;14(1):27–47.
11. Nederlandse Vereniging voor Dermatologie en Venereologie (NVDV). Richtlijn Anogenitale lichen sclerosus. 2012. http://www.mdl.nl/uploads/240/1450/Richtlijn_Lichen_Sclerosus_def_27042012.pdf.
12. Neill SM, Lewis FM, Tatnall FM, Cox NH. British Association of Dermatologists' guidelines for the management of lichen sclerosus 2010. Br J Dermatol. 2010;163(4):672–82.
13. Perez-Lopez FR, Ceausu I, Depypere H, Tamer E, Lambrinoudak I, Rees M, Schenck-Gustafsson K, Tremollieres F, van der Schouw YT, Simoncini T. EMAS clinical guide: vulvar lichen sclerosus in peri and postmenopausal women. Maturitas. 2013;74(3):279–82.
14. Sherman V, McPherson T, Baldo M, Salim A, Gao XH, Wojnarowska F. The high rate of familial lichen sclerosus suggests a genetic contribution: an observational cohort study. J Eur Acad Dermatol. 2010;24(9):1031–4.
15. Funaro D. Lichen sclerosus: a review and practical approach. Dermatol Ther. 2004;17(1):28–37.
16. Van De Nieuwenhof HP, van der Avoort IAM, De Hullu JA. Review of squamous premalignant vulvar lesions. Crit Rev Oncol Hemat. 2008;68(2):131–56.
17. Dalziel KL. Effect of lichen-sclerosus on sexual function and parturition. J Reprod Med. 1995;40(5):351–4.
18. Goldstein A, Creasey A, Pfau R, Phillips D, Burrows L. Sexual dysfunction in women with lichen sclerosus. J Sex Med. 2010;7:137.
19. Van De Nieuwenhof HP, Meeuwis KAP, Nieboer TE, Vergeer MC, Massuger LF, De Hullu JA. The effect of vulvar lichen sclerosus on quality of life and sexual functioning. J Psychosom Obstet Gynecol. 2010;31(4):279–84.
20. Thorstensen KA, Birenbaum DL. Recognition and management of vulvar dermatologic conditions: lichen sclerosus, lichen planus, and lichen simplex chronicus. J Midwifery Women Health. 2012;57(3):260–75.
21. Cooper SM, Gao XH, Powell JJ, Wojnarowska F. Does treatment of vulvar lichen sclerosus influence its prognosis? Arch Dermatol. 2004;140(6):702–6.
22. Renaud-Vilmer C, Cavelier-Balloy B, Porcher R, Dubertret L. Vulvar lichen sclerosus: effect of long-term topical application of a potent steroid on the course of the disease. Arch Dermatol. 2004;140(6):709–12.

A Woman Complaining of Lack of Sexual Desire: Sexological Counseling

20

Rik H.W. van Lunsen and Ellen T.M. Laan

20.1 Introduction and Aims

Absent or reduced sexual desire and/or arousal are the most prevalent sexual problems in women. In general, women present this problem only when there is a partner and when the gynecologist proactively inquires about possible sexual difficulties. The way science defines arousal and desire has been subject to change. In the past "libido" was mainly seen as a biological "drive." Incentive motivation theories, the abundance of evidence that spontaneous sexual desire does not exist, and the knowledge that sexual desire is the result of competent sexual stimuli that activate the sexual response system have led to the conclusion that desire for sexual activity is more determined by the expectation of rewarding experiences than by a biological "drive." Biological factors—neurotransmitters and hormones—are not the source of sexual desire but mainly determine the sensitivity of the sexual system for sexual stimuli. Based on these changed views, in the *Diagnostic and Statistical Manual of Mental Disorders 5th Edition* (DSM-5), the distinction between arousal and desire is abandoned. In women experiencing reduced sexual desire and/or arousal, the diagnosis *female sexual interest/arousal disorder* should not be made if the sexual difficulties are the result of inadequate sexual stimulation. If the problem is situational, a biological cause is most unlikely. Sexuality is a biopsychosocial phenomenon. In this chapter, a biopsychosocial approach to the complaint "lack of sexual desire" will be given.

R.H.W. van Lunsen, MD, PhD (✉) • E.T.M. Laan, PhD
Department of Sexology and Psychosomatic Obstetrics and Gynecology, Division of Obstetrics and Gynecology, Academic Medical Center University of Amsterdam, Amsterdam, The Netherlands
e-mail: h.w.vanlunsen@amc.uva.nl; e.t.laan@amc.uva.nl

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_20

20.2 Definition in Lay Terms

Experienced "lack of sexual desire" is a subjective complaint. Objective criteria to define "normal sexual desire" do not exist. Sexual desire no longer is seen as a "spontaneous drive" but as an emotion that is the result of both adequate sexual stimuli at the right time and at the right place and the expectation—based on previous pleasant encounters—of a pleasurable outcome. In most cases a lack of sexual desire is the end result of experienced sexual difficulties and/or of relational problems resulting from differences in wishes and expectations between partners.

20.3 Didactic Goals

After reading this chapter, you:

- Are able to take a biopsychosocial and sexual history from a woman presenting with a lack of sexual desire and/or arousal
- Are able to take a history from the partner of a woman presenting with a lack of sexual desire and/or arousal
- Are able to take a history from a couple of which the woman complains of a lack of sexual desire and/or arousal
- Are able to assess the possible predisposing, precipitating, maintaining, and contextual factors that contribute to the problem
- Are familiar with the DSM-5 definition of female sexual interest/arousal disorder
- Are familiar with the possible etiologies of problems of decreased sexual desire and arousal
- Are familiar with the multidimensional strategies to treat a couple of which the woman complains of a lack of sexual desire and/or arousal
- Are familiar with indications for additional pharmacological treatment

Case History

Tamara Purple, a 54-year-old married woman with three adult children, postmenopausal for 2 years, visited her general practitioner (GP) several times with climacterial complaints. Her symptoms of hot flashes, nocturnal sweats, and sleeping disturbances were effectively treated with a low-dose continuous combined estrogen-progestagen preparation. Also her complaints of a "dry vagina" and dyspareunia were somewhat improved.

She now tells her GP that in fact her sexual desire has been minimal for many years and after starting the medication, it seems to have vanished completely. There are no major health problems. Besides the hormone replacement therapy (HRT), she is not taking any other medication. She works full time as personal assistant to the CEO of a large chain of hotels. Her husband is a surgeon working in an academic hospital.

20.4 Didactic Questions

- Should someone experience spontaneous sexual desire?
- Is sexual desire mainly the result of internal hormonal and neuroendocrine "push factors?"
- Is a decrease of sexual desire in climacterium and after menopause a result of declining estrogen levels?
- Which maintaining factors usually play an important role once a sexual desire/arousal has developed?
- Are lack of sexual lubrication and dyspareunia in postmenopausal women related to vaginal atrophy?
- What are the core elements of treating a female sexual interest/arousal disorder (FSIAD)?
- What is the place of pharmacotherapy in the treatment of FSIAD?

20.5 Facts and Figures: Definitions, Prevalence, and Classification

20.5.1 Should Someone Experience Spontaneous Sexual Desire?

20.5.1.1 Formal Definition

Sexual desire is a subjective feeling state. What is experienced as a lack of sexual desire is therefore rather subjective and not only depends on the definition of "normal sexual desire" but also on existing differences in opinion on how sexual desire originates. The complex biopsychosocial and contextual nature of sexual desire is reflected in the many synonyms used to describe the motivational state of being interested in sexual activity and/or objects: *sexual desire*, *sexual interest*, *libido*, *sexual drive*, *sexual motivation*, *sexual attraction*, and *lust*. Within medicine and science, opinions on the nature of sexual desire have been subject to change, as is reflected in the radical differences in definitions of "desire disorder" between DSM-4 and DSM-5 [1, 2]. In DSM-4, "hypoactive sexual desire disorder" (HSDD) in women was seen as an entity distinct from arousal. Because feelings of sexual desire and feelings of sexual arousal are difficult to discern and both are elicited in response to adequate sexual cues, former HSDD was merged with the former "female sexual arousal disorder" to create a new diagnostic category "female sexual interest/arousal disorder" (FSIAD) in DSM-5. These changes are based on psychophysiological research that has shown that sexual responses are similar to any other emotional response. As with other emotions, sexual emotions involve altered central and peripheral physiology (e.g., motor preparation, vasocongestion), as well as feelings [3]. Studies using vaginal photoplethysmography have shown that with any competent sexual stimulus, genital responses invariably start within a few heartbeats, regardless of whether one wants or is aware of these responses taking place [4]. Thus, sexual responses start automatically when a stimulus is recognized as sexual. Sexual desire is the result of a positive cognitive elaboration (disinhibition) of preconsciously perceived starting

responses. Ongoing sexual responses are related to motivated behavior based on appraisal of context, stimulation, and expected outcome (sexual memory). In this incentive motivation model, sexual arousal and desire both result from a sensitive sexual response system interacting with sexually competent stimuli [5–7]. A stimulus thus becomes "sexually competent" through learning: when a stimulus has once or repeatedly led to a rewarding sexual experience, such a stimulus is likely to acquire a positive sexual meaning, particularly if the rewarding sexual experience involves orgasm [8]. Only the sensitivity or receptivity (arousability) of the sexual system for sexual stimuli is mediated by neurotransmitters such as dopamine and by hormones—with androgens being the most important.

See the *DSM-5* [2] for the diagnostic criteria for "female sexual interest/arousal disorder" (FSIAD).

20.5.1.2 Prevalence

The prevalence of low sexual desire and of problems with sexual arousal may vary markedly in relation to age, cultural setting, duration of symptoms, and presence of distress [9, 10].

According to DSM-5, the diagnosis of a sexual dysfunction cannot be made unless the symptoms cause clinically significant distress and have persisted for a minimum duration of approximately 6 months. Moreover, the diagnosis should not be made if the sexual difficulties are the result of inadequate sexual stimulation [2]. In most prevalence studies, these criteria are not applied. In the general population, low sexual desire is reported by 20–30 % of all women. When distress is used as a criterion for dysfunction, the prevalence rates decrease by, on average, 50 %. The prevalence of arousal problems lies between 11 and 31 %, but in combination with the criterion of distress, these rates also decrease sharply [11–13]. There is no direct relationship between age or menopausal status and sexual interest. Women aged 31–45 are more motivated to engage in sex than are women aged 18–30. The primary reasons for engaging in sex are pleasure, love, and commitment [14]. After menopause there is a decline in sexual interest, mainly related to mood, physical complaints, and most strongly associated with concurrent negative feelings for the partner and prior negative feelings for the partner [15].

20.5.1.3 DSM-5 Classification

In assessing problems of low desire and arousal, the relational context must be addressed first. A "desire discrepancy," in which there is distress because the woman has a desire for sexual activity less frequently than her partner, is not sufficient to diagnose female sexual interest/arousal disorder. Neither is the diagnosis made when her prerequisites for experiencing arousal and desire, amounting to a lack of adequate sexual stimulation, are not met.

When the criteria of FSIAD are met, including the assessment of adequate sexual stimulation, the following specifiers should be applied:

- *Lifelong or acquired*: The disturbance has been present since the individual became sexually active or began after a period of relatively normal sexual function.

- *Generalized or situational*: The problem is not limited to certain types of stimulation, situations, or partners or only occurs with certain types of stimulation, situations, or partners.
- *Severity*: There is evidence of *mild*, *moderate*, or *severe* distress over the symptoms.

It is questionable, however, whether problems that are situational deserve to be labeled as dysfunctional, because this means that the woman is able to experience sexual arousal and desire once sexually competent stimuli are present [16].

20.6 Etiology and Pathology

Sexual arousal and desire are the result of interplay between a sensitive sexual response system and stimuli (incentives) that activate this system. In this interplay the sensitivity of the system and the meaning and intensity of the real or imaginary stimuli play a role [7]. According to incentive motivation theories supported by cumulating evidence from experimental studies, sexual desire should not be regarded as a biological drive or "libido" that one has or does not have which spontaneously generates sexual desire and precedes sexual arousal. Instead, sexual desire is something that manifests itself when individual conditions for sexual stimulation and motivated behavior are met [7, 17]. The conditions necessary to activate the sexual process are threefold: (1) there must be an intact system that enables sexual responsiveness, (2) adequate sexual stimuli that can activate the sexual system must be present, and (3) the circumstances must be suitable to pursue sexual activity [18].

If one or more of these conditions are lacking or absent, sexual arousal and sexual desire will subside or not occur at all. Sexual activity, however, is not always initiated as a consequence of a process in which sexual arousal and sexual desire are involved. In a large study on people's motives to have sex with a partner, men and women reported a wide variety of motives, such as experiencing physical pleasure, showing affection, satisfying the partner, relieving boredom, or fulfilling a perceived obligation [19]. For women the need for and experiencing of intimacy plays an important role as motive for sexual activity [20], although this motive is not unique to women [21, 22].

20.6.1 Is Sexual Desire Mainly the Result of Internal Hormonal and Neuroendocrine "Push Factors?"

20.6.1.1 Biological Factors

The biological prerequisites for sexual desire and arousal are intact neuroanatomy and sufficient genital blood supply enabling genital responses, and the availability of neurotransmitters and hormones, of which dopamine and testosterone are the most important. These mediators are not the source of sexual desire or arousal but determine how receptive the sexual system is for sexual stimuli. Androgens

modulate the responsivity to sexual stimuli of "the sexual system" both on a central and a peripheral level [23]. There is evidence suggesting that some women are more sensitive to changes in testosterone levels than others [24]. The individual differences in the subtle effects of androgens on sexuality are the reason for inconsistencies in the literature on how androgens might influence sexuality and for the fact that in nonselected populations the differences in sexual functioning between normo-androgenic and androgen-depleted women are small. Whereas some studies found androgens to enhance sexual motivation, the frequency of sexual fantasies, and some aspects of sexual arousal in women [25, 26], other studies did not [27, 28]. Women's androgen insufficiency has been defined as consisting of a pattern of clinical symptoms—sexual problems, persistent unexplained fatigue, and a decreased sense of well-being—in the presence of decreased bioavailable testosterone (T) and normal estrogen status [29]. Nevertheless, some authors recommended against making a diagnosis of androgen insufficiency and treatment of women, based on the absence of a clear correlation between androgen plasma levels and sexual disorders [30]. Others disagree strongly with these negative recommendations and argue that, based on recent data on the role of androgens in women's health, androgen insufficiency is a clinically relevant condition that deserves more attention [31]. The main risk factors for androgen insufficiency in women are age, surgical menopause, the use of estrogen-containing medication (hormone replacement therapy, combined oral contraceptives [COCs]), and chronic illness.

Somatic diseases and medical interventions can lead to diminished sexual desire or disruption of the sexual arousal response. Often it is difficult to discriminate between the direct physiological effects of the condition and psychological factors related to the disease, such as fatigue, pain, or depression. Chronic diseases that might disrupt sexual functioning physiologically as well as psychologically are neurological disorders such as multiple sclerosis or spinal cord injury [32]; endocrine disorders such as hypothyroidism, hyperprolactinemia, and diabetes mellitus [33]; renal failure; and depression [34]. There is evidence for a diminished genital response to sexual stimulation in women with conditions such as spinal cord injury [35], nerve damage as a result of gynecological oncological surgery, after restorative proctocolectomy with ileal pouch anal anastomosis [36, 37], and in women with diabetes mellitus [38].

20.6.2 Is a Decrease of Sexual Desire in Climacterium and After Menopause a Result of Declining Estrogen Levels?

In healthy pre- and postmenopausal women reporting sexual arousal problems, there is no evidence of impaired genital responses [4]. Moreover, there is no indication that physiological menopause has a negative impact on sexual responsivity [39].

Various drugs that act on neurotransmitter systems, such as antidepressants (selective serotonin reuptake inhibitors [SSRIs]) and antipsychotics (dopamine antagonists), have negative effects on sexual desire and sexual arousal. A few antidepressives (agomelatine, bupropion, moclobemide, mirtazapine) have weaker or

no antisexual side effects [40]. Many other drugs such as antihypertensives, antiepileptics, and statins are associated with problems in sexual arousal and desire [41]. Although the sexual effects of antihypertensives have been poorly studied in women, these drugs may have similar adverse effects on the arousal phase as in men, leading to diminished genital swelling and lubrication. It is estimated that of all distressing sexual problems, one-fourth is caused by prescription drugs.

20.6.3 Are Lack of Sexual Lubrication and Dyspareunia in Postmenopausal Women Related to Vaginal Atrophy?

20.6.3.1 Psychological Factors

Sexual desire is mainly dependent on the expectation that engaging in sexual activity will be (sexually and emotionally) rewarding and on contextual factors [42]. If no rewarding experience is expected, it is unlikely that arousal and desire will occur. Various psychological mechanisms may negatively influence the attractiveness of sexual stimuli, such as habituation or associations with negative outcomes. Illustrative is that longer relationship duration is correlated with lower sexual desire [43] and that starting a new relationship is accompanied by stronger feelings of desire [44]. The best predictor of current sexual desire is the woman's prior level of sexual response [45].

Sexual stimuli also can lose their attractiveness when sex repeatedly results in negative outcomes, such as pain or disappointment. A history of sexual violence can lead to strong negative associations with sex [46]. Negative opinions and attitudes due to a sex-negative upbringing are associated with less sexual desire and more sexual problems [47]. A recent study showed that more negative early attachment relationships, more past and/or present psychiatric symptoms, and more negative sexual history are each associated with less ability to trigger sexual desire [48].

Major depression is the most important clinical condition having an impact on desire and arousal [49]. There is a clear correlation between low sexual desire and both depression and antidepressant medication [50, 51].

20.6.3.2 Relational and Other Contextual Factors

Distress about low sexual desire almost exclusively occurs in a relational context. Most women with diminished or no sexual desire indicate that their lack of sexual desire is distressing because it generates tension and conflicts within their relationship. Personal distress of women about sexual problems is best predicted by their level of general emotional well-being and the quality of the emotional bond with the partner during sexual contact [9]. Sexual complaints often are a reaction to unfavorable circumstances by which individual prerequisites for sexual arousal and sexual desire are not fulfilled [52]. Only rarely do single women present with a lack of desire to masturbate or with the complaint of not being interested in sex [6, 16]. Women with complaints of low sexual desire report poorer dyadic adjustment, greater dissatisfaction with conflict resolution in their relationship, and less attraction to and emotional closeness with their partners [53, 54]. Erectile dysfunction

and premature ejaculation of the partner may have a negative impact on the women's sexual desire [55]. Most complaints about low sexual desire occur as result of differences between partners in wishes and expectations with regard to quantity of sexual activities and quality of emotional and physical intimacy.

20.6.4 Which Maintaining Factors Usually Play an Important Role Once a Sexual Desire/Arousal Has Developed?

20.6.4.1 The Interplay Between Biological, Psychological, and Contextual Factors: The Biopsychosocial Paradigm

Each sexual problem is characterized by a variety of predisposing, precipitating, maintaining, and contextual factors [56, 57]. Predisposing factors encompass both congenital physical aspects (e.g., congenital anatomical or hormonal anomalies) and prior life experiences, such as problematic attachments, neglectful caregivers, restrictive upbringing, sexual and physical abuse, and violence. Precipitating factors are those that trigger the problems and are determined by the individual and contextual prerequisites for arousal and desire or by underlying diseases and/or pharmaceutical agents. Maintaining factors are mainly determined by the psychological and behavioral reactions of both partners on the onset of the problem and by the way the couple as a system reacts upon it. Feelings of guilt, performance anxiety, and anger; impaired self-image, body image, or self-esteem; loss of sexual confidence; lack of communication; relational discord; and avoidance of intimate physical contact are among the many possible factors that might prolong and aggravate the problem even when the main precipitating factor no longer exists (e.g., after discontinuation of the medication that caused the problem).

Contextual factors are the actual circumstances that might prevent the couple from investing time and energy in solving the problem. These include such diverse issues as work-related stress, financial struggles, unemployment, fatigue from child-rearing, burdens of caretaking for others, and lack of individual and/or shared quality time. At the time the problem is presented to a caregiver, predisposing, precipitating, maintaining, and contextual factors all might interact in different ways. Although precipitating factors may no longer be present, for instance, a medication that has been discontinued or a critical incident that almost has been forgotten, maintaining psychological and/or contextual factors might prevent the problem from disappearing (Fig. 20.1).

20.7 Specific Diagnostic Aspects

20.7.1 History

Sexual desire and arousal problems are strongly influenced by the relational context. It is therefore imperative to have a diagnostic interview with the couple together and with both members of the dyad separately.

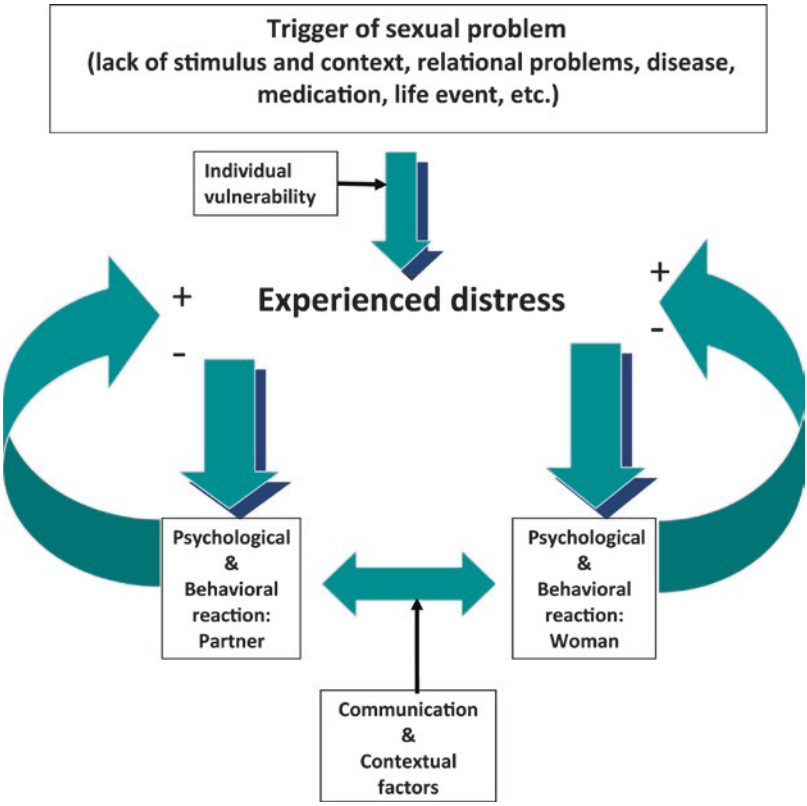


Fig. 20.1 The psychosomatic circle of predisposing, precipitating, maintaining, and contextual factors in experienced distress due to a sexual difficulty

In the *interview with the woman* alone, the most important specifiers should be assessed: Is the problem primary or secondary? Is it generalized or situational? If the problem—as in the vast majority of cases—is secondary, the main question is what were the stimuli and circumstances that induced feelings of arousal and desire in the past? What happened that these prerequisites for arousal no longer work? Are they absent or are they perhaps avoided? When did the problem start and what were the possible physical, psychological, relational, and/or social contributing factors? How satisfied is the women about other aspects of the relationship? Does she miss emotional and/or physical intimacy? Is there sufficient room and time for relational and personal quality time? Does she still find her partner sexually attractive? If the problem is situational, and therefore physical causes are excluded, the main question is: What are stimuli and circumstances that lead to arousal and desire? Is she still able to experience a full sexual response, including lubrication and orgasm? Is this in a relational context or only when masturbating? If the problem is primary and/or generalized, often negative, disappointing, and/or painful sexual experiences are the main cause of the lack of sexual desire and arousal and the tendency to either

avoid sexual encounters or to continue sexual activity out of feelings of guilt, shame, and/or mate-guarding motives.

Typical for hormonal causes of desire problems is that the desire for sex is initially unaffected, but that there is a marked decrease in arousability: responsivity to stimuli that were effective in the past has disappeared. Often this is described as "It feels as though the motor does not start." Physical causes for sexual desire and arousal problems often lead to a discrepancy between central arousal (feelings of desire and arousal) and genital swelling and lubrication, where the former may still be present, and the latter is absent.

In all situations, the way the woman has been coping with differences in desire between partners is crucial with regard to the severity of the problem; if she has accepted sexual activity and penetration without arousal and desire—often leading to pain—on a regular basis, the lack of desire and arousal during sexual activity may gradually turn into aversion.

In the *interview with the partner*, he (or she) is asked about his/her feelings about the sexual relationship and how the problem affects his/her own well-being and sexual functioning. How does she/he deal with any differences in sexual desire, and to what extent does it influence the way she/he relates to the partner? Does she/he see the problem as the identified patient's own problem that should be fixed on an individual level or as a problem that might be dealt with by behavioral changes in the context of the relationship? What changes would she/he like to see taking place? How satisfied is she/he with other aspects of the relationship? What kind of stimuli and contextual factors are important for sexual arousal and pleasure? Does she/he still feel sexual desire for the partner? Does she/he still find her attractive? Does she/he experience sexual difficulties him/herself? Is she/he able to experience a full sexual response? Does she/he masturbate and is this out of frustration or for lust?

In the *interview with the couple*, all interactional aspects of their sexual relationship, in the past and in the present, as well as the way they communicate about wishes and boundaries, are subject of the interview. In secondary arousal and desire problems, sexuality was a source of pleasure in the past. The most important question then is what the main contributing factors of sexual pleasure, arousal, and desire were during those times. They are asked to describe in detail why and how sexual activities in the past and in the present were initiated, how varied their sexual repertoire was and is, and what the role was and is of physical and emotional intimacy, of noncoital sexual activity, etc. The couple interview is above all an opportunity to observe the couple's ability to effectively communicate and to assess their motivation to solve the problem together.

As discussed, most complaints about low sexual desire occur as a result of differences between partners in wishes and expectations. This is illustrated by some quotes of women with experienced low sexual desire as they can be often heard in the consultation room:

> Whenever he even starts to touch me I now have the feeling 'Oh no not again' because it always is the same…he wants sex and is so pushy about it. Even a hug has a sexual meaning. He does not seem to understand that to get in the mood I need to feel connected. Desire never came out of the blue and now I lost it altogether.

> We quarrel a lot about all those crazy daily hassles like who is responsible for what. It all has to do with my feeling that we do not have enough quality time together. After an argument he always wants to make love…I don't.

20.7.2 Additional Diagnostic Tools

In addition to the most important diagnostic tool, the individual and couple histories, the use of validated questionnaires is recommended when there is a need to quantify the arousal/desire problems or to assess the severity of the problem. There are a number of validated questionnaires for the assessment of "female sexual dysfunction" (FSD) [58]. Only those questionnaires that include assessment of the level of distress are suitable as a diagnostic tool.

To diagnose low sexual desire and arousal problems, standard physical examination and/or laboratory tests are generally not indicated, and in the case of a situational problem, such tests are even contraindicated, so as to avoid somatization. However, if there are comorbid complaints of sexual pain or other gynecological symptoms, a pelvic examination is needed to exclude somatic pathology. When history reveals a generalized decreased sexual arousability, relevant hormones may be measured, such as bioavailable and/or free testosterone, prolactin, and TSH. Decreased genital arousal might be the result of underlying cardiovascular disease. If other risk factors are present, it is recommended to measure blood glucose levels and to determine the cholesterol/HDL ratio.

20.7.3 Treatment Summary

In analogy to the multifactorial pathogenesis of sexual desire problems, the diagnostic and therapeutic approach is usually multidimensional taking into account all possible predisposing, precipitating, maintaining, and contextual factors. Therapy might include psychoeducation, basic counseling, individual and couple psychosexual behavioral therapy, and hormonal and psychopharmacological treatment. Although literature on the effectiveness of sex therapy and of cognitive behavioral therapy in FSD is scarce [59], there is an emerging literature that demonstrates a synergistic benefit from the use of multifaceted treatment approaches [57]. Effective treatments also seem to have a broader approach, in which the couple is treated instead of the woman alone and techniques are applied that not only focus on sexual desire but also on improving arousal, orgasm, and sexual satisfaction [7].

In sexology, often a stepped-care approach according to the PLISSIT model is applied [60]. This stepped care begins with the reassurance that low sexual desire and arousal can be normal reactions to changed circumstances (P = permission — to have the problem and to talk about it), followed by psychoeducation (LI = limited information) that calls upon the couple's own problem-solving ability. If this has insufficient results, more intensive help can be provided in the next steps: specific suggestions (SS) and intensive therapy (IT).

20.8 Specific Therapeutic Aspects

20.8.1 What Are the Core Elements of Treating a Female Sexual Interest/Arousal Disorder (FSIAD)?

In the vast majority of cases, complaints of a lack of sexual desire and arousal are secondary and situational. In the absence of physical, hormonal, or iatrogenic contributing factors, these problems are generally the result of an inability to cope with differences in wishes and expectations that develop throughout the relationship, such that over time, a sexual script has emerged that no longer meets the prerequisites for arousal and desire of one of the partners or both. The majority of these couples describe the early stages of their sexual relationship as good and satisfying. In these cases, sexual desire and arousal problems are mainly associated with inadequate erotic stimulation and/or contextual obstacles that have led to disturbances in sexual response. This implies that treatment should mainly be aimed at helping the couple to rediscover those stimuli and contextual factors that were effective in the past and to add (new) stimuli and circumstances to their sexual repertoire. Only the experience of new satisfying sexual events, which result from their investment in restoring the sexual relationship, will lead to renewed sexual arousal and desire.

The therapeutic process starts with an extensive discussion with the couple about all possible contributing, predisposing, precipitating, maintaining, and contextual factors followed by comprehensive psychoeducation on psychological, physical, and relational aspects of sexual desire and arousal. As a next step, specific suggestions may be given to apply new stimuli and circumstances known to be able to elicit desire and arousal, and to focus on one's feelings of pleasure, without aiming at penetration as the ultimate goal of sexual interactions.

In the more intensive *sensate focus* home assignments [61] or individualized modifications thereof, a step-by-step strategy is installed aimed at discovering pleasant physical sensations and, later, effective erotic stimulation. Part of the strategy is that intercourse is prohibited for a longer period, so as to prevent goal-oriented behavior. Another central element is that spectatoring—often an important maintaining factor—is diminished by focusing on one's feelings. In the words of Masters and Johnson, the motto of the exercises is to "self-assert, self-protect, and communicate," meaning that wishes and boundaries must be explicitly expressed and respected by encouraging both partners to communicate effectively. Nowadays, elements of cognitive behavioral therapy are often incorporated in these sensate focus exercises, in order to restructure dysfunctional cognitions that inhibit pleasure, arousal, and desire. Also, partner-relationship therapeutic interventions and more general communication exercises can be incorporated in the therapy.

In *COC users* presenting with decreased arousability and other symptoms of testosterone insufficiency, especially when they experience improvements in the

pill-free interval, switching to a less antiandrogenic formulation or to another contraceptive method may be helpful [62, 63].

20.8.2 What Is the Place of Pharmacotherapy in the Treatment of FSIAD?

Additional *pharmacotherapy* might be useful when hormonal deficiencies are identified. Although in postmenopausal women there is no relationship between a loss of sexual desire, dyspareunia, coital vaginal dryness, and estrogen deficiency [39], local estrogens or systemic estrogen/progestagen formulations may be prescribed. These medications are effective in treating climacterial complaints and help to restore urogenital atrophy, but do not by themselves have a positive effect on arousal and sexual lubrication. On the contrary, systematic estrogens may lead to testosterone deficiency because of their effects on sex hormone-binding globulin (SHBG) levels [64]. Moreover, it has been demonstrated repeatedly that although in postmenopausal women without significant comorbidity, vaginal vasocongestion is indeed lower than in premenopausal women in the unaroused state, they respond with similar levels of vaginal vasocongestion and lubrication to sexual stimuli as premenopausal women [4, 39]. Women on HRT experiencing a decrease in sexual arousability might therefore benefit from adding testosterone or from switching to tibolone, a preparation with combined estrogenic and androgenic effects [65, 66]. PDE5 inhibitors such as sildenafil, vardenafil, and tadalafil are only useful as add-back therapy in SSRI-induced sexual dysfunction [67] and in situations where genital arousal is compromised by cardiovascular and neurological conditions or by nerve damage [68, 69]. No therapeutic effect of sildenafil was found in a randomized controlled trial (RCT) in medically healthy women with FSAD, diagnosed using DSM-IV criteria [70].

In August of 2015, after intense lobbying by several special interest groups, the FDA approved flibanserin, a 5-HT1A agonist, a 5-HT2A antagonist and a weak partial agonist on dopamine D4 receptors, as a medical treatment for HSDD in premenopausal women. A meta-analysis that included published as well as unpublished studies found the clinical benefits of flibanserin to be marginal, with statistically and clinically significant adverse effects [71. In the first year after approval, prescription of the drug has been slow.

Recently, two studies were published in which two different drug combinations (testosterone/sildenafil and testosterone/buspirone) were studied in women with hypoactive sexual desire disorder [72, 73]. Although the authors claim positive effects, others have expressed serious doubts based on identified sources of bias and confounding, questioning the clinical relevance of the findings [74].

Probably, more pharmacological treatments for FSD will be introduced in the future. It is important to keep in mind, however, that drugs are only able to enhance responsivity to sexual stimuli and are therefore unlikely to be beneficial without simultaneous therapeutical focus on psychological, relational, and other contextual factors.

Case History: Continued

Because of the fact that her sexual desire is even further diminished after prescribing HRT, the GP refers Tamara Purple to a gynecologist of a multidisciplinary sexology/ob-gyn team. An extensive history taking then reveals that she has been unhappy with her sex life for many years already. When she was younger, she enjoyed sexual contact with her spouse, particularly when she experienced togetherness and closeness. A romantic evening with a good glass of wine and an attentive husband were sufficient to get her in the mood for sex and responsive for partner initiative. In the early days of their relationship, they spent a lot of time together, went to the movies and the theater, and loved to go out for dinner.

Later on sex was *OK*, although she started missing variety, often did not experience orgasm, and disliked the fact that lovemaking always ended in intercourse, which she did not tell him. Then the kids came, both their careers took much time and effort, and gradually the couple seemed to drift apart. For her, sex became a chore; she did it because she thought he needed it. Often she had difficulty becoming aroused and sometimes faked orgasms so that sex would be over. In these years, intercourse became somewhat uncomfortable, but was not really painful. At times, sex was more rewarding, for instance, when they went away for a weekend or when she accompanied him to a congress abroad. She still fantasized about sex and felt desire (especially when she missed him or watched a movie with a handsome celebrity), and masturbation was pleasant. After the menopause transition, penetration became really painful because of the "vaginal dryness" that only bothered her during sex and not in daily life.

After starting HRT, the estrogen/progestagen combination prescribed by her GP, intercourse became less painful, but she started to notice a complete lack of arousal in response to the stimuli that used to excite her. She tells that now it is as if she has become totally insensitive to anything sexual. Her husband, who had been complaining of the low frequency of their sexual activity for a long time, is becoming more and more frustrated. Occasionally she consents in having sex for the sake of peace. "I just grind my teeth and hope it will be over quickly." There had been times that she tried to talk with him about their problematic sex life, but this always ended in an argument.

The gynecologist therefore ascertains a long-standing situational problem with desire and arousal. She explains to Tamara that when still premenopausal, this lack of desire and arousal did not cause too much discomfort, because premenopausal estrogenic stimulation of the vaginal wall protected her from severe vaginal dryness, even in an unaroused state [75]. Several studies have shown that even though dryness of the vaginal wall in an unaroused state is estrogen dependent, the ability to lubricate during sexual stimulation is not [39, 76]. With this postmenopausal loss of protective estrogens, being sufficiently sexually aroused during intercourse becomes even more vital in preventing painful intercourse. Merely applying local or systemic estrogens may restore the possibility to endure unaroused penetration, but it will certainly not make sex rewarding.

The fact that Tamara noticed a complete disappearance of sexual arousability after starting HRT may be related to the HRT-related rise in SHBG,

which in turn decreased bioavailable testosterone levels [77]. The gynecologist explains that this can be treated by changing the HRT to tibolone or by adding a very low dose of testosterone [64, 78]. She also notes that this change in HRT alone will not solve the long-lasting problems with sexual stimulation and that she should stop her apparent habit of accepting sexual activity that does not meet her prerequisites for arousal and desire. After this extensive psychoeducation, Tamara is motivated to start therapy and accepts an appointment for both her and her husband with one of the certified sex therapists of the multidisciplinary sexology/ob-gyn team.

20.9 Critical Reflection and Conclusive Remarks

The first step in the clinical approach of a woman complaining of lack of sexual desire is a thorough biopsychosocial assessment of the problem, taking into account all possible predisposing, precipitating, maintaining, and contextual factors. Usually, people present with sexual arousal and desire problems long after their onset. The result is that, irrespective of the primary cause of the problem, relational problems often play a maintaining role. In addition, patients often hope for a quick fix and therefore tend to overestimate the role of physical factors. Although physical and hormonal factors should not be overlooked or denied, the clinician should remain aware of the maintaining psychosocial and sexual sequelae. The case history of the patient in this chapter illustrates that simply facilitating painless intercourse in a non-aroused state by prescribing estrogens or lubricants may not be optimal care for women who experience desire and arousal-related complaints that are of contextual origin. These women may benefit more from a behavioral approach that helps them to understand and address the psychological, relational, and contextual factors that, in concert, made them accept sex in a situation that was devoid of any sexual meaning.

20.10 Tips and Tricks

Given the fact that most arousal and desire problems are the result of combination of a lack of sexually competent stimuli and contextual relational factors, these problems are usually secondary and situational. Therefore, questions during history taking should be aimed at identifying circumstances and stimuli that may still be able to evoke desire and arousal and how the current sexual repertoire (solo or with partner) may be altered to enhance the likelihood of a full sexual response, including subjective and genital arousal and orgasm. If arousal and desire are still possible, biological causes are ruled out. The kinds of circumstances and stimuli that still produce a sexual response give a clear indication of a possible solution. Almost invariably, arousal and desire problems only cause distress within a relational context. Therefore, the partner always needs to be involved in the diagnostic and therapeutic process.

20.11 Test Your Knowledge and Comprehension

20.11.1 Open-Book Questions and Answers Based on a Case History

Case

A 38-year-old woman consults you because of "low libido." She thinks that something must be wrong with her because she never feels the desire to have sex with her husband anymore. The problem has already existed for approximately 3½ years, and it causes a lot of distress because of the growing dissatisfaction of her husband, who urged her to visit you to "check your hormones." Although she describes their relationship as "almost ideal," she very much fears that this problem will threaten their marriage. They have a happy but busy life with two kids of 4 and 6 years old. They both work 4 days a week. This does not leave much time for an active social life, but "you at least have to feel spontaneous sexual desire for someone you love and still find attractive." She has no other health problem, does not use any medication, does not smoke, and only occasionally drinks alcohol. Her ob-gyn history is uncomplicated. Both pregnancies and deliveries were "by the book," and she did breastfeed both children for more than half a year. Almost a year ago, her husband had a vasectomy because she wanted to stop taking the pill (a COC containing 20 μg EE and 100 μg levonorgestrel). She had hoped that things would get better after stopping the pill, but that was not the case. She now has a regular menstrual cycle and no serious perimenstrual complaints.

Questions

1. Which hormonal condition could have been one of the precipitating factors of the loss of sexual desire?
   (a) Hypothyroidism
   (b) Hyperprolactinemia
   (c) Testosterone insufficiency
   (d) Estrogen deprivation
2. The kind of oral contraception the patient has used is the pill with the least negative effects on the bioavailability of androgens.
   (a) True
   (b) False
3. What is the most prevalent medical condition in women of this age category causing a loss of sexual arousal and/or desire?
   (a) Hypertension
   (b) Diabetes
   (c) Depression
   (d) PCOS
4. After ruling out any possible nonsexual medical condition that might explain the loss of sexual desire, all criteria for the DSM-5 diagnosis female sexual interest/arousal disorder" are met.
   (a) True
   (b) False

5. The next step in the diagnostic work-up should be:
   (a) Physical examination
   (b) Lab tests (endocrinology, glucose, cholesterol)
   (c) Next appointment together with husband
   (d) Assessment by means of a sexual dysfunction questionnaires

Five Questions Based on the Chapter

6. Hypoactive sexual desire disorder is one of the sexual dysfunctions defined by DSM-5.
   (a) True
   (b) False
7. SSRIs often cause a loss of sexual desire, arousal disorders, and/or anorgasmia.
   (a) True
   (b) False
8. In the majority of cases, sexual arousal and desire problems in women are caused by:
   (a) Hormonal contraceptives
   (b) Contextual factors
   (c) Medication
   (d) Psychiatric conditions
9. Which of the following symptoms is NOT a sign of testosterone insufficiency?
   (a) Hair loss
   (b) Loss of energy
   (c) Decreased sexual arousability
   (d) Decreased muscle strength
10. Dyspareunia and coital vaginal dryness in postmenopausal women are mainly caused by:
   (a) Estrogen depletion
   (b) Testosterone insufficiency
   (c) Cardiovascular aging
   (d) Unaroused intercourse

Answers

1. (b)
2. True
3. (c)
4. False
5. (c)
6. False
7. True
8. (b)
9. (a)
10. (d)

References

1. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 4th ed. Arlington: American Psychiatric Publishing; 2000, text revision.
2. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th ed. Arlington: American Psychiatric Publishing; 2013.
3. Damasio A. Looking for Spinoza: Joy, sorrow, and the feeling brain. Orland: Harcourt Inc; 2003.
4. Laan E, Van Driel E, van Lunsen RHW. Genital responsiveness in healthy women with and without sexual arousal disorder. J Sex Med. 2008;5:1424–35.
5. Janssen E, Bancroft J. The dual control model: the role of sexual inhibition and excitation in sexual arousal and behavior. In: Janssen E, editor. The psychophysiology of sex. Bloomington: University Press; 2007. p. 197–222.
6. Both S, Everaerd W, Laan E. Desire emerges from excitement. A Psychophysiological perspective on sexual motivation. In: Janssen E, editor. The psychophysiology of sex. Bloomington: Indiana University Press; 2007. p. 327–39.
7. Both S, Laan E, Schultz WW. Disorders in sexual desire and sexual arousal in women, a 2010 state of the art. J Psychosom Obstet Gynaecol. 2010;31:207–18.
8. Toates F. An integrative theoretical framework for understanding sexual motivation, arousal, and behavior. J Sex Res. 2009;46:168–93.
9. Brotto LA. The DSM, diagnostic criteria for hypoactive sexual desire disorder in women. Arch Sex Behav. 2010;39:221–39.
10. Graham CA. The DSM, diagnostic criteria for female sexual arousal disorder. Arch Sex Behav. 2010;39:240–55.
11. West SL, D'Aloisio AA, Agans RP, Kalsbeek WD, Borisov NN, Thorp JM. Prevalence of low sexual desire and hypoactive sexual desire disorder in a nationally representative sample of US women. Arch Intern Med. 2008;168:1441–9.
12. Witting K, Santtila P, Varjonen M, Jern P, Johansson A, von der Pahlen B, Sandnabba K. Female sexual dysfunction, sexual distress, and compatibility with partner. J Sex Med. 2008;5:2587–99.
13. Shifren JL, Monz BU, Russo PA, Segreti A, Johannes CB. Sexual problems and distress in United States women: prevalence and correlates. Obstet Gynecol. 2008;112:970–8.
14. Meston CM, Hamilton LD, Harte CB. Sexual motivation in women as a function of age. J Sex Med. 2009;6:3305–19.
15. Dennerstein L, Guthrie JR, Hayes RD, DeRogatis LR, Lehert P. Sexual function, dysfunction, and sexual distress in a prospective, population-based sample of mid-aged, Australian-born women. J Sex Med. 2008;5:2291–9.
16. Derogatis LR, Laan E, Brauer M, van Lunsen RHW, Jannini EA, Davis SR, Fabre L, Smith LC, Basson R, Guay AT, Rubio-Aurioles E, Goldstein A, Pukall C, Kellogg S, Burrows L, Morrison P, Krychman M, Goldstein SW, Goldstein I. Responses to the proposed DSM-V changes. J Sex Med. 2010;7:1998–2014.
17. van Lunsen RHW. Myths and misconceptions about sex and con(tra)ception. In: Briggs P, Kovacs G, Contraception GJ, editors. A casebook from menarche to menopause. New York: Cambridge University Press; 2013. p. 8–17.
18. Everaerd W, Laan E. Desire for passion: energetics of sexual response. J Sex Marital Ther. 1995;21:255–63.
19. Meston CM, Buss DM. Why humans have sex. Arch Sex Behav. 2007;36:477–507.
20. Basson R. Using a different model for female sexual response to address women's problematic low sexual desire. J Sex Marital Ther. 2001;27:395–403.
21. Janssen E, McBride KR, Yarber W, Hill BJ, Butler SM. Factors that influence sexual arousal in men: a focus group study. Arch Sex Behav. 2008;37:252–65.
22. de Graaf H. Seksueel gedrag en seksuele beleving in Nederland. Tijdschrift voor Seksuologie. 2012;36:87–97.

23. Goldstein I, Traish A, Kim N, Munarriz R. The role of sex steroid hormones in female sexual function and dysfunction. Clin Obstet Gynecol. 2004;47:471–84.
24. Bancroft J, Graham CA. The varied nature of women's sexuality: unresolved issues and a theoretical approach. Horm Behav. 2011;59:717–29.
25. Riley A, Riley E. Controlled studies on women presenting with sexual drive disorder: I. Endocrine status. J Sex Marital Therapy. 2000;26:269–83.
26. Turna B, Apaydin E, Semerci B, Altay B, Cikili N, Nazli O. Women with low libido: correlation of decreased androgen levels with female sexual function index. Int J Impot Res. 2005;17:148–53.
27. Alexander JL, Dennerstein L, Burger H, Graziottin A. Testosterone and libido in surgically and naturally menopausal women. Womens Health. 2006;2:459–77.
28. Gerber JR, Johnson JV, Bunn JY, O'Brien SL. A longitudinal study of the effects of free testosterone and other psychosocial variables on sexual function during the natural traverse of menopause. Fertil Steril. 2005;83:643–8.
29. Bachmann G, Bancroft J, Braunstein G, et al. Female androgen insufficiency: the Princeton consensus statement on definition, classification, and assessment. Fertil Steril. 2002;77:660–5.
30. Wierman M, Basson R, Davis S, Khosla S, Miller KK, Rosner W, Santoro N. Androgen therapy in women: an endocrine society clinical practice guideline. J Clin Endocrinol Metab. 2006;91:3697–710.
31. Traish A, Guay AT, Spark RF, Testosterone Therapy in Women Study Group. Are the endocrine society's clinical practice guidelines on androgen therapy in women misguided? J Sex Med. 2007;4:1223–35.
32. Rees PM, Fowler CJ, Maas CP. Sexual function in men and women with neurological disorders. Lancet. 2007;369:512–25.
33. Bhasin S, Enzlin P, Coviello A, Basson R. Sexual dysfunction in men and women with endocrine disorders. Lancet. 2007;369:597–611.
34. Basson R, Schultz WW. Sexual sequelae of general medical disorders. Lancet. 2007;369:409–24.
35. Sipski ML. Sexual function in women with neurologic disorders. Phys Med Rehabil Clin N Am. 2001;12:79–90.
36. Pieterse QD, Ter Kuile MM, Deruiter MC, Trimbos JB, Kenter GG, Maas CP. Vaginal blood flow after radical hysterectomy with and without nerve sparing. A preliminary report. Int J Gynecol Cancer. 2008;18:576–83.
37. Vlug MS, Laan ET, van Lunsen RH, van Koperen PJ, Polle SW, Bemelman WA. Genital and subjective sexual response in women after restorative proctocolectomy with ileal pouch anal anastomosis-a prospective clinical trial. J Sex Med. 2010;7:2509–20.
38. Wincze JP, Albert A, Bansal S. Sexual arousal in diabetic females: physiological and self-report measures. Arch Sex Behav. 1993;22:587–601.
39. Laan E, Van Lunsen RHW. Hormones and sexuality in postmenopausal women: a psychophysiological study. J Psychosom Obstet Gynecol. 1997;18:126–33.
40. Serretti A, Chiesa A. Treatment-emergent sexual dysfunction related to antidepressants: a meta-analysis. J Clin Psychopharmacol. 2009;29:259–66.
41. Conaglen HM, Conaglen JV. Drug-induced sexual dysfunction in men and women. Aust Prescr. 2013;36:42–5.
42. Laan E, Both S. What makes women experience desire? Femin Psychol. 2008;18:505–14.
43. Klusmann D. Sexual motivation and the duration of partnership. Arch Sex Behav. 2002;31:275–87.
44. Avis NE, Zhao X, Johannes CB, Ory M, Brockwell S, Greendale GA. Correlates of sexual function among multiethnic middle-aged women: results from the study of women's health across the nation (swan). Menopause. 2005;12:385–98.
45. Dennerstein L, Lehert P. Modeling mid-aged women's sexual functioning: a prospective, population-based study. J Sex Marital Ther. 2004;30:173–83.

46. Meston CM, Heiman JR. Sexual abuse and sexual function: examination of sexually relevant cognitive processes. J Consult Clin Psychol. 2000;68:399–406.
47. Nobre PJ, Pinto-Gouveia J. Cognitive schemas associated with negative sexual events: a comparison of men and women with and without sexual dysfunction. Arch Sex Behav. 2009;38:842–51.
48. Brotto LA, Petkau AJ, Labrie F, Basson R. Predictors of sexual desire disorders in women. J Sex Med. 2011;8:742–53.
49. Bitzer J, Giraldi A, Pfaus J. Sexual desire and hypoactive sexual desire disorder in women. Introduction and overview. Standard operating procedure (SOP part 1). J Sex Med. 2013;10:36–49.
50. Kennedy SH, Dickens SE, Eisfeld BS, Bagby RM. Sexual dysfunction before antidepressant therapy in major depression. J Affect Disord. 1999;56:201–8.
51. Frohlich P, Meston C. Sexual functioning and self-reported depressive symptoms among college women. J Sex Res. 2002;39:321–5.
52. Bancroft J, Loftus J, Long JS. Distress about sex: a national survey of women in heterosexual relationships. Arch Sex Behav. 2003;32:193–208.
53. Trudel G, Boulos L, Benoit M. Dyadic adjustment in couples with hypoactive sexual desire. J Sex Educ Ther. 1993;19:31–6.
54. Banmen J, Vogel NA. The relationship between marital quality and interpersonal sexual communication. Family Ther. 1985;12:45–58.
55. Dean J, Rubio-Aurioles E, McCabe M, Eardley I, Speakman M, Buvat J, de Tejada IS, Fisher W. Integrating partners into erectile dysfunction treatment: improving the sexual experience for the couple. Int J Clin Pract. 2008;62:127–33.
56. Hawton K, Catalan J. Prognostic factors in sex therapy. Behav Res Ther. 1986;24:377–85.
57. McCabe M, Althof SE, Assalian P, Chevret-Measson M, Leiblum SR, Simonelli C, Wylie K. Psychological and interpersonal dimensions of sexual function and dysfunctions. J Sex Med. 2010;7:327–36.
58. Giraldi A, Rellini A, Bitzer J, Pfaus JG, Laan E, Jannini E, Fugl-Meyer AR. Questionnaires for assessment of female sexual dysfunction: a review and proposal for a standardized screener. J Sex Med. 2011;8:2681–94.
59. ter Kuile MM, Both S, van Lankveld J. Sexual dysfunctions in women. In: Sturmey P, Hersen M, editors. Handbook of evidence-based practice in clinical psychology, Adult disorders, vol. II. Chichester: Wiley; 2011.
60. Annon J. Behavorial treatment of sexual problems, vol. 2. New York: Harper & Row, Medical Department; 1976.
61. Masters WH, Johnson VE. Human sexual inadequacy. Boston: Little, Brown; 1970.
62. van Lunsen RHW, Laan E. Sex, hormones and the brain. Eur J Contracept Reprod Health Care. 1997;2:247–51.
63. Davis SR, Bitzer J, Giraldi A, Palacios S, Parke S, Serrani M, Mellinger U, Nappi RE. Change to either a nonandrogenic or androgenic progestin-containing oral contraceptive preparation is associated with improved sexual function in women with oral contraceptive-associated sexual dysfunction. J Sex Med. 2013;10:3069–79.
64. Floter A, Nathorst-Boos J, Carlstrom K, von Schoultz B. Addition of testosterone to estrogen replacement therapy in oophorectomized women: effects on sexuality and well-being. Climacteric. 2002;5:357–65.
65. Davis SR, van der Mooren MJ, van Lunsen RH, Lopes P, Ribot C, Rees M, Moufarege A, Rodenberg C, Buch A, Purdie DW. Efficacy and safety of a testosterone patch for the treatment of hypoactive sexual desire disorder in surgically menopausal women: a randomized, placebo-controlled trial. Menopause. 2006;13:387–96.
66. Nijland EA, Weijmar Schultz WC, Nathorst-Boos J, Helmond FA, van Lunsen RH, Palacios S, Norman RJ, Mulder RJ, Davis SR. Tibolone and transdermal e2/neta for the treatment of female sexual dysfunction in naturally menopausal women: results of a randomized active-controlled trial. J Sex Med. 2008;5:646–56.

67. Nurnberg HG, Hensley PL, Heiman JR, Croft HA, Debattista C, Paine S. Sildenafil treatment of women with antidepressant- associated sexual dysfunction: a randomized controlled trial. JAMA. 2008;300:395–404.
68. Sipski ML, Rosen RC, Alexander CJ, Hamer RM. Sildenafil effects on sexual and cardiovascular responses in women with spinal cord injury. Urology. 2000;55:812–5.
69. Caruso S, Rugolo S, Agnello C, Intelisano G, Di ML, Cianci A. Sildenafil improves sexual functioning in premenopausal women with type 1 diabetes who are affected by sexual arousal disorder: a double-blind, crossover, placebo-controlled pilot study. Fertil Steril. 2006;85:1496–501.
70. Laan E, van Lunsen RHW, Everaerd W, Riley A, Scott E, Boolell M. The enhancement of vaginal vasocongestion by sildenafil in healthy premenopausal women. J Womens Health Gend Base Med. 2002;11:357–65.
71. Jaspers L, Feys F, Bramer W, Franco O, Leusink P, Laan, E. Efficacy and safety of flibanserin for the treatment of Hypoactive Sexual Desire Disorder in women: A systematic review and meta-analysis of randomized controlled trials. JAMA Int Med. 2016;176:453–62
72. Poels S, Bloemers J, van Rooij K, Goldstein I, Gerritsen J, van Ham D, van Mameren F, Chivers M, Everaerd W, Koppeschaar H, Olivier B, Tuiten A. Toward personalized sexual medicine (Part 2): Testosterone combined with a PDE5 inhibitor increases sexual satisfaction in women with HSDD and FSAD, and a low sensitivity system for sexual cues. J Sex Med. 2013;10:810–23.
73. Rooij K, van Poels S, Bloemers J, Goldstein I, Gerritsen J, van Ham D, van Mameren F, Chivers M, Everaerd W, Koppeschaar H, Olivier B, Tuiten A. Toward personalized sexual medicine (Part 3): Testosterone combined with a serotonin1a receptor agonist increases sexual satisfaction in women with HSDD and FSAD, and dysfunctional activation of sexual inhibitory mechanisms. J Sex Med. 2013;10:824–37.
74. Leusink P, Boeke AJ, Laan E. Toward personalized sexual medicine: where is the evidence? J Sex Med. 2014;11(9):2357–8.
75. van Lunsen RHW, Laan E. Genital vascular responsiveness and sexual feelings in midlife women: psychophysiologic, brain, and genital imaging studies. Menopause. 2004;11:741–8.
76. Leiblum S, Bachmann G, Kemmann E, Colburn D, Schwartzman L. Vaginal atrophy in the postmenopausal woman: the importance of sexual activity and hormones. JAMA. 1983;249:2195–8.
77. Mathur RS, Landgreve SC, Moody LO, Semmens JP, Williamson HO. The effect of estrogen treatment on plasma concentrations of steroid hormones, gonadotropins, prolactin and sex hormone-binding globulin in post-menopausal women. Maturitas. 1985;7:129–33.
78. Davis SR. Androgen therapy in women, beyond libido. Climacteric. 2013;16 Suppl 1:18–24.

Part II

Fundamental Introduction to the Concepts of Clinical Roles, the Meta-competences, and POG Competency Profiles

A Theoretical and Empirical Study of the Core of the Psychosomatic Approach to Obstetrics and Gynecology: Meta-Competences, Clinical Roles, and POG Competency Profiles

21

Frits C. Meijering, Harry B.M. van de Wiel, and K. Marieke Paarlberg

21.1 Introduction

The professional roles that are relevant for all clinicians are summarized in the CanMEDS model shown in Fig. 21.1 [1]. Their relevance lies in the behavioral repertoire associated with the various roles; these behaviors can be used to deal with a variety of complex problems in a wide range of situations. The advantage of the clusters of knowledge, skills, and attitudes that go with these behaviors is that they are universal. Communication, collaboration, etc., transcend specialties and disciplines. They are *meta-competences* that can be applied in equal measure by other professionals such as midwives and even by HR staff, managers, and executives.

For this chapter, our point of departure was the 2005 version of the CanMEDS. Because this model is constantly in flux, to a certain extent the roles are also described on the basis of the 2015 draft version of CanMEDS 2015, in which

F.C. Meijering, MEd
NHL University of Applied Science, Department of Social Work, Groningen, The Netherlands
e-mail: f.c.meijering@gmail.com

H.B.M. van de Wiel, PhD (✉)
Wenckebach Institute, University of Groningen, University Medical Centre Groningen, Groningen, The Netherlands
e-mail: h.wiel@umcg.nl

K.M. Paarlberg, MD, PhD
Department of Obstetrics and Gynecology, Gelre Hospitals, Apeldoorn Location, Apeldoorn, The Netherlands
e-mail: km.paarlberg@xs4all.nl

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_21

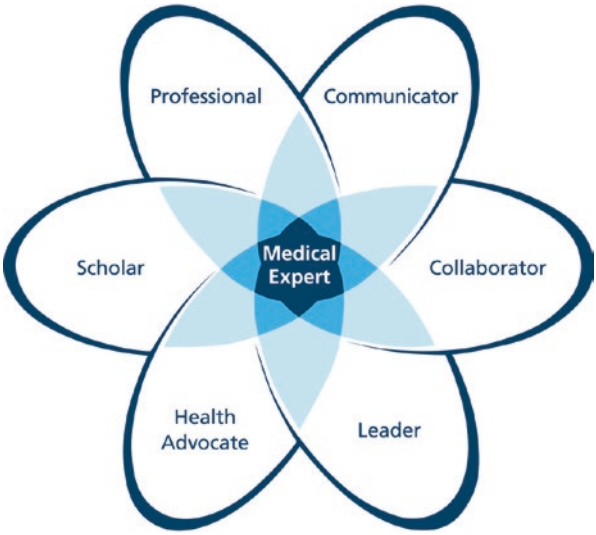


Fig. 21.1 The CanMEDS Roles Framework. (Copyright © 2015 The Royal College of Physicians and Surgeons of Canada. http://www.royalcollege.ca/rcsite/canmeds-e (Reproduced with permission)

the roles have been defined in even greater detail. We will distinguish the following seven roles:

- Professional
- Collaborator
- Communicator
- Manager (also leader/organizer)
- Scholar (also knowledge worker/tutor)
- Health advocate (also innovator/ethicist/lawyer/quality manager)
- Medical expert

Occasionally, the related secondary roles such as leader, tutor, organizer, etc., will also be touched upon in this chapter.

A great advantage of thinking in terms of meta-competences is that it offers a common frame of reference—a universal language to describe what a person needs to do and not do in order to become, to be, and to continue to be a good professional. The disadvantage of a meta-level approach is that the ideas and terminology that go with it soon tend to become abstract and incomprehensible. At present, this is reflected in the world of medical training, which is changing at an ever-increasing pace. The gap between the education architects and the clinical lecturers who do the actual teaching is growing wider every day. Because of all the different educational concepts and jargon, often clinicians can no longer see the educational wood for the trees. For this reason, the main aim of this contribution is to provide insight into thinking in meta-competences as an aid to shaping teaching and training in practice. The following topics will be addressed:

- A literature review – a compact outline of the principles on which working with meta-competences are based, as applied to clinical settings.

- A small-scale empirical study of what authors in a specific sub-domain of healthcare, psychosomatic obstetrics, and gynecology, regard as core competences.
- An ongoing case report, which illustrates the links between theory, empirical research, and practice. We will follow the experiences of a number of colleagues who have to deal in various ways with an external review of the teaching given to trainees in obstetrics and gynecology. They take on changing roles, as is highlighted by putting those roles in parentheses in italic type.

Case Report

Prof. Esther Crimson feels honored but also a little apprehensive. She has been asked to chair the assessment committee for an external peer review of training in a regional training hospital. She is honored first and foremost because she has finally reached a position in which she can make a difference (*innovator*, *leader*). As an expert in her field, she knows better than anyone else where the shortcomings in training lie (*knowledge worker*).

If she is honest with herself, her vanity also plays a role because of course "the Crimson Committee" sounds very flattering (*professional*). However, she also feels uncomfortable because she feels that as an educator she is not really a star (*knowledge worker*, *trainer*). While she scores above average for her lectures and seminars, this is not the same as developing "competence-oriented training in a learning landscape centered on co-creation and co-leadership" (*innovator*).

Fortunately, she will be supported by an expert staff member, David Olive, with whose help she can also select the other members of the committee (*collaborator*, *knowledge worker*). Of course there is also a manual setting out the procedure, and the primary focus is on self-evaluation by the institution itself (*leader*). To prepare herself as well as possible, Esther immerses herself in the information David has sent her in order to learn as much as possible about the self-evaluation report, the criteria for selecting committee members, and above all in "competence-oriented training" (*knowledge worker*, *trainer*).

21.2 Further Examination of Theory

1. The concept of competence
2. Thinking tools
3. Educational architecture
4. Training in practice
5. Conclusions (based on the literature)

21.2.1 The Concept of Competence

Even in ancient Greece and Rome, people were interested in the question of how to tackle problems competently. Odysseus is regarded as the model of a clever and

pragmatic problem-solver. In the past, competence has been more or less synonymous with the ability to act. Over the past century, the concept has broadened considerably and related terms have been introduced, such as "habits" [2, 3], "tacit knowledge" [3], "embodied cognition" [4–6], "capital" [7], "agency" [8], "capabilities" [9], and "thinking tools" [10].

For the purposes of this book, we will use the following pragmatic definition:

"Competences consist of the repertoire of behaviors and actions a health professional can use to solve complex problems in a wide range of situations in an inventive and creative way." This definition is closely linked to the six characteristic properties attributed to competences by Merriënboer et al. [11]:

1. Competences are context-dependent: the choice made from the broad repertoire of behaviors depends on what is required at a particular time, in a specific situation.
2. Competences are indivisible: they are *clusters* of skills, knowledge, attitudes, characteristics, and understanding which in terms of content are inseparable from each other.
3. Competences can change in the course of time and evolve as personal attributes over the years along with the health professional's lifelong learning.
4. Learning and development processes are crucial to the acquisition of competences.
5. Competences are linked to specific activities and tasks; they are manifested in behavior that is visible and can therefore also be tested.
6. Competences are related to each other in a certain way. The acquisition of a competence requires the presence of other competences.

These characteristics make it possible to use competences as building blocks to arrive at an inventive and creative solution for each problem. Regardless of whether the problem to be solved is a clinical one or, for example, how to implement a new training curriculum, in all situations the health professional, like an architect, has to design the ideal plan. Perhaps this sounds somewhat abstract and technocratic, but to thinkers, concepts and theories are what tools are to tradesmen. Concepts are the mental tools that enable people to cope, to exercise a certain degree of influence on their environment, and to act effectively and efficiently in a variety of contexts [12].

Case Report: Continued

When Esther Crimson and her team arrive at the hospital, she is cordially welcomed by an enthusiastic pair. Juliette Sapphire introduces herself as the trainer (*leader*) and Pascal Orange as her deputy trainer (*collaborator*). Together they form a kind of training tandem and as such they have taken on the worthy but labor-intensive task of writing the self-evaluation report. This report will serve as a starting point for the entire review procedure and also as a common thread running through it.

They have also drawn up a schedule for the review team to talk to the training group, the trainee gynecologists, the dean of the faculty, co-trainers from other disciplines in the hospital, the Chair of the Board of Management, the clinical midwives, the nurses, and the manager of the hospital's Learning Center. In short, a wide variety of people will make an appearance, with Juliette and Pascal acting as a uniting factor.

Although there is a full—if not overloaded—agenda, Esther thinks it is important to take plenty of time to get to know their hosts for the day personally (*communicator*, *collaborator*). She always does this with her patients, and in this case too, her investment in the relationship pays itself back many times over. By first asking Juliette and Pascal what they are proud of, she immediately creates an open and pleasant atmosphere.

Because they feel safe, Juliette and Pascal soon have the confidence to confess that in spite of their careful preparation, something has gone wrong. Some of the information requested is not available (*leader*, *organizer*). Fortunately, most of the basic documents such as the annual reports about procedures (operations and deliveries) and patient numbers are in fact present, as are the minutes of the training meetings over the past year and the dates and topics of the teaching sessions. What is missing is the results of the annual internal surveys about the training environment (*leader*, *trainer*).

Even though contacts with the trainee gynecologists usually go smoothly (*collaborator*), the evaluation of perceptions of this kind is always somewhat stressful, because it reflects the trainees' subjective perception, and just as with patient experiences, it is always subject to the mood of the day. What a person says about yesterday's experience depends on both today and yesterday. Esther realizes immediately that this is a good time to make a virtue of necessity (*leader*, *innovator*), precisely because this is a matter of subjective perception. She resolves to simply ask the trainees about this when she talks to them. After all, a dialogue is a much better tool for assessing mood and atmosphere than a written survey (*communicator*). However, she also decides to use this omission as a test case for the organizational creativity and stress resistance of the training tandem (*leader*, *professional*). And just as she thinks of this, she also realizes that in the same communication action she can make it clear that responsibility must always be placed where it belongs (*professional*).

"So what do you suggest now?" she asks, in a tone that is both friendly and firm. Fortunately, it turns out the trainers are made of the right stuff; they suggest that no matter how stressful this may be for themselves, the trainees' evaluation should simply be put on the agenda of the interviews with the trainees (*professional*). They will get back to the Central Training Committee about the missing survey results. When this suggestion seems to meet with everyone's approval, Esther remembers the wise words of one of her own trainers: "Medicine may be a career for doers, but words are the deeds of the powerful" (*communicator*).

David Olive uses the natural pause that follows to raise a more formal point. “Madam Chair, I have noticed that over the past year many training meetings have been cancelled (*Leader*, *Knowledge Worker*). The meetings of this Trainers’ group also have a relatively low attendance rate. Can anybody here explain this to me?”

Juliette replies slightly annoyed, “Yes, just in terms of our own teaching, this is actually a difficult issue. To encourage the trainees to make their own contribution, 2 trainees are given responsibility for each session in the teaching program. Some pairs are more active than others, but there are other factors as well. All the gynecologists, and sometimes guest speakers, take turns to give lectures. Everyone agreed to this, but apparently in practice it’s very difficult to leave the operating theater or the outpatient clinic on time. Even though the secretary makes sure the colleagues in question are scheduled not to be working with patients at those times, it sometimes happens that the teaching session has to be cancelled at the last minute because there is no lecturer (*Organizer*). A second factor is the presence of the trainees themselves. Either they’re still in the operating theater, or they’re still working in the delivery rooms, or they’re at a different location, they’re off duty after their work, they’re on holiday, pregnant, or whatever, so that there are never enough trainees present at the teaching sessions. It drives me mad.”

Esther sees the frustration on Juliette’s face and uses the same strategy as before, asking “And what have you done to solve this problem?” Pascal answers quickly. He knows Juliette. If she is frustrated about something that is not going the way she wants it to, she can sometimes go overboard in her reaction (*collaborator*, *communicator*, *professional*). He says calmly, “That is a very legitimate question. I think up till now we have all just been very irritated, but no-one has felt called upon or able to do anything about it.” Juliette nods as he speaks, a little embarrassed (*communicator*). Pascal then speaks to her directly, “Juliette, I do think it would be a good idea to discuss this point with the whole training team some time. After all, it’s our joint responsibility, not just yours or mine. I also think it would be good to have a meeting with the trainees and see if we can come up with some creative solutions for the teaching program (*Innovator*, *Knowledge Worker*). I recently saw an option for a simple digital connection that enables people at other locations to follow a presentation. I already wanted to talk to you about that, but this is a very good reason to do so” (*communicator*, *collaborator*, *leader*). Esther and David exchange a quick glance. Then Esther summarizes the intentions stated and David records them in the minutes. Esther concludes by saying, “Thank you for your thoughtful answer.”

21.2.2 Thinking Tools

Just as there is a world of clinical reasoning hidden beneath clinical actions, the CanMEDS roles and the meta-competences that go with them are above all the product of methodical problem-solving thinking. To put it more strongly, they themselves can be characterized as thinking tools [10]. Building on Popper's 3-world theory [13], Veening et al. [14] differentiate domains in which these thinking tools can be used: the physical domain, the psychological domain, and the social and cultural domain. Since ideas about these three domains form the core of the biopsychosocial (BPS) model (see also Chap. 24), we will discuss them briefly in the sections that follow.

21.2.2.1 The Physical Domain

The basis of our problem-solving capacity is physical. Based on neurobiological research, Damasio stresses that intelligence cannot be localized to one area of the brain and is not limited to the seat of our consciousness [5, 6]. A certain type of thinking activates several parts of the nervous system. In this context, Den Boer refers to "embodied cognition": The brain is in constant interaction with the body and the environment [4]. The brain is not static but plastic. Stressful circumstances have a negative impact on the micro-architecture of the brain. Polanyi draws attention to the importance of sensorimotor knowledge, which is literally embodied [3]. This knowledge is tacit and partly also preverbal, which is why it can only be made explicit to a limited extent. In other words, we know more than we are aware of. This is, in fact, essential, because this implicit background knowledge enables us to focus on complex problems that require our attention. While sensory knowledge can be converted into symbolic and theoretical knowledge [15], experienced professionals generally rely on their physical behavioral repertoire when solving problems. This is why gaining clinical experience—building up "flight time"—is so important.

21.2.2.2 The Psychological Domain

We need symbols and concepts, such as images and language, to make physical knowledge explicit. Through communication we share our knowledge and experience and gradually develop something like a shared sense of common practice. Emotions, as a hybrid of physical experiences and mental representations, play an important role in communication. In particular, intense emotions such as rage, disgust, or horror can have an adverse effect on clinical reasoning because emotions of this kind are accompanied by irrelevant or irrational thoughts. One of the characteristics of professionalism is the ability to regulate one's own behavior in spite of the emotions that will inevitably arise. This ability to control one's own behavior—referred to as self-management—is based on insight into one's own personal and professional values. Relating these values to the demands of the context enables a professional to reconcile even fundamental contradictions. This is referred to as

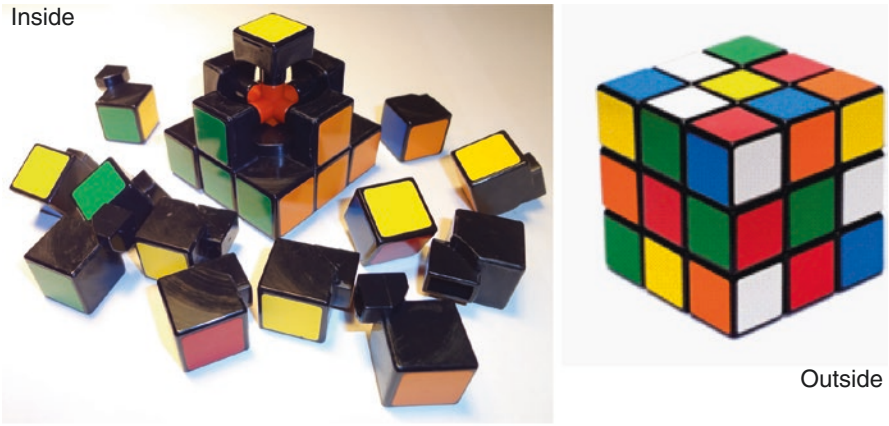


Fig. 21.2 The Rubik's Cube® (Rubik's Brand LTD, London, UK) reflects competences: core as indivisible unit; exterior manifests itself integrally in the biological, psychological, and sociocultural domains. (Left photo by Hangsna https://commons.wikimedia.org/wiki/File:Rubiks_cube_inside.JPG#file. Used under Creative Commons license: CC BY-SA 3.0: http://creativecommons.org/licenses/by-sa/3.0; Right photo: Rubik's Cube® (Used by permission of Rubik's Brand LTD, www.rubiks.com)

"clinical leadership." A few examples of dilemmas in which leadership is essential are those involving

- Professional autonomy versus interdependence
- Individual interests versus group interests
- Loyalty to the patient versus loyalty to the organization
- Identification with one's own profession versus identification with the organization
- Professional interests versus financial interests
- Work interests versus private interests

To be able to weigh the conflicting interests against each other, you must be able to put yourself in the conflicting positions that go along with these interests. This ability, to put yourself in different positions, is known as empathy. Empathy is one of the most fundamental prerequisites of leadership and professionalism.

21.2.2.3 The Social or Communal Domain (of Ideas and Theories)

Effective action also depends on the social and cultural environment in which one is acting. A professional can be dysfunctional in one context but act effectively in a different situation using the same competences. Behavior depends on the situation and the context. Every profession has its own special features, such as clothing, language (professional jargon), etc., by which the members can recognize each other. In addition to this recognizability, conventions and symbols also give the professionals in the group something they can rely on. However, while conventions

and symbols may provide a kind of support, they can also lead to rigidity and irrational behavior.

To summarize, we can imagine that competences are like a Rubik's cube: the core is an indivisible unit whose exterior always manifests itself integrally in the biological, psychological, and sociocultural domains (Fig. 21.2).

This approach to competences as thinking tools to shape the development and training of healthcare professionals is completely in line with the BPS model, which is the core of the psychosomatic approach to disease and health.

Case Report: Continued

As an experienced organizer, Esther Crimson has made sure that in spite of the busy program, there are regular points at which the committee can evaluate how things are going. When Esther considers her team, she realizes that she has not only made the right choices but has also been lucky. Choosing the members of the assessment committee, which was allowed five members only, had been one of the privileges of the Chair. Along with David Olive, the official secretary, Esther had soon come to the conclusion that the committee needed to be a reflection of the underlying training model.

Thinking "practice what you preach," she had therefore drawn up a list of their ideal team based on the CanMEDS roles. They would ask Jules Copper, a trainer at a university hospital in the north of the country, because he could fulfill the role of *professional expert* better than anyone else. Myrna Bronze, a trainer at a training hospital in the south of the country, is known throughout the country for her *communicative and collaboration skills*. Donna Cobalt, although she had only been in training for a relatively short time, had already, several times and at a national level, shown herself to be an outstanding representative of, and *advocate* for, the training interests of trainee specialists. When David Olive told her that he had worked as a special education expert for almost 10 years and had now been working for 5 years as a policy officer, Esther knew he would be ideal for the role of *knowledge worker*. All that was left was actually her modest task of getting this motley group to function as a team, in spite of—or perhaps thanks to—their diversity (*leader*, *professional*) and ensuring that the right things were done in the right way (*professional*). Fortunately, all the candidates accepted the invitation, and it turned out that their collaborative qualities were not only on paper—they could in fact work well together in real life. This became clear immediately at the next discussion that day—the meeting with the trainers' group.

Esther is glad they had agreed on a clear distribution of tasks in advance (*leader*, *communicator*, *collaborator*). As the Chair (*leader*, *innovator*), her role would mainly be limited to procedural leadership of the discussions (*leader*). The discussion soon gets underway when Jules Copper questions the

number of procedures the trainees are able to perform at the clinic (*medical expert*). "If they learn so many minimally invasive techniques, then surely they won't be able to perform open surgery anymore? How do you solve this?"

The trainers have also prepared themselves well and agreed on a distribution of tasks (*leader*). As the most communicative member of the group, Pascal smoothly takes over from Juliette and says, "That's not a problem at all. Minimally invasive surgery is the technique of the future (*Innovator*). The trainees are trained very well in it and that also enhances their open surgery skills. They will always continue to do open caesarean sections and be able to resolve the complications, because even in the coming centuries babies are not going to be born by laparoscopy. We are also working with the university hospital on a simulation program called 'Medical Procedures, Knowledge and Science,' which will be able to provide effective training in open surgery, including all kinds of potential complications." Jules Copper laughs and admits Pascal has a point.

Soon the discussion moves on to the simulation program that is being developed, touching on topics such as e-learning, serious gaming, and working with knowledge platforms and learning landscapes. For a moment, Esther is worried that this part of the discussion will go over her head and she is about to cut the discussion short (*leader*). However, since she can feel the enthusiasm of the others almost physically, she decides to wait for a while (*professionalism*) and to rely on the qualities of her committee members (*collaborator*). For herself, she takes note that she needs to delve deeper into the concept of competence-oriented training, which is evidently quite complex (*professionalism*, *knowledge worker*).

21.2.3 The Architecture of Teaching

If we want to describe complex behavior in a way that is lucid but still sufficiently detailed, for instance, for the purposes of training and assessment, we need a flexible structure. Thinking in terms of competences provides such a structure, but that is not all it does. Competences can be both clustered (into meta-competences) and divided (into sub-competences). In other words, competences can be both *integrated* and *differentiated*—they are *fractals* (Fig. 21.3).

Building in modules enables us to customize the architecture of our teaching. We can build different constructions all the time, ranging from simple lessons to whole curricula, while using the same set of universal didactic building blocks. Moreover, to some extent, meta-competences have the same characteristics as competences (discussed earlier in this chapter), but due to their integration at a higher level of abstraction, they also have some specific characteristics. These specific characteristics are particularly helpful when it comes to understanding the functional link

Fig. 21.3 Meta-competences in action, by using a limited number of conceptual building blocks, an infinite number of practical constructions can be made (Making of Rubik Florence Rey, Invader, 2005, Paris. Copyright: space-invaders.com; used with permission)

between teaching objectives (what you are aiming to achieve) and modes of instruction (how you operationalize these objectives):

- Meta-competences are relatively independent, functional modes of action that can come to the fore or retreat to the background in turn—as in the term "Gestalt switch" in psychology. Each meta-competence represents a particular "logic" or way of thinking, a heuristic that is needed to solve complex problems. Communication with a patient during a gynecological examination requires a different approach from clinical reasoning during that same examination. In our case study, we constantly see one or more roles coming to the fore. While the Chair's focus as a *communicator* is on making sure people understand each other, as an *organizer* her main concern is to ensure things go quickly and smoothly.
- There is some tension between the different meta-competences as competing values—only one aspect can come to the fore at one time. At the beginning in particular, the focus on communication can have an adverse effect on other aspects such as innovation or leadership. The more professional a person becomes, the easier it will be to deal with the contradictions, paradoxes, sticking points, frictions, and moral dilemmas that are inevitably associated with this profession and with working in a complex context. The various building blocks represent a force field of competing values.

- Meta-competences are complementary thinking paths that can reinforce each other (flow) or oppose each other (resistance) and that can be combined by making cross-connections. When meta-competences have a negative impact on each other, constraints, paradoxes, tensions, barriers, blocks, paralysis, and frustration can arise. People end up in a negative spiral when they are unable to resolve conflicting values. If it is the other way around, a great deal of synergy or even flow results. The meta-competence areas reinforce each other and act like a flywheel. An example of negative impact is the unnecessary nervous unrest sometimes generated by the division of attention. The opposite, synergy, is also possible, for instance if, during a consultation, a practitioner communicates about a technical hitch by saying, "This is always a bit tricky, so if I don't say anything, it doesn't mean there's something seriously wrong. I just have to concentrate."
- Meta-competences are interdependent and together constitute a coherent whole or system. Cross-connections can be made between meta-competences. People can switch to and fro. Sometimes the emphasis is on communication, at other times on leadership or knowledge. Meta-competences can change perspectives, taking a first-person, second-person, or third-person perspective (I, you, we, it). Approaching a problem from a different meta-competence area makes room for inventive and creative solutions. Personal and professional development strengthens meta-competences, resulting in a creative spiral. This flexibility also makes it possible to recognize or deliberately establish certain patterns, so that a clearer profile can be put forward. All meta-competences are still important and present in the background, but certain competences are prominent at a particular point, in a particular situation, or with a particular disorder.

21.2.4 The Real World

The meta-competences model (MCM) has many advantages, particularly from the perspective of "clinical governance," which has been described as "a framework through which organizations are accountable for continuously improving the quality of their services and safeguarding high standards of care by creating an environment in which excellence in clinical care will flourish" [16]. Here we will focus on leadership and innovation and in particular on their relevance to psychosomatic obstetrics and gynecology and the biopsychosocial model (BPS model) that goes with it.

1. In its healthcare philosophy, the MCM is very much in line with the BPS model. It acknowledges clinical complexity, particularly in relation to functional symptoms, moral dilemmas, and integrated multidisciplinary care. Personal leadership is required to solve complex problems of this kind in an inventive or creative way, with the aid of a range of heuristics or modes of thought such as the exact sciences, psychology, and the humanities.

2. The MCM is premised on participation and self-management on the basis of rationality. There are two aspects: the undercurrent of emotional intelligence (EQ) and the upper current of cognitive intelligence (IQ). The combination of the two aspects (care and cure) is the basis of individual empowerment and social participation. Empowerment is also based on lifelong learning.
3. The MCM provides a theoretical frame of reference in the form of a network of integrated concepts and dimensions. This can help clinicians to arrive at a clear-cut definition (a diagnosis, for example) and also to operationalize their actions in terms of specific behavior (treatment).
4. The MCM focuses primarily on individual professionals, who are the basic units, but it can also easily be used at higher aggregation levels: micro, meso, and macro. The competence of a team or organization can also be mapped out, providing a rational basis for specialist differentiation.
5. The MCM is a generic framework. Specific details can be filled in to match practically any context. This means that a limited number of building blocks (meta-competences) can be used to design an infinite number of customized programs (architecture).
6. The MCM functions as a knowledge platform and as such provides a basis for countless applications, such as in clinical leadership, self-assessment, coaching, HR development programs, educational programs, curricula, health and welfare programs, and incentive programs.
7. The model is a *system* consisting of elements (types of behavior) and six aspects or meta-competences. These meta-competences, which can also be regarded as kinds of capital, are interdependent and emergent: the whole is more than the sum of the parts. Thanks to the connections between the meta-competences, added benefits arise in the shape of an innovative concept that can then be developed into a prototype.
8. The MCM reduces complexity and thus increases the transparency of the competence approach. The 40 or more types of behavior generally included in other approaches are clustered into a limited number of overarching meta-competences. The model is simple and is therefore itself an example of lean design. The MCM uses images, mind maps, or diagrams for representation and visualization.
9. The MCM has a dynamic structure because the different meta-competences represent different mental software programs or heuristics. Each mental program fulfills a specific role in the system. Individuals use different mental programs when making choices and decisions.
10. There is an inherent tension between the meta-competences, which is conducive to finding inventive or creative solutions to complex problems. Meta-competences represent competing values, which enable people to think outside of the box by changing their thinking strategy [17]. Healthcare involves many tough issues, such as authority in horizontal teams (partnerships, multidisciplinary consultations), fair remuneration, the allocation of resources, etc. Choosing a different angle—for instance, taking a development perspective

instead of an equality perspective—makes it possible to solve even problems of this kind. Healthcare professionals switch between different meta-competences. Lateral connections enable the emergence of innovative solutions [18].

Case Report: Continued

The next group on the schedule is the one it is all really about: the trainee gynecologists. At the preliminary meeting, the committee members had agreed that Donna Cobalt, herself a trainee and in that sense a primus inter pares, would be the first to speak. It turns out she has embraced her role as representative of the trainees' interests with vigor. After the usual, more or less standard opening questions, the issue of dealing with medical incidents is soon raised. It seems that such incidents have in fact occurred, including over the past year. Although the trainees think the gynecologists gave them adequate support after these incidents (*professional*, *collaborator*), they also believe it should be possible for them to talk to a confidential adviser outside their own department (*professional*).

Donna asks what is preventing them from turning tragic incidents into useful learning experiences. Apart from the trainees' personal inhibitions—no one is proud of mistakes—it seems there are also some other obstacles. Although the staff members never say anything about this out loud, the trainees sense a huge amount of fear of damage to the department's reputation. While normally the staff tries to support the trainees as much as possible and to act as a team (*collaborator*), the team spirit is put under a lot of pressure as soon as there is a chance an incident might be made public.

The staff acknowledges the truth of this but seems to be hiding behind their own emotions and hospital politics. The trainees quote Juliette almost literally, "Yes, yes… but you know incidents like this really take their toll, on us too" and "At our hospital we haven't made any standard arrangements for counseling for trainees in these situations yet, but it would be a good idea to do that" (*communicator*, *leader*).

One of the other trainees speaks up, "That sounds understandable and plausible, but it actually makes any further discussion impossible. And in the meantime nothing happens and we're all waiting for each other."

Donna had been paying attention when Esther reminded Juliette and Pascal of their initiative and responsibility. "OK," she says, "it's good that you've brought this up, because a safe working and learning environment is one of our priority areas. What action have you yourselves taken to address this?"

The trainees react positively to this challenge, and it soon becomes evident that they have already thought quite a lot about this issue. "I recently heard that at one of the university hospitals they have developed a kind of quick scan in the form of a one-hour Prospective Risk Inventory (PRI). Apparently that works well." Donna compliments the trainees on their proactive approach and promises to put this point on the agenda for the meeting with the Chair of the hospital's Central Training Committee (*professional*, *collaborator*, *knowledge worker*). Everyone agrees with this and David Olive makes a note of it for his report.

21.2.5 Conclusions

To summarize, based on the literature we can conclude that

- There have been rapid developments in medical training, with "ordinary" teaching being replaced by "complex" learning landscape architecture.
- The various CanMEDS roles and in particular the meta-competences that go with them play a crucial role in training.
- To meet the requirements of both customization and cross-disciplinary universality, flexible didactic operationalization is essential, in the form of modular teaching units analogous to Rubik's cubes or LEGO building blocks.

At the cross-disciplinary level there is a high degree of consensus about the importance and nature of the clinical meta-competences. Although many sub-competences have been distinguished in theory, the literature does not offer any insight into which sub-competences are or should be given priority in training programs. On the assumption that "all building blocks are equal but some are more equal than others," we examined which sub-competences are core competences within the domain of psychosomatic obstetrics and gynecology (POG).

21.3 Empirical Approach

21.3.1 Introduction

For a proposed book on psychosomatic obstetrics and gynecology, 20 pairs of internationally recognized experts were each asked to write a chapter. Each pair consisted of one author with a medical background and one with a background in psychosocial research and professional training. In addition to writing the chapter, they were also asked to draw up a chapter-specific competence profile based on the seven CanMEDS roles. These profiles were then used to create an overarching psychosomatic competence profile.

The following topics were discussed:

1. Methodology
2. Results
3. Conclusions (based on empirical research)

21.3.2 Methodology

Forty authors of a book on psychosomatic obstetrics and gynecology were asked to prioritize the seven CanMEDS competences and sub-competences. In order to do so, they were sent a digital copy of the seven roles including all the sub-competences, based on the 2005 CanMEDS competence profile. The authors were asked to highlight their personal top 25–30 % of the competences in relation to the specific subject or domain they had discussed in their chapter.

The competences designated by 50% or more of the authors as important for dealing with the problems they had discussed in their chapter have been highlighted in Table 21.1 and are listed separately below. The bar graph shows the resulting distribution of the sub-competences.

See http://www.royalcollege.ca/portal/page/portal/rc/canmeds for a full description of roles, competences, and sub-competences.

21.3.3 Results

All of the competences mentioned below come directly from the CanMEDS Website (http://www.royalcollege.ca/portal/page/portal/rc/canmeds):

1. *Scholar*
   - Recognize and reflect learning issues in practice.
   - Integrate new learning into practice.
   - Integrate critical appraisal conclusions into clinical care.
2. *Health advocate*
   - Identify the health needs of an individual patient.
3. *Communicator*
   - Establish positive therapeutic relationships with patients and their families that are characterized by understanding, trust, respect, honesty, and empathy.
   - Listen effectively.
   - Gather information about a disease but also about a patient's beliefs, concerns, expectations, and illness experience.
   - Deliver information to a patient and family, colleagues, and other professionals in a humane manner and in such a way that it is understandable, encourages discussion and participation in decision-making.
   - Encourage discussion, questions, and interaction in the encounter.
   - Maintain clear, accurate, and appropriate records of clinical encounters and plans.
4. *Collaborator*
   - Work with others to assess, plan, provide, and integrate care for individual patients (or groups of patients).
   - Participate effectively in interprofessional team meetings.
   - Demonstrate a respectful attitude toward other colleagues and members of an interprofessional team.
5. *Professional*
   - Exhibit appropriate professional behaviors in practice, including honesty, integrity, commitment, compassion, respect, and altruism.
   - Maintain appropriate relations with patients.
6. *Leader*
   - Work collaboratively with others in their organizations.

Table 21.1 Competency profile overview

CanMEDS meta-competences	Percentage in bars
1. Scholar	
1.1 Maintain and enhance professional activities through ongoing learning	
1.1.1 Describe the principles of maintenance of competence	10.0%
1.1.2 Describe the principles and strategies for implementing a personal knowledge management system	5.0%
1.1.3 Recognize and reflect learning issues in practice	50.0%
1.1.4 Conduct a personal practice audit	10.0%
1.1.5 Pose an appropriate learning question	5.0%
1.1.6 Access and interpret the relevant evidence	30.0%
1.1.7 Integrate new learning into practice	65.0%
1.1.8 Evaluate the impact of any change in practice	20.0%
1.1.9 Document the learning process	5.0%
1.2 Critically evaluate medical information and its sources, and apply this appropriately to practice decisions	
1.2.1 Describe the principles of critical appraisal	25.0%
1.2.2 Critically appraise retrieved evidence in order to address a clinical question	30.0%
1.2.3 Integrate critical appraisal conclusions into clinical care	55.0%
1.3 Facilitate the learning of patients, families, students, residents, other health professionals, the public and others, as appropriate	
1.3.1 Describe principles of learning relevant to medical education	0.0%
1.3.2 Collaboratively identify the learning needs and desired learning outcomes of others	25.0%
1.3.3 Select effective teaching strategies and content to facilitate others' learning	25.0%
1.3.4 Demonstrate an effective lecture or presentation	10.0%
1.3.5 Assess and reflect on a teaching encounter	10.0%
1.3.6 Provide effective feedback	25.0%
1.3.7 Describe the principles of ethics with respect to teaching	5.0%
1.4 Contribute to the development, dissemination, and translation of new knowledge and practices	
1.4.1 Describe the principles of research and scholarly inquiry	0.0%
1.4.2 Describe the principles of research ethics	0.0%
1.4.3 Pose a scholarly question	0.0%
1.4.4 Conduct a systematic search for evidence	35.0%
1.4.5 Select and apply appropriate methods to address the question	5.0%
1.4.6 Appropriately disseminate the findings of a study	45.0%
2. Health Advocate	
2.1 Respond to individual patient health needs and issues as part of patient care	
2.1.1 Identify the health needs of an individual patient	75.0%
2.1.2 Identify opportunities for advocacy, health promotion and disease prevention with individuals to whom they provide care	40.0%
2.2 Respond to the health needs of the communities that they serve	
2.2.1 Describe the practice communities that they serve	5.0%
2.2.2 Identify opportunities for advocacy, health promotion and disease prevention in the communities that they serve, and respond appropriately	45.0%
2.2.3 Appreciate the possibility of competing interests between the communities served and other populations	0.0%
2.3 Identify the determinants of health for the populations that they serve	
2.3.1 Identify the determinants of health of the populations, including barriers to access to care and resources	45.0%
2.3.2 Identify vulnerable or marginalized populations within those served and respond appropriately	45.0%
2.4 Promote the health of individual patients, communities, and populations	
2.4.1 Describe an approach to implementing a change in a determinant of health of the populations they serve	35.0%
2.4.2 Describe how public policy impacts on the health of the populations served	10.0%
2.4.3 Identify points of influence in the healthcare system and its structure	25.0%
2.4.4 Describe the ethical and professional issues inherent in health advocacy, including altruism, social justice, autonomy, integrity and idealism	20.0%
2.4.5 Appreciate the possibility of conflict inherent in their role as a health advocate for a patient or community with that of manager or gatekeeper	5.0%
2.4.6 Describe the role of the medical profession in advocating collectively for health and patient safety	15.0%
3. Communicator	
3.1 Develop rapport, trust, and ethical therapeutic relationships with patients and families	
3.1.1 Recognize that being a good communicator is a core clinical skill for physicians, and that effective physician-patient communication can foster patient satisfaction, physician satisfaction, adherence and improved clinical outcomes	45.0%
3.1.2 Establish positive therapeutic relationships with patients and their families that are characterized by understanding, trust, respect, honesty and empathy	70.0%
3.1.3 Respect patient confidentiality, privacy and autonomy	45.0%
3.1.4 Listen effectively	65.0%
3.1.5 Be aware and responsive to nonverbal cues	50.0%
3.1.6 Effectively facilitate a structured clinical encounter	20.0%

(continued)

Table 21.1 (continued)

CanMEDS meta competences	Percentage in bars
3.2 Accurately elicit and synthesize relevant information and perspectives of patients and families, colleagues, and other professionals	
3.2.1 Gather information about a disease, but also about a patient's beliefs, concerns, expectations and illness experience	70.0%
3.2.2 Seek out and synthesize relevant information from other sources, such as a patient's family, caregivers and other professionals	15.0%
3.3 Accurately convey relevant information and explanations to patients and families, colleagues and other professionals	
3.3.1 Deliver information to a patient and family, colleagues and other professionals in a humane manner and in such a way that it is understandable, encourages discussion and participation in decision-making	70.0%
3.3 Develop a common understanding on issues, problems and plans with patients, families, and other professionals to develop a shared plan of care	
3.4.1 Effectively identify and explore problems to be addressed from a patient encounter, including the patient's context, responses, concerns, and preferences	45.0%
3.4.2 Respect diversity and difference, including but not limited to the impact of gender, religion and cultural beliefs on decision-making	40.0%
3.4.3 Encourage discussion, questions, and interaction in the encounter	55.0%
3.4.4 Engage patients, families, and relevant health professionals in shared decision-making to develop a plan of care	40.0%
3.4.5 Effectively address challenging communication issues such as obtaining informed consent, delivering bad news, and addressing anger, confusion and misunderstanding	40.0%
3.5 Convey effective oral and written information about a medical encounter	
3.5.1 Maintain clear, accurate, and appropriate records of clinical encounters and plans	55.0%
3.5.2 Effectively present verbal reports of clinical encounters and plans	5.0%
3.5.3 When appropriate, effectively present medical information to the public or media about a medical issue	15.0%
4. Collaborator	
4.1 Participate effectively and appropriately in an interprofessional healthcare team	
4.1.1 Clearly describe their roles and responsibilities to other professionals	10.0%
4.1.2 Describe the roles and responsibilities of other professionals within the health care team	20.0%
4.1.3 Recognize and respect the diversity of roles, responsibilities and competences of other professionals in relation to their own	45.0%
4.1.4 Work with others to assess, plan, provide and integrate care for individual patients (or groups of patients)	95.0%
4.1.5 Where appropriate, work with others to assess, plan, provide and review other tasks, such as research problems, educational work, program review or administrative responsibilities	5.0%
4.1.6 Participate effectively in interprofessional team meetings	70.0%
4.1.7 Enter into interdependent relationships with other professions for the provision of quality care	10.0%
4.1.8 Describe the principles of team dynamics	0.0%
4.1.9 Respect team ethics, including confidentiality, resource allocation and professionalism	10.0%
4.1.10 Where appropriate, demonstrate leadership in a healthcare team	5.0%
4.2 Effectively work with other health professionals to prevent, negotiate, and resolve interprofessional conflict	
4.2.1 Demonstrate a respectful attitude towards other colleagues and members of an interprofessional team	65.0%
4.2.2 Work with other professionals to prevent conflicts	15.0%
4.2.3 Employ collaborative negotiation to resolve conflicts	0.0%
4.2.4 Respect differences, misunderstandings and limitations in other professionals	10.0%
4.2.5 Recognize one's own differences, misunderstanding and limitations that may contribute to interprofessional tension	20.0%
4.2.6 Reflect on interprofessional team function	30.0%
5. Professional	
5.1 Demonstrate a commitment to their patients, profession, and society through ethical practice	
5.1.1 Exhibit appropriate professional behaviors in practice, including honesty, integrity, commitment, compassion, respect and altruism	90.0%
5.1.2 Demonstrate a commitment to delivering the highest quality care and maintenance of competence	35.0%
5.1.3 Recognize and appropriately respond to ethical issues encountered in practice	50.0%
5.1.4 Appropriately manage conflicts of interest	20.0%
5.1.5 Recognize the principles and limits of patient confidentiality as defined by professional practice standards and the law	25.0%
5.1.6 Maintain appropriate relations with patients.	65.0%
5.2 Demonstrate a commitment to their patients, profession and society through participation in profession-led regulation	
5.2.1 Appreciate the professional, legal and ethical codes of practice	40.0%
5.2.2 Fulfil the regulatory and legal obligations required of current practice	30.0%
5.2.3 Demonstrate accountability to professional regulatory bodies	0.0%
5.2.4 Recognize and respond to others' unprofessional behaviors in practice	20.0%
5.2 5 Participate in peer review	10.0%
5.3 Demonstrate a commitment to physician health and sustainable practice	
5.3.1 Balance personal and professional priorities to ensure personal health and a sustainable practice	20.0%
5.3.2 Strive to heighten personal and professional awareness and insight	40.0%
5.3.3 Recognize other professionals in need and respond appropriately	25.0%

CanMEDS meta competences	Percentage in bars
6. Leader	
6.1 Participate in activities that contribute to the effectiveness of their healthcare organizations and systems	
6.1.1 Work collaboratively with others in their organizations	75.0%
6.1.2 Participate in systemic quality process evaluation and improvement, such as patient safety initiatives	25.0%
6.1.3 Describe the structure and function of the healthcare system as it relates to their specialty, including the roles of physicians	25.0%
6.1.4 Describe principles of healthcare financing, including physician remuneration, budgeting and organizational funding	0.0%
6.2 Manage their practice and career effectively	
6.2.1 Set priorities and manage time to balance patient care, practice requirements, outside activities and personal life	15.0%
6.2.2 Manage a practice including finances and human resources	0.0%
6.2.3 Implement processes to ensure personal practice improvement	30.0%
6.2.4 Employ information technology appropriately for patient care	30.0%
6.3 Allocate finite healthcare resources appropriately	
6.3.1 Recognize the importance of just allocation of healthcare resources, balancing effectiveness, efficiency and access with optimal patient care	40.0%
6.3.2 Apply evidence and management processes for cost-appropriate care	20.0%
6.4 Serve in administration and leadership roles, as appropriate	
6.4.1 Chair or participate effectively in committees and meetings	10.0%
6.4.2 Lead or implement a change in health care	40.0%
6.4.3 Plan relevant elements of health care delivery (e.g., work schedules)	0.0%
7. Medical Expert	
7.1 Function effectively as consultants, integrating all of the CanMEDS Roles	
7.1.1 Effectively perform a consultation	40.0%
7.1.2 Effective use of CanMEDS competencies	5.0%
7.1.3 Identify and respond to ethical issues	10.0%
7.1.4 Prioritize professional duties in multiple patients and problems	10.0%
7.1.5 Compassionate/patient-centered care	90.0%
7.1.6 Ethical dimensions in medical decision-making	35.0%
7.1.7 Medical expertise outside health care	10.0%
7.2 Establish and maintain clinical knowledge, skills and attitudes appropriate to their practice	
7.2.1 Apply knowledge of the clinical, socio-behavioural, and fundamental biomedical sciences	60.0%
7.2.2 Describe the framework of competencies relevant to the physician's specialty	0.0%
7.2.3 Apply lifelong learning skills of the Scholar Role to implement a personal program	30.0%
7.2.4 Contribute to the enhancement of quality care and patient safety in their practice	35.0%
7.3 Perform a complete and appropriate assessment of a patient	
7.3.1 Effectively identify and explore issues to be addressed in a patient encounter	85.0%
7.3.2 Elicit a history that is relevant, concise and accurate to context and preferences	30.0%
7.3.3 Perform a focused physical examination that is relevant and accurate	20.0%
7.3.4 Select medically appropriate investigative methods in a resource-effective and ethical manner	15.0%
7.3.5 Demonstrate effective clinical problem solving and judgment to address patient problems	60.0%
7.4 Use preventive and therapeutic interventions effectively	
7.4.1 Implement an effective management plan in collaboration with a patient and their family	65.0%
7.4.2 Demonstrate effective, appropriate, and timely application of preventive and therapeutic interventions relevant to the physician's practice	25.0%
7.4.3 Ensure appropriate informed consent is obtained for therapies	35.0%
7.4.4 Ensure patients receive appropriate end-of-life care	0.0%
7.5 Demonstrate proficient and appropriate use of procedural skills, both diagnostic and therapeutic	
7.5.1 Ensure appropriate informed consent is obtained for procedures	35.0%
7.5.2 Appropriately document and disseminate information related to procedures performed and their outcomes	25.0%
7.5.3 Ensure adequate follow-up is arranged for procedures performed	45.0%
7.6 Seek appropriate consultation from other health professionals, recognizing the limits of their expertise	
7.6.1 Demonstrate insight into their own limitations of expertise via selfassessment	35.0%
7.6.2 Demonstrate effective, appropriate, and timely consultation of another health professional as needed for optimal patient care	85.0%
7.6.3 Arrange appropriate follow-up care services for a patient and their family	25.0%

7. (*Medical*) *expert*
   - Compassionate/patient-centered care.
   - Apply knowledge of the clinical, socio-behavioral, and fundamental biomedical sciences.
   - Effectively identify and explore issues to be addressed in a patient encounter.
   - Demonstrate effective clinical problem-solving and judgment to address patient problems.
   - Implement an effective management plan in collaboration with a patient and their family.

21.3.4 Conclusions Based on Empirical Research

On the basis of the data—roughly 40 personal opinions of internationally recognized experts in psychosomatic obstetrics and gynecology—it can be concluded that *interactivity* plays a key role in this domain. The high priority given to the meta-competences collaboration, communication, and professionalism corresponds to what Watzslawick referred to as the *relational aspect*—the way people regulate their interactions with one another [19]. This relational aspect is manifested in the often implicit instructions as to how the explicit message is to be understood. Clearly, the emphasis in POG is on meta-communication and thus on zooming out from the medical problem itself to the "question behind the question," "the patient behind the symptoms," "the woman behind the patient," etc. The biomedical approach seems to concentrate on zooming in at the medical level, focusing on which mechanisms play a role and how things work. The emphasis is then much more on roles such as organizer, knowledge worker, and innovator.

21.4 General Discussion

"At the turn of the century, medical education, inspired by a renewed emphasis on the essential abilities physicians need for optimal patient outcomes and on preparing students for clinical practice, switched from problem-based learning to an outcomes or competencies based approach," according to Wouda [20]. In this context, competence-based learning has been extended to all healthcare professionals, and competences have been pragmatically defined as "the repertoire of behaviors and actions healthcare professionals can use to solve complex problems in a wide range of situations in an inventive and creative way." Although this competence approach is often presented as new, it is, in fact, neither new nor specific to healthcare, in which it is mainly associated with lifelong learning. The idea that the basis of personal and above all professional development lies in lifelong learning was propagated by John Dewey in the early twentieth century [2, 21]. However, this idea has become extremely topical in postmodern society because individual development and the course of an individual's life have become less and less predictable. There

is no standard biography for individual employees or for organizations. On the contrary, during their lives, people experience a variety of living arrangements and often work in a number of different jobs, positions, and occupations. Professionals also often make fundamental choices that change the course of their lives. This demands reflection, self-management, and personal leadership [22]. Moreover, in recent years, the standards for professional competence have been set much higher; being good at your job is no longer enough. In short, it is not so much the diploma you obtain as your later development that determines your professional life. This requires an approach to training that facilitates and motivates this personal development.

On the basis of a literature review and a small-scale empirical study, we came to the conclusion that the meta-competence model (MCM), derived from the CanMEDS roles, provides a solid foundation for such an approach. The MCM enables trainees to conceptualize the competences and to make appropriate choices from meaningful activities. Competences serve as resources to continue to learn proactively. They manage themselves and each other, which also means that roles are often reversed. Lecturers learn from students and treating practitioners learn from patients. The idea that human learning capacity is the basis of personal and organizational success reflects the importance of growth and development from an organizational perspective. The shift from "human resource management" to "human resource development" is in line with the current trend toward sustainability but also reflects the importance of interactivity. This emphasis on interaction is also manifested in the importance attached to the meta-competences of communication, collaboration, and professionalism. The same trend is reflected in recent care models such as the chronic care model [23]. This model uses concepts such as self-management and empowerment, but ultimately the pivotal concern is *productive interaction* between care provider and care consumer. This requires the ability to zoom both in and out on problems or issues, examining both what is happening and how it is happening and also what the problem means in the specific context. In short, what is clinically manifested is also visible in the world of training and development.

This tendency to think in parallel lines is not unique to healthcare. Prahalad scales the competence concept up to the organizational level [24]. Successful companies and organizations have a core competence that distinguishes them from their competitors. An organization's core competence is developed by mobilizing internal resources within the organization. Human resources are an organization's most important resources and the organization that makes the best use of these will be the most successful in terms of yields, quality, etc. Sen points out that even economic transactions are not only about exchanging goods and services but also about encouraging personal *development*. In trade and commerce, people learn to listen to each other and communicate in various ways, and intercultural exchange occurs [9].

Sen distinguishes two essential elements of competence: rational economic action and moral functioning. People are not atomistic individuals; they depend on other people, and, in the long term, investing in education is the most effective form

of development cooperation and care. Clinicians know better than anyone else how vulnerable people are and how dependent they are on the care of others [25, 26]. Trust is an essential factor. Two types of trust are involved: confidence in professional expertise and personal trust in each other as human beings [27]. People can have confidence in formal contracts, procedures, protocols, organizations, economic and political systems, etc.—a kind of confidence based on rational considerations and formal guarantees. Apart from this, people can also trust other individuals. Personal trust goes beyond self-interest and is based on social norms, values, personal affinity, empathy, and routine behavior [27].

Since in spite of all storage systems knowledge is still personal, healthcare professionals are and will remain "owners" of their own knowledge and thus of their capital. In the knowledge economy, the doctrine of scarcity is essentially reversed. In the first place, because equal accessibility—democratization—of knowledge leads to better distribution than hierarchical distribution. In this respect, leadership mainly means facilitating this accessibility rather than trying to steer knowledge in the "right" direction. In the second place, sharing knowledge does not lead to a reduction but to an increase in knowledge. Sharing knowledge means multiplying it. At a somewhat lower integration level, this has become painfully evident: In social media and on the Internet, there is now truly an overload of information.

Lifelong learning to convert information into knowledge and wisdom is not a fad, but the path to success in the knowledge economy. However, a prerequisite is that there must be a challenging working and living environment that provides incentives for ongoing development.

Case Report: Continued

At the meeting with the hospital's Central Training Committee (COC), Esther, as Chair, discusses the issue raised by the trainees regarding support after incidents. The Chair of the COC admits that more active steps should have been taken on this point, and promises to take the matter up soon with the Board of Management. After all, this is not only a training issue; it also concerns HR policy.

Esther agrees to this proposal and is about to proceed to the next item on the agenda. However, as an experienced secretary, David is aware of the fact that the road to hell is paved with good intentions. He speaks to Esther in a neutral tone: "Madam Chair, do you want me to record this in the minutes as an official action point?"

Esther understands the hint and gives an equally pointed response, "I think that would be a good action point for you as secretary, Mr. Olive."

The Chair of the COC exchanges a glance with his regular coworker to indicate that they will really have to get to work on this matter (*leader*, *organizer*).

21.5 Critical Reflection

It sounds so good: knowledge workers managing themselves and each other in flexible organizations such as "communities of practice," network organizations, or "adhocracies" [28] and in the course of their work evolving into reflective professionals. However, in real life it is still difficult to achieve this ideal. On the basis of extensive research, including a thorough literature review and an empirical study of his own into the disappointing effects of communication training for medical professionals, Wouda draws the following conclusion, "The implementation of our recommendations would require a great deal of effort. Therefore we doubt whether expertise in professional communication can be fully attained during medical training… Apparently, an expert level of communication competence in clinical practice is difficult to attain. Especially, the transfer of communication competence acquired in formal learning conditions, into clinical practice appears to be problematic… The lack of transfer of communication competence acquired in educational settings, into clinical practice is often attributed to the inhibiting influence of clinical culture and supervisors… Learning is possible and does occur; however, it needs a cultural climate of continuing positive reinforcement of favorable communication behavior in clinical practice. This condition echoes characteristics that are familiar from psychosomatic patient care or to put it in didactical terms: 'Practice what you preach!' " [20].

Wouda therefore proposes that the CanMEDS communication competences should not be regarded as end points in medical education, but as guidelines to improve communication competence through deliberate practice throughout a professional career [20]. This suggestion, in combination with the didactic concept of role inversion (learning by teaching) attributed to Aristotle and Polanyi's views on tacit knowledge [3], depends entirely on the capacity to make implicit knowledge explicit. For this purpose, Nonaka and Takeuchi [29] developed the SECI model (socialization, externalization, combination, and internalization) (Fig. 21.4).

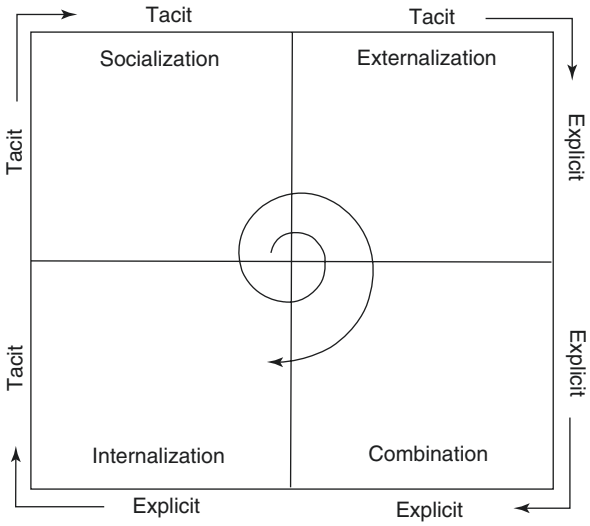


Fig. 21.4 The SECI model (after Nonaka and Takeuchi [29]) (Used under Creative Commons license: CC BY-SA 3.0: https://commons.wikimedia.org/wiki/File:SECI_Model.jpg)

This means that in order to be successful, individual competence-based learning must be organized in the context of a learning organization. Above all, a curriculum should be created that encourages professionals to develop their competences by means of deliberate practice throughout their professional careers.

Case Report: Continued

Although a few tough nuts have been cracked, particularly at the meeting with the training group, the rest of the day goes well. The atmosphere during the drinks reception at the end of the day is excellent. Throughout the day, the committee had heard a great deal of praise not only for Juliette and Pascal as trainers but also for the department as a whole. Evidently the team has succeeded in creating a pleasant and constructive training environment (*communicator*, *collaborator*).

Esther concludes the review with a heartfelt word of thanks on behalf of the committee, referring explicitly to the openness and enthusiasm of everyone involved. Of course, she also reminds everyone of a number of provisional recommendations and briefly explains what the rest of the procedure will entail. After saying goodbye to Juliette and Pascal, it is time to disband her own team.

As an old hand, David had reminded her in between meetings that a team must be disbanded just as carefully as it is put together. Esther has a special word of thanks for each member. “And last but not least…David! The main focus of an external review is on professional knowledge and training expertise, but you have guided us through a multitude of abbreviations, frameworks, criteria, guidelines, and procedures in an extremely efficient and friendly way. Because of this we, as a committee, were able to concentrate on our core tasks. On behalf of all of us, thank you very much!”

When Esther gets home that evening, she feels as though she has been away for a week.

References

1. Frank JR, Snell L, Sherbino J. The Draft CanMEDS 2015; Physician Competency Framework - Series IV. Ottawa: Royal College of Physicians and Surgeons of Canada; 2015.
2. Dewey J. Human nature and conduct. New York: H. Holt and Company; 1922.
3. Polanyi M. Personal knowledge. London: Routledge & Kegan Paul; 1978.
4. den Boer JA. Neurofilosofie. Boom: Amsterdam/Meppel; 2003.
5. Damasio AR. Descartes’ error: emotion, reason, and the brain. New York: Grosset/Putnam; 1994.
6. Damasio AR. Looking for Spinoza. Joy, Sorrow, and the Feeling Brain. New York: Harcourt; 2003.
7. Bourdieu P. Economisch kapitaal, cultureel kapitaal, sociaal kapitaal. In: Pels D, editor. Opstellen over smaak, habitus en veldbegrip. Amsterdam: Van Gennip; 1989.
8. Giddens A. Modernity and self and society in the late modern age. Cambridge: Polity; 1991.
9. Sen A. Development as freedom. Oxford/New York: Oxford University Press; 2001.

10. Dennett DC. Intuition Pomps and other tools of thinking. New York: W.W. Norton & Company; 2013.
11. van Merriënboer JJG, van der Klink MR, Hendriks M. Competenties: van complicaties tot compromis. Over schuifjes en begrenzers. Onderwijsraad: Den Haag; 2002.
12. Greenwood DJ, Levin M. Introduction to action research: social research for social change. Thousand Oaks: Sage Publications; 1998.
13. Popper K. Objective knowledge. Oxford: Clarendon; 1972.
14. Veening EP. Over de werkelijkheid van drie werelden. Een pleidooi voor herziening van Poppers 'Driewereldentheorie'. Wageningen: Ponsen & Looijen; 1998.
15. Jorna RJ, van Engelen JML, Hadders H. Duurzame innovatie: organisaties en de dynamiek van kenniscreatie. Assen: Koninklijke Van Gorcum; 2004.
16. Scally G, Donaldson LJ. The NHS's 50th anniversary: clinical governance and the drive for quality improvement in the new NHS in England. Br Med J. 1998;317(7150):61–5.
17. Quinn RE, Fearman SR. Becoming a master manager. A competing values approach. Hoboken: John Wiley & Sons; 2010.
18. de Bono E. Six thinking hats. Toronto: Mica Management Resources, Inc; 1985.
19. Watslawick P, Beavin JB, Jackson D. Pragmatics of human communication. A study of interactional patterns, pathologies and paradoxes. New York: W.W. Norton and Co; 1967.
20. Wouda JC. Patient education in medical-specialist consultations. Groningen: Rijksuniversiteit Groningen; 2014.
21. Dewey J. Democracy and education. An introduction to the philosophy of education. New York: MacMillan Company; 1916.
22. Covey S. The seven habits of highly effective people. New York: Free Press; 1989.
23. Wagner EH, Austin BT, Von KM. Improving outcomes in chronic illness. Manag Care Q. 1996;4(12):25.
24. Prahalad CK, Hamel G. The core competence of the corporation. Harv Bus Rev. 1990;68:79–91.
25. Tronto JC. Moral boundaries. A political argument for an ethic of care. London: Routledge; 1993.
26. Verkerk MA, van Dartel H. Ethiek en action research: op weg naar reflectieve zelfzorg. In: Boog B, Slagter M, Jacobs-Moonen I, Meijering F, editors. Focus op Actionresearch: De professional als handelingsonderzoeker. Assen: Van Gorcum; 2015.
27. Nooteboom B. Trust: forms, foundations, functions, failures and figures. Cheltenham: Edward Elgar; 2002.
28. Mintzberg H. Structures in fives. Designing effective organizations. Englewood: Prentice Hall; 1983.
29. Nonaka I, Takeuchi H. The knowledge-creating company. New York: Oxford University Press; 1995.

Part III

Clinical Roles and Meta-competences: The Building Blocks of Psychosomatic Obstetrics and Gynecology

Introduction

22

Harry B.M. van de Wiel and K. Marieke Paarlberg

22.1 Introduction

The aim of the third and final part of this book is to provide insight into the fundamental building blocks of psychosomatic obstetrics and gynecology (POG). This insight enables health care professionals to put women's healthcare problems in different perspectives and to use the capacities of many disciplines to help women to resolve them. Although the importance of this approach was already noted in the early 1950s by eminent colleagues such as Balint and Engel, its full merit becomes more and more visible in our current era of empowerment and connectivity. Each day it becomes clear that most patients do not need *a God to treat them* but a *professional to guide them* [1] and that is exactly what the psychosomatic approach supports.

22.2 Back to the Future

Within the domain of Obstetrics and Gynecology, the cultural trend toward patient empowerment and multidisciplinary co-creation was already understood in the second half of the last century. For more than 30 years, the International Society for Psychosomatic Obstetrics and Gynecology (ISPOG) advocates an ideology that sees a female patient as a subject and not as an object. No matter which health-related

H.B.M. van de Wiel (✉)
Wenckebach Institute, University of Groningen, University Medical Centre Groningen, Groningen, The Netherlands
e-mail: h.wiel@umcg.nl

K.M. Paarlberg
Department of Obstetrics and Gynecology, Gelre Hospitals, Apeldoorn Location, Apeldoorn, The Netherlands
e-mail: km.paarlberg@xs4all.nl

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_22

problems she has to face, the patient is and will always be a woman who carries responsibility for herself and who has her own cultural background and life history. Within ISPOG, there always has been a great interest in health literacy, especially what Lauret [2] referred to as *liberating literature* and participation in social support networks. Because nowadays patients are expected to set their own goals in life and to choose their own way of problem solving within and outside of health care, this psychosomatic perspective is rapidly gaining importance. The patient of the future is the "ISPOG patient" of the last 30 years!

22.3 More Transitions

In order to become highly valued as guides, it is not only health professionals in obstetrics and gynecology who have to keep developing themselves. The organizations of which they are part and which they represent, such as teaching hospitals and university clinics, also have to transform themselves into learning organizations [3]. And in order to bridge the gap between the need for safety and quality management on the one hand and innovation and ownership on the other, Clinical Governance has to be implemented. With its striving for integrated care for patients (microlevel) as well as for constant improvement of health care organizations (macrolevel), it shares the same ideological roots as psychosomatic medicine [4]. This means that what is relevant for patients is, mutate mutandis, also relevant for health care professionals in obstetrics and gynecology and for health care institutions.

22.4 Architecture

In order to establish this necessary growth and transformation, integration has to take place of all kinds of personal and organizational resources into so-called competences. These competences—everything that is needed to do a job properly—can be seen as the *building blocks and plans* of medical practice.

POG distinguishes itself from the more traditional bio-medical approach by using another kind of architecture, by using other building plans, and by emphasizing other building blocks.

In Part I, 20 different building plans of frequently occurring medical problems in Obstetrics and Gynecology are described. In Part II, an overall psychosomatic "building block profile" is sketched, using the CanMEDS roles as constituting elements. In this part, more fundamental insight is given into the building blocks themselves, by linking the CanMEDS roles or meta-competences to everyday clinical situations. However, before doing so, we will put the bio-psycho-social approach in a historical frame. We use the way patient education was advocated for and taught as an illustration of the interaction between social and cultural developments and medical practice.

References

1. Bloem B. Lecture on the 15th congress of the International Psychosocial Oncology Society. 2013.
2. Lauret M. Liberating literature. London: Routledge; 1991.
3. Senge PM. The fifth discipline; the art and practice of the learning organization. New York: Currency Doubleday; 1990.
4. van de Wiel HB, Heineman E, Weijmar Schultz WC. The psychosomatic character of clinical governance. J Psychosom Obstet Gynaecol. 2010;31(1):1–2.

History: A Historical Perspective on Patient Education in Clinical Practice and in Medical Education

23

Jan C. Wouda, Harry B.M. van de Wiel, and K. Marieke Paarlberg

23.1 Introduction

In Part II of this book, we discussed the meta-competences or professional roles that a physician should master in order to be a medical expert [1]. Communicator is one of these roles. This role is especially important for gynecologists and other health-care personnel who adhere to the biopsychosocial (BPS) model, since communication is their main tool to understand the patient fully, to put her complaints, worries, and questions in their historical perspective and to consult with the patient about diagnostic procedures and findings, treatment options, disease prognosis, and health consequences.

Over the last 50 years, communication skills training (CST) has been a regular part of medical education in most Western countries. However, until recently, CST programs mainly focused on the skills of history-taking, and patient-education skills were less addressed. With patient education, we refer to the use of educational methods, such as the provision of information, advice, and behavior modification techniques, to influence the patients' knowledge, opinions, and health and illness behavior in order to ensure that the patient is able to collaborate effectively in deciding on the care that she or he receives and can make the best possible

J.C. Wouda (✉)
Ahmas Foundation, Groningen, The Netherlands
e-mail: j.c.wouda@umcg.nl

H.B.M. van de Wiel
Wenckebach Institute, University of Groningen, University Medical Centre Groningen, Groningen, The Netherlands
e-mail: h.wiel@umcg.nl

K.M. Paarlberg
Department of Obstetrics and Gynecology, Gelre Hospitals, Apeldoorn Location, Apeldoorn, The Netherlands
e-mail: km.paarlberg@xs4all.nl

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_23

contribution to that care [2]. Furthermore, CST programs in medical and other healthcare education are usually limited to training activities isolated from clinical practice. As a consequence, most healthcare staff has been insufficiently prepared for their patient-education tasks in clinical practice.

In order to understand the deficiencies in patient-education skills of healthcare workers, especially of those adhering to the BPS model of care, this chapter provides a historical overview of patient education in clinical practice and in medical training. The critical-reflections paragraph that concludes this chapter contains some recommendations to remedy these deficiencies.

23.2 Patient Education in Medical Consultations: A Historical Overview

23.2.1 The 1950s and 1960s

Until the late 1950s, the medico-centric perspective dominated the patient-physician relationship. The physician had authority and was solely responsible for decisions about diagnosis and treatment. Especially in medical-specialist consultations, patient education only consisted of disease-related information, often in incomprehensible medical language and treatment-related instructions. Patients were not expected to participate actively in diagnosis and treatment decisions, and their ideas, beliefs, and values were not taken very seriously.

In his book *The Doctor*, *His Patient and the Illness*, Michael Balint was one of the first to stress the importance of good patient-physician communication [3]. He stated that the physician himself was the most used medicine in general practice, and that despite our lack of knowledge about the effects of reassurance and advising, both are probably the most frequently used types of medical treatment. He asked for recognition of the emotional as well as the physical aspects of a patient's complaint and was probably the first to advocate the skills of attentive listening to patients. Balint's ideas inspired many general practitioners, especially in their approach to patients with medically unexplained complaints. However, these ideas mainly focused on the diagnosis of physical complaints, and patient education was still not really part of the picture. Although the study of patient adherence dates back to the 1940s, and the terms "compliance" and "adherence" were first used in 1966 [4], in specialist-medicine consultations less than 5 % of consultation time was used for patient education [5].

23.2.2 The 1970s and 1980s

In the 1970s and 1980s, the patient-physician relationship changed dramatically due to several developments. First, in the late 1960s and early 1970s, many protest movements and emancipatory organizations struggled for equality on various terrains. Patients' rights advocates and organizations were established, including

patient self-help groups and self-care movements. Patients claimed their place as active participants in the consultation and fought for self-determination and legal rights. These social changes eventually resulted in legislation concerning the provision of information, informed consent, privacy protection, and the right to complain about the care received. Furthermore, in the late 1970s and early 1980s, socially active general practitioners founded healthcare centers and addressed not only psychosocial issues but also health-determining societal conditions and inequalities. They regarded patient education as an important means of engaging their patients in illness prevention, improvement of living conditions, and community-based healthcare.

Second, medico-technical developments complicated treatment decisions. Diagnostic and treatment options expanded rapidly. For several diseases, equivalent treatments became available, other diseases that were untreatable before or lethal in the short-term became chronic conditions, and patients' life spans could be prolonged substantially. Thus, physicians had to take into account patients' wishes and quality of life considerations.

Third, patient education is embedded in the wider field of health promotion, which flourished in the 1970s due to the rise of behavioral and lifestyle-related diseases. The 1974 Lalonde report acknowledged for the first time that not only biomedical aspects are important in defining health but that also citizens in general and patients in particular could improve their health through behavioral factors related to their lifestyle [6]. At first, health promotion activities mainly used knowledge transfer as the influencing technique, but gradually, other behavior modification techniques, originating in social psychology and educational research, were used in health promotion interventions.

Fourth, political and economic factors also supported the promotion of health education, self-determination, patient participation, and health responsibility, since healthcare costs increased substantially in the 1980s, and the economic climate led to the call for reductions in governmental costs.

All these developments forced physicians to pay more attention to patient-centered communication and patient education in their consultations. The concept of patient-centered communication originated from the power-shift model in which the patient-centered exchange of information opposes the doctor-centered exchange of information, especially in the diagnostic phase of a consultation [7]. Gradually, the concept of patient-centeredness was extended to all phases of the consultation and became a moral philosophy with core values such as considering patients' ideas, wishes, and perspectives, encouraging patients to provide input into and participate in their care and enhancing partnership and understanding in the patient-physician relationship [8–10]. Thus, patient education became an inseparable part of patient-centeredness, and physicians were supposed to promote patient participation and shared decision-making [11]. However, only general practitioners embraced these ideas, and the research on patient-physician communication that blossomed in the early 1990s mainly involved primary-care consultations. In primary care, which is by definition more connected to societal movements than hospital care, patient education directed at behavior modification and lifestyle change became part of illness

prevention and treatment. In medical specialist consultations, patient education was not yet taken very seriously [12–14].

23.2.3 The 1990s

In the 1990s, patient education became more and more a natural part of primary-care consultations. This development was supported by legislation, on the one hand, and media attention, on the other. In most Western countries, patients' rights were firmly anchored in health laws [15], and the media paid ample attention to health and the healthcare system. Numerous programs were broadcasted about health problems and the healthcare system, varying from educational programs about coping with illness, medical procedures, and the work of physicians to entertainment programs about patients' experiences and physicians' misconduct. Thus, the general public became more aware of their rights and became more critical about the care they received, which forced physicians to be more transparent about their work and achievements. Medical specialists, especially in oncology, also became more aware of the importance of patient education for secondary prevention and improvement in quality of life [16]. Medico-technical innovations played a role too. Patients were confronted with more complex and specialized procedures, patients faced more healthcare choices that were consequential, and patients with chronic conditions had to adhere to complex drug and lifestyle recommendations in order to achieve prolonged quality of life. Furthermore, patient-education research became a grown-up discipline with national and international research platforms, journals, and congresses [17].

23.2.4 The Twenty-First Century

In the first decade of this century, electronic information supply by the Internet became commonplace, and patients with Internet access now collect health information away from the traditional patient-physician encounter [18–20]. Furthermore, health and health-related subjects are nowadays a dominant topic in the societal discourse, with ample attention paid to subjects related to healthy lifestyles, such as healthy food, losing weight, and physical exercise. These societal developments revived the ideas from the 1980s about patient participation and self-management. However, patients are now better-informed healthcare consumers, which place greater demands on accessibility, service, and outcomes [21]. Just as in the 1980s, idealistic motives as well as politico-economic interests underlie these claims for patient involvement, patient empowerment, and self-determination, and patients are encouraged to take responsibility for their own health and recovery. For instance, the Dutch National Board of Public Health published a memorandum in which patient participation was strongly advocated, the training in patient education of healthcare professionals and especially of physicians was emphasized, and professional organizations were obliged to include patient-education competences in their registration prerequisites [22].

From the 1990s up until the present, the concept of patient-centeredness has dominated the research of physicians' patient-education behavior and outcomes. However, patient-centeredness has turned out to be a complex and elusive concept, which does not come with a sound theoretical framework from which the patient-education objectives of a consultation and the matching communication tasks of the physician can be derived [8, 23–27]. The evidence about the effects of patient-centered communication on patient outcomes has also remained limited [9, 27–29]. As a consequence, functional models of patient education have emerged, which clarify the relationships between physicians' patient-education goals and communicative behaviors, on the one hand, and patients' responses and outcomes, on the other [29–32]. Some models elucidate the prerequisites and processes that determine the outcomes of patient-education activities [29, 33, 34]. Patient-education elements, such as fostering the relationship, listening to patients' wishes and concerns, proper explaining, and involving the patient in treatment decisions, have had unmistakably positive effects on patient satisfaction, comprehension, recall, and adherence [35–41]. However, the effects of enhancing patient participation and shared decision-making in medical consultations on intermediate outcomes, such as adherence to regimes and self-management, and on health outcomes are less convincing [42, 43]. On the other hand, more advanced patient-education methods, which directly aim to improve health decisions and health behavior, such as facilitating regime adherence, risk communication, usage of decision aids, and motivational interviewing, have been quite successful [44–49].

Despite the call for more attention to patient education in clinical practice and in medical specialist training, patient education is still undervalued in medical specialist consultations [50, 51]. This lack of interest may be attributable to several factors. First, patient education in medical specialist consultations is not rewarded financially or otherwise. The financial reimbursement of medical practice is usually based on the performance of diagnostic procedures and medical treatments and not on the time invested in individual patients. Time constraints and the medical problem-solving culture even discourage patient-education efforts. Especially for healthcare workers who adhere to the BPS model, this financial and cultural system works out badly since they often use time-consuming patient-education methods such as counseling and refrain from medical procedures that are more harmful than beneficial for the patient at hand. Second, patient education in hospitals, especially for patients with chronic conditions, is often transferred to other healthcare providers, such as specialized nurses, nurse practitioners, dietitians, physiotherapists, and psychologists, discharging medical specialists from their patient-education duties. Thus, medical specialists are neither encouraged nor compelled to demonstrate excellent patient education.

23.3 Patient Education in Medical Curricula: A Historical Overview

In the last 50 years in medical education, the teaching of communication skills in general and patient-education skills in particular developed parallel to the societal and healthcare developments described previously.

23.3.1 Knowledge-Centered Teaching

Until the early 1970s, the Flexner Report was what shaped undergraduate medical education [52]. Basic and clinical sciences were separated. Basic sciences, such as anatomy, physiology, histology, and biochemistry, were dealt with in the initial years, while clinical sciences, such as pathology, pharmacology, and surgery, were covered in later years. The distinctive medical specialties and their related knowledge and skills, such as history-taking and physical examinations, were addressed just before students began their internships. Lectures were the dominant teaching method, and examinations focused on knowledge reproduction. Sometimes the curriculum contained lectures about psychology with patient-physician communication as one of the topics. However, the teaching of communication skills was not embedded in the curricula [53], and most medical students graduated without ever interviewing a patient under direct supervision [53].

23.3.2 Problem-Based Learning

In the 1970s, some medical schools such as the McMaster University in Hamilton, Canada, and the Maastricht University in the Netherlands, developed a problem-based curriculum with small-group tutoring and skills training. Communication skills training (CST), including small-group sessions with videoed demonstrations, role-play exercises, feedback, and reflection, acquired a fixed place in these curricula [54, 55]. However, CST programs have traditionally concentrated on the first, diagnostic half of the consultation. Patient-education issues were less often addressed [56–61].

Several factors promoted this attention to the diagnostic part. First, the curricula still suffered from the historically developed imbalance, reflected in clinical practice, between the teaching of "diagnosis" and "problem management" [62]. Second, medical education adopted much of the social sciences curricula, which already contained social-skills programs, based on the ideas of Carl Rogers [63] and Allen Ivey [64], with much attention paid to listening skills and, to a lesser extent, to the skills of conversational control. Third, the CST programs prepared students for their main task during their internships, which is questioning patients about their complaints and health status. Interns were not supposed to educate patients. Thus, students were not taught patient-education skills with one curious exception: breaking bad news. Although breaking bad news is regarded as one of the most challenging consultations, many CST programs contained one or two small-group sessions with role-play exercises in breaking bad news, while students still lacked basic patient-education knowledge and skills [61].

The problem-based curricula and CST programs also required new assessment procedures and instruments. In addition to knowledge assessment, skills assessment was needed. The Objective Structured Clinical Examination (OSCE) was developed in order to reliably assess clinical skills in standardized conditions [65]. For the teaching and assessment of communication skills, several guidelines and

accompanying assessment instruments were developed [66, 67]. Nearly all guidelines and assessment instruments were based on the concept of patient-centeredness and used checklists or rating scales featuring required communication behaviors, ordered according to the different phases of a consultation. The instruments differed in their empirical validation. However, these instruments lacked a theoretical basis that would have clarified the shifting consultation goals and the physician's tasks along with matching the communication skills to attain these goals nor did they predict clinical outcomes [27, 31, 68].

Although most instruments contained items concerning patient-education issues, such as explaining and shared decision-making, patient-education skills were hardly assessed in undergraduate OSCEs, since communication skills training and assessment of students focused on history-taking.

23.3.3 Postgraduate Education

In the late 1970s, communication skills training also became part of general-practice vocational training [69–72]. At first, the main educational approach consisted of reflection on real patient encounters. Since the 1990s, in several Western countries, patient-physician communication issues have been addressed in primary care and general-practice vocational training by means of assessment of and feedback on videoed consultations with real patients [69, 71, 73–77]. Also starting in the 1990s, communication workshops and courses were offered to medical specialist residents and consultants especially in the field of oncology. These elective courses mainly concerned exploring patients' concerns and breaking bad news, using didactics, demonstrations, role-play with feedback, and reflection as teaching methods [78, 79]. Some workshops for consultants even focused on the teaching of communication skills to students and residents [80–82]. Other workshops focused attention on the use of learned skills in clinical practice [83]. However, assessment of communication performance in clinical practice was lacking [84]. In the Netherlands, elective courses and workshops for consultants were offered [85]. Several initiatives used videoed outpatient consultations for assessment and feedback [14, 86]. In some Western countries, elective communication courses were offered in residency training [87, 88], and in the late 1990s, compulsory courses were incorporated in the training of Dutch residents in obstetrics and gynecology and in surgery [89, 90]. These courses addressed challenging patient-education issues such as breaking bad news and dealing with conflict, nonadherence, and complaints. However, the effects of these courses on residents' communication behavior in clinical practice were not investigated.

Recently, in a Dutch study, a small but significant improvement of the patient-education competency of residents was found due to a workplace-based training program using videoed outpatient consultations for assessment and feedback [91]. In Switzerland, a compulsory psychosomatic training for residents in obstetrics and gynecology consisting of small-group case discussions demonstrated an increase in self-reported psychosomatic competences. However, whether the

residents also improved their patient-education skills in clinical practice was not examined [92].

23.3.4 Competency-Based Learning

At the turn of the century, medical education, inspired by a renewed emphasis on the essential abilities that physicians need for optimal patient outcomes and on preparing students for clinical practice, switched from problem-based learning to an outcomes-based or competency-based approach. The CanMEDS competency framework, which was developed in the 1990s, is probably the best-known example of this approach [1]. Nowadays, all Dutch medical-specialist curricula are based on this competency framework [93]. The CanMEDS framework comprises numerous competences organized thematically around 7 "meta-competences" or roles that a physician should master. At the heart of the framework lies the physician's role as a medical expert, complemented by six generic roles such as communicator, collaborator, and manager. As medical experts, physicians integrate all areas of expertise defined by the CanMEDS framework. Thus, expertise that is defined as the superior and stable ability to handle challenging situations [94] is the benchmark for the assessment of physicians' ability to handle clinical situations. Challenging patient-education issues that are mentioned in the CanMEDS framework are obtaining informed consent; delivering bad news; addressing anger, confusion, and misunderstanding; and dealing with nonadherence.

The introduction of the CanMEDS framework in undergraduate and postgraduate curricula influenced the teaching of communication skills in several ways. First, since the key competences of the communicator role explicitly refer to patient-education competences, the teaching of patient-education skills was gradually implemented in undergraduate curricula [95, 96] and in postgraduate courses [97]. However, during their internships, students still focus their attention on history-taking and time management and are still not supposed to educate their patients [98]. Second, the concept of patient-centeredness was criticized and regarded as being unsuitable as a leading concept for communication programs [27, 30]. Today, a functional approach is advocated, in which the physicians' communication tasks and matching skills are derived from the goals and desired outcomes of the consultation [29–31, 99]. Third, workplace-based learning came into focus. Workplace-based learning means that students and residents improve their competences by applying their knowledge and practicing their skills in supervised clinical situations followed by constructive feedback and reflection. New assessment methods matching workplace-based learning were also developed, such as the mini-clinical evaluation exercise (mini-CEX), the direct observation of procedural skills (DOPS), and multisource feedback [100, 101]. All the assessments, feedbacks, and reflections that a learner has collected are documented in the learner's portfolio. As mentioned previously, communication assessment and feedback based on videoed consultations already existed in primary care and general-practice vocational training. In undergraduate education, several initiatives have since been developed using

videoed consultations for self-assessment, feedback, and reflection [102]. One program used videoed consultations for communication assessment and feedback in medical specialist training [91].

23.4 Critical Reflections

Training in communication skills is a regular part of undergraduate medical curricula nowadays, and most undergraduate communication skills programs also teach patient-education skills. However, the effects of communication skills training programs are not impressive. Small to moderate improvements have been found in students' communication competency after one or more communication courses [103–108], but deterioration in students' communication competency over time has also been reported [109–111]. Furthermore, although communication skills training appears to be effective in improving targeted communication skills, the effects of communication skills training on performance and outcomes in clinical practice remain obscure [104]. Postgraduate communication courses also appear to have positive effects on the communication competency of practicing physicians [75, 78, 79, 103, 112–116], but these effects are limited [84, 117, 118]. Only interventions for residents and consultants, which specifically address communication behavior in clinical practice, seem to have some positive effects on behavior and outcomes [115, 119, 120]. Even the ample attention paid to communication skills in general-practice training has hardly any effect at all on clinical communication behavior [75, 76]. Furthermore, the effects of patient-physician communication education on consultation outcomes, such as patient satisfaction, understanding, adherence, self-management, and health status, are nearly absent [28, 121–124]. Veldhuijzen [27] therefore concluded that "These findings point to the sobering conclusion that the vast effort to shape or change how doctors communicate with their patients has in fact been rather ineffective in practice."

Apparently, an expert level of communication competency in clinical practice is difficult to attain. The transfer of communication competency, acquired in formal learning conditions, into clinical practice appears to be especially problematic [125–128]. The lack of transfer is often attributed to the inhibiting influence of clinical culture and supervisors' rejective behavior [64, 129–138]. Continuing positive reinforcement of favorable communication behavior in clinical practice might diminish these negative effects [139]. However, even if the clinical culture supports the performance of learned communication behavior, the transfer of this behavior into clinical practice will not be clear-cut. Several studies have indicated that the performance of communication skills in clinical practice is case specific, meaning that a good or even excellent performance in one encounter does not guarantee the same high level of performance in other encounters. This implies that a set of generic or transferable communication skills that show a high level of stability and have applicability to a wide range of encounters does not exist. The effect of communication education will therefore be limited if the training is restricted to a predetermined set of skills in standardized and simulated situations, which is the case

in most communication skills training programs. Thus, contextual learning as provided by workplace-based learning is considered essential nowadays for clinical communication competency development [125, 127, 136, 137].

Video-on-the-job, which means videoing outpatient and clinical consultations and discussing them with peers and/or supervisors, provides an excellent opportunity for workplace-based learning of communication skills. It is an extension of the aforementioned mini-CEX and appears to be a valuable teaching method for feedback and reflection with positive effects on communication performance in clinical practice [71, 91, 140, 141]. Thus, video-on-the-job could be a valuable tool for the improvement of the patient-education competency of workers in psychosomatic obstetrics and gynecology.

Acknowledgment This chapter is an adapted version of earlier work of the first author: Wouda JC. Patient education in medical-specialist consultations. Thesis. University of Groningen, The Netherlands. 2014.

References

1. Frank J, editor. The CanMEDS 2005 physician competence framework. Ottawa: The Royal College of Physicians and Surgeons of Canada; 2005.
2. Van den Borne HW. The patient from receiver of information to informed decision-maker. Patient Educ Couns. 1998;34:89–102.
3. Balint M. The doctor, his patient, and the illness. London: Pittman Medical Publishing Corp; 1957.
4. DiMatteo MR. Evidence-based strategies to foster adherence and improve patient outcomes. JAAPA. 2004;17:18–21.
5. Waitzkin H. Information control and the micropolitics of health care. Soc Sci Med. 1976;10:263–76.
6. Lalonde M. A new perspective on the health of Canadians. Ottawa: Government of Canada; 1974.
7. Byrne PS, Long BEL. Doctors talking to patients. Exeter, UK: Royal College of General Practitioners; 1984.
8. Epstein RM, Franks P, Fiscella K, Shields CG, Meldrum SC, Kravitz RL, Duberstein PR. Measuring patient-centered communication in patient-physician consultations: theoretical and practical issues. Soc Sci Med. 2005;61:1516–28.
9. Mead N, Bower P. Patient-centred consultations and outcomes in primary care: a review of the literature. Patient Educ Couns. 2002;48:51–61.
10. Stewart MA. Towards a global definition of patient centred care. Br Med J. 2001;322:444–5.
11. Taylor K. Paternalism, participation and partnership – the evolution of patient centeredness in the consultation. Patient Educ Couns. 2009;74:150–5.
12. Levinson W, Chaumeton N. Communication between surgeons and patients in routine office visits. Surgery. 1999;125:127–34.
13. Webber GC. Patient education: a review of the issues. Med Care. 1990;28:1089–103.
14. Wouda J, Van de Wiel HBM, Van den Toren EW, Vinke JM. With ones heart on ones sleeve [Het hart op de tong]. Medisch Contact. 1993;48:276–8.
15. Nys H. Comparative health law and the harmonization of patients' rights in Europe. Eur J Health Law. 2001;8:317–31.
16. Epstein RM. Assessment in medical education. N Engl J Med. 2007;356:387–96.

17. Hoving C, Visser A, Mullen PD, Van den Borne B. A history of patient education by health professionals in Europe and North America: from authority to shared decision making education. Patient Educ Couns. 2010;78:272–81.
18. Buetow S, Jutel A, Hoare K. Shrinking social space in the doctor-modern patient relationship: a review of forces for, and implications of, homologisation. Patient Educ Couns. 2009;74:97–103.
19. Lee C, Wang Gray S, Lewis N. Internet use leads cancer patients to be active health care consumers. Patient Educ Couns. 2010;81S:63–9.
20. McMullan M. Patients using the Internet to obtain health information: how this affects patient-health professional relationship. Patient Educ Couns. 2006;63:24–8.
21. Dieterich A. The modern patient – threat or promise? Physicians' perspectives on patients' changing attributes. Patient Educ Couns. 2007;67:279–85.
22. Raad voor de Volksgezondheid, Zorg. The participating patient [De participerende patiënt]. Den Haag: Min. Volksgezondheid, Welzijn en Sport; 2013.
23. Clayton MF, Latimer S, Dunn TW, Haas L. Assessing patient-centered communication in a family practice setting: how do we measure it, and whose opinion matters? Patient Educ Couns. 2011;84:294–302.
24. J.C.J.M. de Haes. Dilemmas in patient centredness and shared decision making: a case for vulnerability. Patient Educ Couns. 2006;62:291–8.
25. Duggan PS, Geller G, Cooper LA, Beach MC. The moral nature of patient-centredness: is it "just the right thing to do?". Patient Educ Couns. 2006;62:271–6.
26. Salmon P, Young B. Core assumptions and research opportunities in clinical communication (review). Patient Educ Couns. 2005;58:225–34.
27. Veldhuijzen JW. Challenging the patient-centred paradigm: designing feasible guidelines for doctor patient communication. Thesis: Maastricht University; 2011.
28. Dwamena F, Holmes-Rovner M, Gaulden CM, Jorgenson S, Sadigh G, Sikorskii A, Lewin S, Smith RC, Coffrey J, Olomu A. Interventions for providers to promote a patient-centred approach in clinical consultations. Cochrane Database Syst Rev. 2012;12:CD003267.
29. Street RL. How clinician-patient communication contributes to health improvement: modelling pathways from talk to outcome. Patient Educ Couns. 2013;92:286–91.
30. De Haes H, Bensing J. Endpoints in medical communication research, proposing a framework of functions and outcomes. Patient Educ Couns. 2009;74:287–94.
31. Hulsman RL. Shifting goals in medical communication. Determinants of goal detection and response formation. Patient Educ Couns. 2009;74:302–8.
32. Street RL, Makoul G, Arora NK, Epstein RM. How does communication heal? pathways linking clinician-patient communication to health outcomes. Patient Educ Couns. 2009;74:295–301.
33. Bylund CL, Peterson EB, Cameron KA. A practitioner's guide to interpersonal communication theory: an overview and exploration of selected theories. Patient Educ Couns. 2012;87:261–7.
34. Cameron KA. A practitioner's guide to persuasion: an overview of 15 selected persuasion theories, models and frameworks. Patient Educ Couns. 2009;74:309–17.
35. Arbuthnott A, Sharpe D. The effect of physician-patient collaboration on patient adherence in non-psychiatric medicine. Patient Educ Couns. 2009;77:60–7.
36. Beach MC, Sugarman J, Johnson RL, Arbelaez JJ, Duggan PS, Cooper LA. Do patients treated with dignity report higher satisfaction, adherence and receipt of preventive care? Ann Fam Med. 2005;3:331–8.
37. Beck RS, Daughtridge R, Sloane PD. Physician-patient communication in the primary care office: a systematic review. J Am Board Fam Pract. 2002;15:25–38.
38. Fuertes JN, Mislowack A, Bennet J, Paul L, Gilbert TC, Fontan G, Boylan LS. The physician-patient working alliance. Patient Educ Couns. 2007;66:29–36.
39. Ruiz-Moral R, de Torres LA P, Jaramillo-Martin I. The effect of patients' met expectations on consultation outcomes. A study with family medicine residents. J Gen Intern Med. 2007;22:86–91.

40. Silverman J, Kurtz S, Draper J. Skills for communicating with patients. 2nd ed. London: Radcliff Medical Press; 2005.
41. Zachariae R, Pedersen CG, Jensen AB, Ehrnrooth E, Rossen PB, von der Maase H. Association of perceived physician communication style with patient satisfaction, distress, cancer-related self-efficacy and perceived control over the disease. Br J Cancer. 2003;88:658–65.
42. Faber M, Harmsen M, Van der Burg S, Van der Weijden T. Shared decision-making and self-management [Gezamenlijke besluitvorming & zelfmanagement]. Nijmegen: Scientific Institute for Quality of Healthcare, UMC St Radboud; 2013.
43. Griffin SJ, Kinmonth AL, Veltman MW, Gillard S, Grant J, Stewart M. Effect on health-related outcomes of interventions to alter the interaction between patients and practitioners. A systematic review of trials. Ann Fam Med. 2004;2:595–608.
44. Britt E, Hudson SM, Blampied NM. Motivational interviewing in health settings: a review. Patient Educ Couns. 2003;53:147–55.
45. Edwards A, Gray J, Clarke A, Dundon J, Elwyn G, Gaff C, Hood K, Iredale R, Sivell S, Shaw C, Thornton H. Interventions to improve risk communication in clinical genetics: systematic review. Patient Educ Couns. 2008;71:4–25.
46. Lundahl B, Moleni T, Burke BL, Butters R, Tollefson D, Butler C, Rollnick S. Motivational interviewing in medical care settings: a systematic review and meta-analysis of randomized controlled trials. Patient Educ Couns. 2013;93:157–68.
47. Noordman J, Van der Weijden T, Van Dulmen S. Communication-related behavior change techniques used in face-to-face lifestyle interventions in primary care: a systematic review of the literature. Patient Educ Couns. 2012;89:227–44.
48. O'Connor AM, Bennet CL, Stacey D, Barry M, Col NF, Eden KB, Entwistle VA, Fiset V, Holmes-Rovner M, Khangura S, Llewellyn-Thomas H, Rovner D. Decision aids for people facing health treatment or screening decisions. Cochrane Database Syst Rev. 2003;1:CD001431.
49. Van Dulmen S, Sluijs E, Van Dijk L, De Ridder D, Heerdink R, Bensing J. Patient adherence to medical treatment: a review of reviews. BMC Health Serv Res. 2007;7:55–68.
50. Ruiz-Moral R, Perez Rodriguez E, Perula de Torres LA, De la Torre J. Physician-patient communication: a study on the observed behaviours of specialty physicians and the ways their patients perceive them. Patient Educ Couns. 2010;64:242–8.
51. Weiland A, Van de Kraats RE, Blankenstein AH, Van Saase JLCM, Van der Molen HT, Bramer WM, Van Dulmen AM, Arends LR. Encounters between medical specialists and patients with medically unexplained physical symptoms: influences of communication on patient outcomes and use of health care: a literature review. Perspect Med Educ. 2012;1:192–206.
52. Philips SP. Models of medical education in Australia, Europe and North America. Med Teach. 2008;30:705–9.
53. Wakeford R. Communication skills training in United Kingdom medical schools. In: Pendleton D, Hasler J. Doctor-patient communication. London: Academic Press; 1983;Ch 13:233–247.
54. Baumal R, Benbassat J. Current trends in the educational approach for teaching interviewing skills to medical students. Isr Med Assoc J. 2008;10:552–5.
55. Silverman J. Teaching clinical communication: a mainstream activity or just a minority sport. Patient Educ Couns. 2009;76:361–7.
56. Frederikson L, Bull P. An appraisal of the current status of communication skills training in British medical schools. Soc Sci Med. 1992;34:515–22.
57. Hargie O, Dickson D, Boohan M, Hughes K. A survey of communication skills training in UK schools of medicine: present practices and prospective proposals. Med Educ. 1998;32:25–34.
58. Irwin WG, McClelland R, Loves AHG. Communication skills training for medical students: an integrated approach. Med Educ. 1989;23:387–94.

59. Joesbury HE, Bax NDS, Hannay DR. Communication skills and clinical methods: a new introductory course. Med Educ. 1990;24:433–7.
60. Silverman J, Archer J, Gillard S, Howells R, Benson J. Initial evaluation of EPSCALE, a rating scale that assess the process of explanation and planning in the medical interview. Patient Educ Couns. 2011;82:89–93.
61. Wouda J, Van de Wiel HBM. Communication skills: a diagnosis and an advice [Communicatieve vaardigheden: een diagnose en een advies]. Bull Med Onderwijs. 1992;11:116–8.
62. Metcalfe D. The mismatch between undergraduate education and the medical task. In: Pendleton D, Hassler J, editors. Doctor-patient communication. London: Academic Press 1983;Ch 12:227–32.
63. Rogers C. On becoming a person: a therapist's view of psychotherapy. Boston: Houghton Mifflin Company; 1961.
64. Ivey AE. Microcounseling. Springfield: Thomas; 1971.
65. Brannick MT, Erol-Korkmaz HT, Prewett M. A systematic review of the reliability of objective structured clinical examination scores. Med Educ. 2011;45:1181–9.
66. Boon H, Stewart M. Patient-physician communication assessment instruments: 1986–1996 in review. Patient Educ Couns. 1998;35:161–76.
67. Kraan HF, Crijnen AAM, Van der Vleuten CPM, Imbos T. Evaluation instruments for medical interviewing skills. In: Lipkin M, Putnam S, Lazare, editors. The medical interview: clinical care, education and research. New York: Springer Verlag; 1995; Ch 39:460–72.
68. Epstein RM, Hundert EM. Defining and assessing professional competence. JAMA. 2002;287:226–35.
69. Evans A, Gask L, Singleton C, Bahrami J. Teaching consultation skills: a survey of general practice trainers. Med Educ. 2001;35:222–4.
70. Pieters HM, Touw-Otten FWWM, de Melker RA. Simulated patients in assessing consultation skills of trainees in general practice vocational training: a validity study. Med Educ. 1994;28:226–33.
71. Ram P, Grol R, Rethans JJ, Schouten B, Van der Vleuten C, Kester A. Assessment of general practitioners by video observation of communicative and medical performance in daily practice: issues of validity, reliability and feasibility. Med Educ. 1999;33:447–54.
72. Van Zalinge EAB, Schadé E. Consultation in general practitioners vocational training [Consultvoering in de opleiding tot huisarts]. Huisarts Wetenschap. 1991;34:356–8.
73. Campion P. A new video assessment for the MRCGP exam. Educ Prim Care. 2004;15:153–8.
74. Edwards A, Tzelepis A, KlingBeil C, Melgar T, Speece M, Schubiner H, Burack R. Fifteen years of a videotape review program for internal medicine and medicine-pediatrics residents. Acad Med. 1996;71:744–8.
75. Hobma S, Ram P, Muijthens A, Van der Vleuten C, Grol R. Effective improvement of doctor-patient communication: a randomised controlled trial. Br J Gen Pract. 2006;56:580–6.
76. Kramer AWM, Düsman H, Tan LHC, Jansen JJM, Grol RPTM, Van der Vleuten CPM. Acquisition of communication skills in postgraduate training for general practice. Med Educ. 2004;38:158–67.
77. Tate P, Foulkes J, Campion P, Field S. Assessing physicians' interpersonal skills via videotaped encounters: a new approach for the royal college of general practitioners membership examination. J Health Commun. 1999;4:143–52.
78. Fallowfield L, Jenkins V, Farewell V, Saul J, Duffy A, Eves R. Efficacy of a cancer research UK communication skills training model for oncologists: a randomised controlled trial. Lancet. 2002;359:650–6.
79. Maguire P, Booth K, Elliott C, Jones B. Helping health professionals involved in cancer care acquire key interviewing skills – the impact of workshops. Eur J Cancer. 1996;32A:1486–9.
80. Bird J, Hall A, Maguire P, Heavy A. Workshop for consultants on the teaching of clinical communication skills. Med Educ. 1993;27:181–5.

81. Bylund CL, Brown RF, Lubrano di Ciccone B, Levin TT, Gueguen JA, Hill C, Kissane DW. Training faculty to facilitate communication skills training: development and evaluation of a workshop. Patient Educ Couns. 2008;70:430–6.
82. Falvo DR, Herbert M, Tippy P. Training faculty to evaluate patient education skills of residents. Fam Med. 1988;20:207–10.
83. Razavi D, Merckaert I, Marchal S, Libert Y, Conradt S, Boniver J, Etienne AM, Fontaine O, Janne P, Klastersky J, Reynaert C, Scalliet P, Slachtmuylder JL, Delvaux N. How to optimize physicians' communication skills in cancer care: results of a randomized study assessing the usefulness of posttraining consolidation workshops. J Clin Oncol. 2003;21:314–9.
84. Butler L, Degner L, Baile W, Landry M, Communication Team SCRN. Developing communication competency in the context of cancer: a critical interpretive analysis of provider training programs. Psychooncology. 2005;14:861–72.
85. Dugardyn R. Nu nog de achterblijvers! Communicatietrainingen voor medisch specialisten. Tijdschrift Gezondheidsvoorlichting. 1997;34:26–8.
86. Gaasbeek I, Feller E. Videotraining on the job. Tijdschrift Gezondheidsvoorlichting. 1995;12(4):9–10.
87. Langewitz WA, Eich P, Kiss A, Wossmer B. Improving communication skills – a randomised controlled behaviourally oriented intervention study for residents in internal medicine. Psychosom Med. 1998;60:268–76.
88. Morgan ER, Winter RJ. Teaching communication skills. An essential part of residency training. Arch Pediat Adolesc Med. 1996;150:638–42.
89. Wouda J, Van de Wiel HBM, Weijmar Schulz WCM. Communication-skills training for gynaecologists: why and how [Training communicatieve vaardigheden voor gynaecologen – het waarom en het hoe]. Ned T Obst Gynaec. 1992;105:130–6.
90. Wouda J, Van de Wiel HBM, Zwierstra RP, Ottow RT. The 'Communication and Cooperation' course for surgical residents [De cursus 'Communicatie en Samenwerking' voor artsassistenten]. T Med Onderwijs. 2000;19:142–50.
91. Wouda JC, Van de Wiel HBM. The effects of self-assessment and supervisor feedback on residents' patient-education competency using videoed outpatient consultations. Patient Educ Couns. 2014;97:59–66.
92. Tschudin S, Kaplan Z, Alder J, Huang D, Bitzer J, Leeners B. Psychosomatics in obstetrics and gynaecology – evaluation of a compulsory standardized teaching program. J Psychosom Obstet Gynaecol. 2013;34:108–15.
93. Scheele F, Teunissen P, Van Luijk S, Heineman E, Fluit L, Mulder H, Meininger A, Wijnen-Meijer M, Glas G, Sluiter H, Hummel T. Introducing competency-based postgraduate medical education in the Netherlands. Med Teach. 2008;30:248–53.
94. Ericsson KA. Deliberate practice and acquisition of expert performance: a general overview. Acad Emerg Med. 2008;15:988–94.
95. Gillard S, Benson J, Silverman J. Teaching and assessment of explanation and planning in medical schools in the United Kingdom: cross sectional questionnaire survey. Med Teach. 2009;31:328–31.
96. Von Fragstein M, Silverman J, Cushing A, Quilligan S, Salisbury H, Wiskin C. UK consensus statement on the content of communication curricula in undergraduate medical education. Med Educ. 2008;42:1100–7.
97. Jones JM, Papadakos J, Bennet C, Blacker S, Catton P, Harth T, Hatton-Bauer J, McGrath K, Schwartz F, Turnbull G. Maximizing your patient education skills (MPES): A multi-site evaluation on an innovative patient education skills training course for oncology health care professionals. Patient Educ Couns. 2011;84:176–84.
98. Small RM, Soriano RP, Chietero M, Quintana J, Parkas V, Koestler J. Easing the transition: medical students' perception of critical skills required for the clerkships. Educ Health. 2008;21:192.
99. Carlson LE, Feldman-Stewart D, Tishelman C, Brundage MD, Communication Team SCRN. Patient-professional communication research in cancer: an integrative review of

research methods in the context of a conceptual framework. Psychooncology. 2005;14:812–28.
100. Davis MH, Ponnamperuma GG, Wall D. Workplace-based assessment. In: Dent JA, Harden RM, editors. A practical guide for medical teachers. Edinburgh: Churchill Livingstone Elsevier; 2009;Ch 45:341–8.
101. Norcini J, Burch V. Workplace-based assessment as an educational tool. AMEE Guide 31. Dundee, UK: Association for Medical Education in Europe; 2007.
102. Hammound MM, Morgan HK, Edwards ME, Lyon JA, White C. Is video review of patient encounters an effective tool for medical student learning? a review of the literature. Adv Med Educ Pract. 2012;3:19–30.
103. Aspegren K. Teaching and learning communication skills in medicine-a review with quality grading of articles. Med Teach. 1999;21:563–70.
104. Henwood PG, Altmaier EM. Evaluating the effectiveness of communication skills training: a review of research. Clin Perform Qual Health Care. 1996;4:154–8.
105. Humphris GM, Kaney S. Assessing the development of communication skills in undergraduate medical students. Med Educ. 2001;35:225–31.
106. Shapiro SM, Lancee WJ, Richards-Bentley CM. Evaluation of a communication skills program for first-year medical students at the University of Toronto. BMC Med Educ. 2009;9:11–8.
107. Smith S, Hanson JL, Tewksbury LR, Christy C, Talib NJ, Harris MA, Beck GL, Wolf FM. Teaching patient communication skills to medical students: a review of randomized controlled trials. Eval Health Prof. 2007;30:3–21.
108. Yedidia MJ, Gillespie CC, Kachur E, Schwartz MD, Ockene J, Chepaitis AE, Snyder CW, Lazare A, Lipkin Jr M. Effect of communications training on medical student performance. JAMA. 2003;3(290):1157–65.
109. Bombeke K, Van Roosbroeck S, De Winter B, Debaene L, Schol S, Van Hal G, Van Royen P. Medical students trained in communication skills show a decline in patient-centred attitudes: an observational study comparing two cohorts during clinical clerkships. Patient Educ Couns. 2011;84:310–8.
110. Hook KM, Pfeiffer CA. Impact of a new curriculum on medical students' interpersonal and interviewing skills. Med Educ. 2007;41:154–9.
111. Pfeiffer C, Madray H, Ardolino A, Willms J. The rise and fall of students' skill in obtaining a medical history. Med Educ. 1998;32:283–8.
112. Butow P, Cockburn J, Girgis A, Bowman D, Schofield P, D'Este C, Stojanovski E, Tattersall MHN. Increasing oncologists' skills in eliciting and responding to emotional cues: evaluation of a communication skills training program. Psychooncology. 2008;17:209–18.
113. Bylund CL, Brown R, Gueguen JA, Diamond C, Bianculli J, Kissane DW. The implementation and assessment of a comprehensive communication skills training curriculum for oncologists. Psychooncology. 2009;19:583–93.
114. Fellowes D, Wilkinson S, Moore P. Communication skills training for health care professionals working with cancer patients, their families and/or carers (Review). Cochrane Database Syst Rev. 2004;2:CD003751.
115. Girgis A, Cockburn J, Butow P, Bowman D, Schofield P, Stojanowski E, D'Este C, Tattersall MHN, Doran C, Turner J. Improving patient emotional functioning and psychological morbidity: evaluation of a consultation skills training program for oncologists. Patient Educ Couns. 2009;77:456–62.
116. Gysels M, Richardson A, Higginson IJ. Communication training for health professionals who care for patients with cancer: a systematic review of effectiveness. Support Care Cancer. 2004;12:692–700.
117. Cegala DJ, Lenzmeier BS. Physician communications skills training; a review of the theoretical backgrounds, objectives and skills. Med Educ. 2002;36:1004–16.
118. Hulsman RL, Ros WJ, Winnubst JA, Bensing JM. Teaching clinically experienced physicians communication skills. A review of evaluation studies. Med Educ. 1999;33:655–68.

119. Barth J, Lannen P. Efficacy of communication skills training in oncology: a systematic review and meta-analysis. Ann Oncol. 2011;22:1030–40.
120. Tulsky JA, Arnold RM, Alexander SC, Olsen MK, Jeffreys AS, Rodriguez KL, Sugg-Skinner C, Farrell D, Abernethy AP, Pollak KI. Enhancing communication between oncologists and patients with a computer-based training program: a randomized trial. Ann Intern Med. 2011;155:593–601.
121. Claramita M, Majoor G. Comparison of communication skills in medical residents with and without communication skills training as provided by the Faculty of Medicine of Gadjah Mada University. Educ Health. 2006;19:308–20.
122. Fossli Jensen B, Gulbrandsen P, Dahl F, Krupat E, Frankel RM, Finset A. Effectiveness of a short course in clinical communication skills for hospital doctors: results of a crossover randomized controlled trial (ISRCTN22153332). Patient Educ Couns. 2011;84:163–9.
123. Uiterhoeve RJ, Bensing JM, Grop RP, Demulder PH, Van Achterberg T. The effect of communication skills training on patient outcomes in cancer care: a systematic review of the literature. Eur J Cancer Care. 2009;19:442–57.
124. Zimmerman L, Del Piccolo L, Finset A. Cues and concerns by patients in medical consultations: a literature review. Psychol Bul. 2007;133:438–63.
125. Essers G, Van Dulmen S, Van Weel C, Van der Vleuten C, Kramer A. Identifying context factors explaining physician's low performance in communication assessment: an explorative study in general practice. BMC Fam Pract. 2011;12:138.
126. Rethans JJ, Norcini JJ, Baron-Maldonado M, Blackmore D, Jolly BC, LaDuca T, Lew S, Page GG, Southgate LH. The relationship between competence and performance: implications for assessing practice performance. Med Educ. 2002;36:901–9.
127. Van de Eertwegh V, Van Dulmen S, Van Dalen J, Scherpbier AJJA, Van der Vleuten CPM. Learning in context: Identifying gaps in research on the transfer of medical communication skills to the clinical workplace. Patient Educ Couns. 2013;90:184–92.
128. Wallenstein J, Heron S, Santen S, Shayne P, Ander D. A core competency-based objective structured clinical examination (OSCE) can predict future resident performance. Acad Emerg Med. 2010;Suppl 2:S67–71.
129. Brown J. Transferring clinical communication skills from the classroom to the clinical environment: perceptions of a group of medical students in the United Kingdom. Acad Med. 2010;85:1052–9.
130. Dosanjh S, Barnes J, Bhandari M. Barriers to breaking bad news among medical and surgical residents. Med Educ. 2001;35:197–205.
131. Essers G, Van Weel-Baumgarten E, Bolhuis S. Mixed messages in learning communication skills? students comparing role model behaviour in clerkships with formal training. Med Teach. 2012;34:e659–65.
132. Hodges BD, Kuper A. Theory and practice in the design and conduct of graduate medical education. Acad Med. 2012;87:25–33.
133. Hutul OA, Carpenter RO, Tarpley JL, Lomis KD. Missed opportunities: a descriptive assessment of teaching and attitudes regarding communication skills in a surgical residency. Curr Surg. 2006;63:401–9.
134. Rosenbaum ME, Axelson R. Curricular disconnects in learning communication skills: what and how students learn about communication during clinical clerkships. Patient Educ Couns. 2013;91:85–90.
135. Sandhu RS, Ong BN, Cooper V, Hassel AB. Attitudes and perceptions of rheumatologists regarding consultation skills training for specialist trainees: a qualitative study. Clin Med. 2010;10:8–12.
136. Van Dalen J. Communication skills in context: trends and perspectives. Patient Educ Couns. 2013;92:292–5.
137. Van den Eertwegh V, Van Dalen J, Van Dulmen S, Van der Vleuten C, Scherpbier A. Residents' perceived barriers to communication skills learning: comparing two medical working contexts in postgraduate training. Patient Educ Couns. 2014;95:91–7.

138. Williams C, Cantillon P, Cochrane M. The doctor-patient relationship: from undergraduate assumptions to pre-registration reality. Med Educ. 2001;35:743–7.
139. Heaven C, Clegg J, Maguire P. Transfer of communication skills training from workshop to workplace: the impact of clinical supervision. Patient Educ Couns. 2006;60:313–25.
140. Nilsen S, Baerheim A. Feedback on video recorded consultations in medical teaching: why students loathe and love it – a focus-group based qualitative study. BMC Med Educ. 2005;5:28.
141. Noordman J, Verhaak P, Van Dulmen S. Web-enabled feedback: a method to reflect on the communication skills of experienced physicians. Patient Educ Couns. 2011;82:335–40.

Scholar: A Scholar Who Cannot See the Woods for the Trees: The Biopsychosocial Model as the Scientific Basis for the Psychosomatic Approach

24

Harry B.M. van de Wiel and K. Marieke Paarlberg

24.1 Introduction and Aims

The International Society for Psychosomatic Obstetrics and Gynecology (ISPOG) advocates a broad approach to obstetrics and gynecology as a discipline. In this context, breadth means paying attention to the role played by biological, psychological, and social factors in the illness and health of gynecological patients. This broad perspective is in contrast with the biomedical model, which is common in Western medicine; the biomedical model is first and foremost a depth perspective, which reduces illness to a problem in underlying biological processes. George L. Engel coined the term "biopsychosocial model" (BPS model) in 1977 to refer to a combination of zooming both in and out in relation to health issues. The BPS model is a way of thinking that helps to understand complex health problems and complaints without ignoring the influence and importance of biomedical, personal, and social factors. In principle, in this book we use the BPS model as a point of departure. The advantage of working with the BPS model is that you not only find out *how* things work—the depth perspective—but also gain an understanding of the meaning of a certain complaint or symptom, *why* a certain phenomenon exists. While this principle is always important, it is crucial in regard to:

- *Functional symptoms*: Many physical complaints serve as warning signals or are otherwise healthy reactions to an unhealthy situation; this is why they are called

H.B.M. van de Wiel, PhD (✉)
Wenckebach Institute, University of Groningen, University Medical Centre Groningen, Groningen, The Netherlands
e-mail: har.wiel@planet.nl

K.M. Paarlberg, MD, PhD
Department of Obstetrics and Gynecology, Gelre Hospitals, Apeldoorn Location, Apeldoorn, The Netherlands
e-mail: km.paarlberg@xs4all.nl

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_24

functional complaints. If we eliminate complaints like these, we run the risk of depriving patients of their solutions, with all the iatrogenic consequences that go with that. This is often the case with physical syndrome diagnoses such as premenstrual syndrome (PMS), postnatal depression (PND), etc., but also with psychological and social problems.

- *Ethical dilemmas*: Many health issues relating to obstetrics and gynecology are associated with moral considerations or ethical dilemmas. This requires a different kind of knowledge than solely biomedical knowledge.
- *Far-reaching consequences of medical procedures*: Many treatments, such as gynecological cancer interventions, have far-reaching consequences for the patient, not only physically but also psychologically and socially. This requires specific expertise from fields other than biology.
- *Comorbidity or multimorbidity*: Due to the simultaneous occurrence of problems which in themselves are straightforward, unexpected and unpredictable interactions and effects may arise. Problems like these also require an approach different than one based purely on biomedical science.

What these domains have in common is that using the biomedical model does not provide a satisfactory basis for adequate treatment, in spite of all the in-depth knowledge of biological processes that is available. However, although there are many advantages to using the BPS model, it is by no means the gold standard in everyday practice. The standard is specialization to an ever-increasing degree, and this is inevitably accompanied by zooming in at the expense of zooming out. After all, specialists distinguish themselves by focusing on those specific pathological processes that belong to their discipline. Psychiatrists focus on dysfunctions of the brain, endocrinologists on hormonal disorders, etc. This specific distinction is precisely what gives a specialty its right to exist in society and the practitioner his or her professional identity. In recent decades, medicine has become highly specialized; specialties have been added, and within existing specialties, numerous subspecialties have come into existence. This has led to a perspective that is progressively becoming deeper but also narrower. We know a huge amount about *how* physical processes take place but understand very little about why they exist or what they mean to the patient.

To counteract this understandable but undesirable development, in this chapter we will take a closer look at the incongruence between the breadth perspective and the depth perspective. We will do this on the basis of one of the domains listed earlier, namely, *syndrome diagnoses or functional symptoms*, because it is in this area that the risk of iatrogenic effects as a result of not using the BPS model is the highest. Since with syndrome diagnoses symptoms are nearly always classified on the basis of the *Diagnostic and Statistical Manual of Mental Disorders* (DSM), we will then zoom in the potential iatrogenic consequences of using this classification model (from the "deep" perspective) too much. But, first of all, to practice what we preach, we will zoom out and place our message in the overarching context of clinical practice.

The following topics will be discussed:

1. Clinical reasoning
2. "The" diagnosis as the rule
3. The exception: syndrome diagnoses
4. The alternative: the BPS model
5. Multidisciplinary approach
6. Changing perspectives
7. Oppositions

24.2 Clinical Reasoning

The basis of all medical action is clinical reasoning, in the specific form of the triad of *etiology*, *diagnosis*, and *treatment*. This triad is the basis not only of the health professional's clinical action but also of the patient's rationale in seeking help and of the social legitimization of the medical profession. Although the three elements are closely connected, for didactic reasons, we will make some brief explanatory comments about each separately:

- *Etiology*: The etiology is the *explanatory model* used to identify certain symptoms or problems and to provide a suitable solution. If too much stress is put on a bone, it will break. To heal the fracture, the bone must first be straightened and then set to enable spontaneous healing. Etiology itself builds on research findings and views within a certain profession but also on practitioners' own experience and attitudes.
- *Diagnosis*: In strictly medical terms, diagnosis means the identification of a disease on the basis of the symptoms. Because the concept of disease is closely related to suffering and therefore to experience, we will use the broader definition formulated by Dellemann (2008): "Diagnosis is a characterization of the experience of disease as an example of a more general phenomenon, but also a specification of the typical features of this experience; the name of the diagnosis is a designation of this shared general phenomenon of the disease experience" [1]. Diagnosis therefore refers both to the process (diagnostics) and the outcome ("the" diagnosis). The reasoning behind diagnostics builds on the etiology, which is generally used implicitly and in turn is itself the basis of the action plan: the treatment. This same reasoning is also the basis of policy decisions and public consensus regarding a particular complaint.
- *Treatment*: The treatment is the goal toward which the practitioner's efforts are directed, and in this sense it guides the overarching process of clinical reasoning. However, it is also a means of attaining medical goals such as a cure, palliation, prevention, or reassurance. If the theory of the problem is correct, then treatment is "merely" the logical culmination of the triad, and the practitioner can take action with confidence.

24.3 "The" Diagnosis as the Rule

The triad outlined earlier is the core of the concept of clinical reasoning—finding an explanation of the relationships among phenomena, their causes, their clinical progression, their consequences, their interventions, and their prognosis. Dellemann defines clinical reasoning as "the theory of the problem, which, like all theories, is used to establish a logical relationship between the phenomena observed (symptoms or health issues) and other phenomena" [1]. This relationship is the point of departure for the entire approach to a symptom or problem. The diagnosis is the connecting link between thinking (etiology) and acting (treatment). It is in fact both a concept—the diagnosis—and a process—the diagnostic process. Then, for pragmatic reasons, the concept is elevated into a pars pro toto, a clinical picture in which various characteristic properties of the symptom and its treatment are summarized into "the" diagnosis. The diagnosis is the rule or gold standard in medicine: no diagnosis, no treatment!

24.4 The Exception: Syndrome Diagnoses

Although rules and gold standards are handy, they are not infallible. The restriction that there must be a biomedical explanation for a symptom or problem means that many medical problems and issues are placed outside the realm of medicine and as a result also often outside healthcare. The fact is that for many clinical problems (see the *Introduction* section), there is no straightforward biomedical explanation. The most obvious category of problem is that of *syndrome diagnoses* or *functional symptoms*. A typical feature of syndrome diagnoses is that there are several layers to the problems; something that is a problem at the biological level may be a healthy reaction at the psychosocial level—a justified warning signal or even an unconscious solution. To illustrate this, we will take an example of a symptom of this kind, which is discussed in detail elsewhere in this book (Chap. 17 on vaginismus).

"Vaginismus is commonly described as a persistent difficulty in allowing vaginal entry of a penis or other "objects" (e.g., tampons, fingers, speculum), despite the woman's expressed wish to do so" (see Chap. 17). Vaginismus can be eliminated very simply by an injection of botulinum toxin to paralyze the vaginal sphincter muscles if the complaint is seen as the mechanical consequence of a dysfunctional vaginal sphincter. In that case the diagnosis will focus on determining whether or not the patient is a suitable candidate for this procedure. However, a health professional who sees the same complaint as a logical and healthy—albeit unconscious—fear of losing control and in particular of penetration of the vagina, will choose a different diagnostic path, one focused on a different treatment goal.

Although the dangers of overly rigid application of the biomedical model are now widely known, "the map is not the territory" [2], and in fact this model is still the gold standard in everyday practice. The model even serves as the basis for thinking in terms of and working with guidelines and protocols. Taking a different

perspective is seen as a departure from the norm and must therefore be accounted for. To counteract this, we will present the BPS model so that readers can make their own decision. While in many cases working according to the BPS model leads to better healthcare, it is also complex and time-consuming, especially in the beginning. Using the BPS model also highlights several oppositions that compel the user to take a certain stand. This can be a difficult thing to do, which is why we will discuss some of these oppositions explicitly.

24.5 The Biopsychosocial Model as an Alternative

What syndrome diagnoses, medical ethics issues, the psychosocial consequences of drastic medical interventions, and multimorbidity have in common is that they cannot be explained on the basis of a unidimensional explanatory model. There is no conclusive biomedical theory of the problem in terms of "the diagnosis." To engage in sound clinical reasoning in spite of this, that reasoning will have to be expanded in at least two fundamental directions:

1. Biology as the sole domain of knowledge will have to be exchanged for a triad of knowledge domains—biology, psychology, and the humanities. The use of this triad can be referred to as the *multidisciplinary approach*.
2. Practitioners will have to alternate between a broad perspective and a deep perspective instead of taking only a deep perspective; both perspectives have clear pros and cons, which is why *alternating perspectives* is a characteristic feature of the BPS model.

But there is more! Building on the three-world theory [3] and, as illustrated by Fig. 24.1, combining the biological, psychological, and social perspectives gives rise to a unique new meta-perspective. It is unique, like the emerging equilateral triangle in Fig. 24.1, in that it has new features that cannot be reduced to the three domains from which it is derived. In fact these unique characteristics, such as safety, synergy, and flow, as well as their counterparts, are what enable us to construct a sound triad of etiology, diagnosis, and treatment.

24.5.1 Multidisciplinary Approach

As we have seen, certain complaints—we will focus on syndrome diagnoses to illustrate the point—require health professionals to go beyond standard medical knowledge, because biological knowledge alone is unable to provide an adequate explanatory model. If we nevertheless limit ourselves to it, we will get no further than an analytical, empirical description of the symptoms in combination with a long list of risk factors. Although in themselves these descriptions can provide a helpful initial structuring framework, they are not diagnoses; there is no explanatory model, no theory about the symptoms, and therefore no conclusive clinical

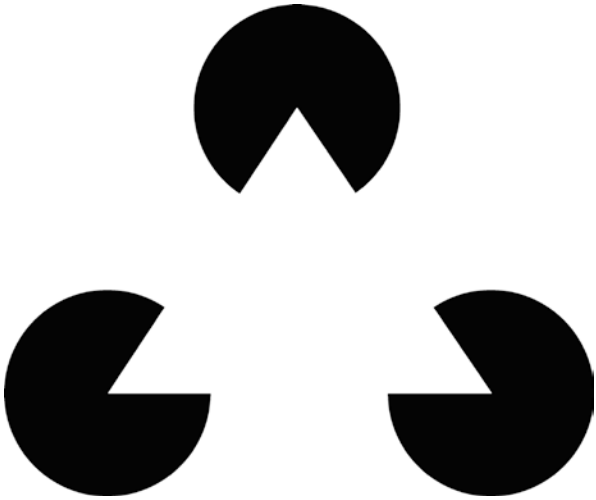


Fig. 24.1 This figure illustrates the combination of the bio-, psycho-, and social perspectives, resulting in a unique new meta-perspective with new features that cannot be reduced to the three constituting domains, like the emerging equilateral triangle. These unique characteristics, like safety, synergy, and flow, but also their counterparts, enable us to practice what we call *POG* (psychosomatic obstetrics and gynecology) and help us to construct a sound triad of etiology, diagnosis, and treatment

reasoning. Such reasoning is only possible if we are prepared to look at the symptoms from a psychological or social perspective. However, this requires knowledge and skills in those two fields, which not only cover different knowledge but also have a different view of knowledge and of human beings. Whereas the biomedical model is based on the exact sciences, the social sciences and the humanities each use a different paradigm. It is difficult, if not impossible, to combine all this knowledge, which is in itself specialized, in one person. A commonly used method to combine knowledge, expertise, and creative skills is to work with multidisciplinary consultations.

24.5.2 Changing Perspectives

The aim of the BPS approach is to be able to see both the big picture and the relevant components that are causing problems somewhere in the system. This requires both the skill to zoom in and observe closely how processes work and the ability to zoom out to gain a sense of the meaning of those processes. Both perspectives are needed to ultimately arrive at sound clinical reasoning. This is particularly important in cases in which the conventional mechanical models of disease prove inadequate. The reasoning then soon tends to be limited to postulating a kind of black box, in which a wide range of "risk factors" often play a role. The accompanying complicated diagrams and flowcharts speak volumes, and the way diagnostics and treatment are given shape usually suggests the development of schools of thought. A

practitioner who does not believe in this has no other option than trial and error. It is not for nothing that in cases of this kind people talk about a "diagnosis by exclusion" or a "last resort diagnosis." Only by zooming in and, in particular, by zooming out continually and therefore seeing the symptoms from a broader perspective is it possible to gain an understanding of their meaning. There are advantages to these necessary changes of perspective, but they also lead to a different way of thinking about diagnostics and different working procedures in clinical practice, such as:

- A diagnosis is not a static end result but is subject to progressively increasing understanding. Diagnostics is like peeling an onion: you gradually get closer and closer to the core of the problem. This is why practitioners refer to a working diagnosis rather than "the" diagnosis.
- As the working diagnosis changes, the whole clinical reasoning generally also changes, including the objectives of the treatment. In the case referred to, for instance, it could change from "being able to have sexual intercourse" into "achieving a satisfactory partner relationship and/or experience of your own sexuality."
- Since progressively increasing understanding can also be confusing, it is important to be transparent in terms of the action plan and to engage the patient actively in the treatment. This puts the physician in the role of coach rather than treating practitioner.
- If the practitioner is unable to zoom both in and out and unable to find the meaning of the complaints, diagnostics can also be harmful. Diagnostic tests, which are sometimes numerous, can in themselves lead to injury and side effects. It is also possible for an incorrect diagnosis to be made, which in the case of syndrome diagnoses or psychosocial problems is also very difficult to correct at a later stage. With this kind of problem the risk of stigmatization and hospitalization is high.

24.6 Oppositions

The BPS model has different points of departure from the conventional biomedical model. Opting for the BPS model is therefore not merely a pragmatic expansion in terms of knowledge domains and perspectives in order to be able to treat certain problems more effectively or more easily. It is a fundamental choice that has a bearing on several epistemological oppositions such as that between objectivity and subjectivity. In the section that follows, a few of these oppositions will be discussed in greater detail.

24.6.1 Generic Versus Specific

Zooming in, as is often done with the biomedical approach, means staying within the paradigm of your own discipline. This is practical, because it means that your

points of departure are quite clearly related to each other and can be shared with other practitioners in your discipline, since they all belong to the same paradigm—that of the exact sciences. Zooming out, as is the intention when using the BPS model, inevitably means also scrutinizing your own way of looking at things. Moreover, the BPS model combines the exact sciences paradigm of biology with the paradigms of the social sciences and humanities, which also differ from each other. Because findings from the exact sciences paradigm are easier to generalize internationally—unlike groups of people, iron molecules behave in exactly the same way in Japan as they do in the Netherlands—and research aims to be as universal as possible, in terms of research-based evidence, there is a hierarchy, with the exact sciences at the top. However, as far as relevance is concerned, it is often the other way round: in controlled laboratory conditions, you can know something for sure, but human beings do not live in such controlled conditions. If you zoom in, you see less but with greater certainty and generalizability. If you zoom out, you see more, but not as clearly.

24.6.2 Subjective Versus Objective

While using different perspectives improves the quality of diagnostics, the improvement depends to a significant extent on the quality, background, and personal characteristics of the person carrying out the diagnosis. This subjectivity is at odds with the aim enshrined in scientific tradition to achieve objectivity in terms of "replicability" and "independence from the observer." In the case of syndrome diagnoses and behavioral or mood disorders, it is almost impossible to meet these criteria, and treatment and prognostic implications, for instance, are always limited, because often understanding progresses, including in terms of treatment goals. All these changes have an adverse effect on repeatability and therefore also on reliability in the scientific sense. In practice, there are several strategies for dealing with this problem. You can systematically check all the different lines of enquiry; the lists that are often abundantly available are very handy when doing this. You can also, more or less artificially, stick to the goals set at an earlier point to determine the effectiveness of the interventions on the basis of the results attained, as is often done in intervention research. You also can be guided by intuition, matching your questions to the conversational flow or to the treatment in the broader sense. As you proceed, observing and identifying, you will slowly but surely arrive at more and more clear-cut working hypotheses, which you can then test by asking further questions. However, by definition strategies are in themselves context dependent and can therefore change depending on the situation. The diagnostic process imitates human observation: the first impression is the diagnosis, which is then tested or, more often, substantiated. Gradually the health professional finds out who the other person is, where the problems come from, why previous solutions were not successful, etc. In themselves, syndrome diagnoses are easy to make, but unfortunately they provide little insight, let alone guidelines for treatment. These must be gained in the process of working with the patient.

24.6.3 Labeling Or Ignoring

When it comes to syndrome diagnoses, the name plays a special role. If something has no name, it does not exist and is therefore not medically or socially acknowledged. To put it differently, the fact that there is a diagnosis contributes greatly to the strength of the rationale behind the way a certain disorder is seen in various circles. For the patient, a plausible rationale is often a prerequisite before he or she is prepared to undergo treatment at all. For the health professionals involved, a rationale of this kind is an ideal guideline for their actions. The patient wants plausibility; the health professional wants an evidence base. These two can be contradictory. In practice this is usually resolved by mentioning the syndrome diagnosis in passing, saying, for example, "this is popularly known as PMS." This provides the recognition the patient needs at the beginning of the process, and gradually this terminology can be abandoned if this seems appropriate. The same principle can be applied to "standard" follow-up tests. Even though you know that a certain scan will not help to find a sound diagnosis, it may be a prerequisite for the patient to feel they are being taken seriously. Formal discussions with one's own fellow practitioners are trickier. There are plenty of "conservative" professionals who dismiss any kind of "liberal" approach to diagnostics or treatment as quackery. The question that then arises is what a person sees as the function, task, or role of diagnostics or even of medicine. The point of departure we take is that medicine is a practical profession whose primary purpose is to care for the patient. Obviously this does not exclude a role relating to more general knowledge, that is, in research, but it does highlight this book's position.

24.6.4 Pathophysiology Versus Burden of Suffering

Unlike mechanical injuries such as wounds, lesions, fractures, etc., functional symptoms are physically not very tangible, but psychologically they are not very understandable either. Nevertheless, they require a professional reaction, even if this means no medical treatment. Because of this, before responding to the content of a diagnosis, it is important to realize that the phenomenon of a "diagnosis" is not tangible either. A diagnosis is an agreed working plan that is convenient or useful to a greater or lesser extent. Its usefulness largely depends on the definition of the symptoms or problems for which the diagnosis is regarded as a working plan. Depending on the definition chosen for the problem, the significance and form of the working plan in terms of finding a solution will vary. Often problems or complaints are formulated in terms of "disease" even though the pathology formally required for this is absent. This may sound like an academic discussion, but the outcome of this discussion has far-reaching consequences for society. The absence of a "pathophysiological substrate" may be a reason not to be able or permitted to refer to a condition as a disease and therefore, for instance, to refuse to treat it or to pay for its treatment. There is no disease and therefore there are no healthcare expenses. In this context it is important to realize that the conceptualization of

problems—thinking about pathology—is never value-free. It is impossible to use terms such as "unhealthy," "disorder," "abnormal," etc., without having certain values and standards regarding what constitutes a good life or health, without an overarching view of humanity. Although basic principles of this kind determine thinking about pathology, they are rarely expressed, let alone examined. In this sense, in clinical practice *thinking about pathology is pathological*. However, the absence of a reference point certainly does not stop us from energetically measuring and testing. The question is what purpose all these good measurements serve. It is only now that the financial limits of medical interventions are becoming evident that the public debate we need about what should and should not be regarded as pathological and therefore what warrants healthcare is beginning. The awkward thing about clinical practice is that there are so many situations in which this debate is obsolete. As regards mechanical problems such as fractures, wounds, or protracted labor, medical pragmatism is a blessing. However, this blessing can become a curse when it is used at the wrong point or for the wrong reasons, as with syndrome diagnoses. Because these conditions involve "too much of a good thing" —fear, sadness, etc., are in themselves healthy reactions—it is crucial in cases of this kind to carefully and explicitly identify what is "good" and "normal" and therefore what good clinical practice is. This can only be done by seeing complaints in the patient's personal context.

24.6.5 Reliability Versus Validity

Because diagnoses determine the legitimacy of the entire clinical course of action, one of the basic principles in medicine is that the diagnosis must be right—that is, correct, logical, and relevant. In this context concepts from the theory of testing are used. The diagnosis is seen as a kind of sample that can be classified not only in terms of reliability but also in terms of validity. In the thinking of the exact sciences, reliability (as mentioned previously) refers to reproducibility, that is, the extent to which a disorder can be identified again and again over time or with the same degree of certainty by a different practitioner. This works very well with mechanical problems: A broken leg is a broken leg. However, with mental and social problems, reliability is very difficult to attain. To be able to meet the requirements of evidence-based medicine, nonetheless, in recent years health professionals have taken to using smaller and smaller units of observation. This is evident from the nature of the targets of observation but also from the fact that instead of a clinical interview with open questions, which can go anywhere and everywhere, practitioners opt for structured interview techniques, observers with identical training in a certain area, self-reporting questionnaires (SRQs), etc. This enhances the reliability of statements considerably. Unfortunately this "atomic" approach, in which smaller and smaller components are examined with increasing reliability, has an adverse effect on the coherence and therefore the meaning of the whole picture. Moreover, a study of this kind is

only feasible if sub-targets are chosen and the groups in question are not too heterogeneous. The consequence is that often it is difficult to apply the results of many such studies to groups of patients in real life. In short, the gain in reliability goes hand in hand with a loss of validity in practice. What is said is true, but it does not say very much.

24.6.6 Outcome Versus Process

Validity is a compelling concept for clinicians: something that is valid is strong, reliable, and well founded. It is important to realize that in relation to a diagnosis, validity means that the diagnosis must have predictive value, since future actions will depend on it. It is precisely in this respect that syndrome diagnoses fall far short of "real" diagnoses. Functional symptoms can be understood and explained in retrospect, but unlike the course of bone fractures or normal wound healing, it is virtually impossible to predict them, let alone influence them. Practitioners try to compensate for this unpredictability by seeking solid ground in the way the validation process is shaped:

- Firstly, descriptive diagnostic criteria for a disorder are determined on the basis of existing knowledge; in the case of syndrome diagnoses, this usually involves long lists of risk factors.
- Then matching diagnostic measuring instruments are developed.
- In a process of internal validation, optimal threshold values are determined, and the measuring instruments are tested for internal consistency and reliability. This is the stage at which things go wrong with syndrome diagnoses, since it is rarely or never possible to determine precise threshold values. It always involves a subjective assessment by the clinician, whether or not in consultation with the patient, of what is seen as "too intense," "too long," "too much," etc.
- On this basis the original criteria can be adjusted, after which a new cycle of testing can begin.

With syndrome diagnoses, clinicians are forced to resort to the first 2 steps, as is reflected in the endless definitions and operationalizations, all slightly different from each other, of more or less the same symptoms. Sometimes a consensus meeting is held that serves mainly to get the research ranks back into line. However, the gap between research and practice is rarely bridged and usually the consensus reached does not last long. From a historical perspective, we see a Christmas tree pattern: from a certain stem, usually the initial definition posited by a certain pioneer, other ideas fan out in all directions. After a while the confusion becomes too great, and attempts are made to agree on a redefinition—a new stem. This pattern then repeats itself continually, as we see with the history of syndromes such as premenstrual dysphoric disorder (PMDD), postpartum depression (PPD), etc.

24.6.7 Describing Versus Classifying

It is often assumed that in the case of syndrome diagnoses, research is all about making lists of risk factors. Researchers believe they are gathering unbiased information derived from empirically acquired knowledge. But classification is never value-free. Taxonomy always builds on implicit or explicit theoretical points of view—the rationale as formulated in the etiology. These values determine which variables are included or ignored in epidemiological research. This etiology therefore reflects various underlying ontological and epistemological values, such as what the purpose of clinical action is and what its core values are. This is why it is important, especially where there are no "hard diagnoses," to spell out the dialogue about etiology, the underlying explanatory model, and the values on which that model is in turn based. Here we will use the *Diagnostic and Statistical Manual for Mental Disorders* (DSM) to illustrate that an overly pragmatic approach, using explicit criteria for every disorder in the classification and several axes for diagnostic evaluation, can have disastrous consequences.

24.6.8 Pro-DSM Versus Contra-DSM

One of the great advantages of a classifying approach such as the DSM is that researchers and clinicians use a shared "language" to describe psychopathology. As such, this uniformity of language has significantly increased the intradisciplinary reliability of diagnostics performed. Exchange between practice and theory has also clearly benefited from this form of user-friendliness. The DSM gives clinicians a solid foothold in uncertain situations and also helps them to express their observations in terms that can be understood by patients, practice managers, and health insurers. A second advantage of the DSM as a classification system is that it looks rational; the DSM defines complaints in terms of nature (quality), intensity (quantity), and their consequences for psychological and social functioning. In short, it is an extremely attractive communication aid between various target groups, because it provides both the language and the rationale to shape common action.

There are also arguments against using the DSM. The first objection is that the DSM itself does not meet the criteria for strict taxonomy. To meet those criteria, the categories must:

1. *Be mutually exclusive*: An animal cannot be both a fish and a mammal.
2. *Be jointly exhaustive*: No animals may exist that do not belong to the existing species.
3. *Be exact*: It must always be possible to determine on the basis of specific characteristics—legs, feathers, fins, etc. —whether or not an animal belongs to a certain class.
4. *Be absolute*: An animal cannot be a fish in the first year and then later be a bird.

Psychopathological characteristics are rarely exact, and are not defined by a single crucial attribute. There is hardly ever a one-to-one relationship between symptoms and diagnosis. This is also reflected in the constant battle regarding the definition of disorders such as PMDD, PND, etc. It is actually also true of the etiology of major DSM disorders such as schizophrenia; even for these, there is very little evidence in terms of a clearly demonstrated pathophysiological substrate and long-term stability. Completely in line with this, response to treatment is also not specific for different individual diagnoses [1, 4]. In this context reference is often made to the influence of the placebo effect or nonspecific treatment factors—which in practice are welcome but are disruptive as regards theory. The placement of various disorders on the various axes is also controversial. An element that puts one disorder on axis one puts another on axis two. Finally, there is another significant limitation that is particularly relevant in the context of this book. Relationship problems and conditions associated with a high risk of complaints, one of the core domains of the BPS model, are not covered in the current DSM. The same applies to a certain extent to life stage issues.

In short, what is missing in current pragmatic classification systems such as the DSM is the complex relationship between culture and mental—and other—disorders. This is particularly evident in relation to personality disorders, the area in which the requirements of a strict classification system are the most at odds with the essential characteristics of behavior as defined in terms of personality. The behavior in question is sometimes appropriate and sometimes not, and what is regarded as appropriate depends not only on the context but also to a significant extent on the particular culture. In other words, in this area the convenient depth perspective, which sees disorders as distinct natural units, clashes with the breadth perspective, in which categories represent only one way of organizing information—a way that has been agreed on for pragmatic reasons.

24.7 Changing Perspectives

Based on the previous discussion, methodologically speaking it could be asserted that as far as syndrome diagnoses are concerned there are no valid diagnoses. However, validity can also be seen more broadly: in terms of what a diagnosis is worth or, pragmatically, how "convenient" (helpful) it is. Of course, what something is worth depends on who is asking the question and in what situation. While technically it makes sense to opt for as narrow as possible an interpretation of validity, in the case of practical, socially oriented problems, it is important to use a broad perspective. The depth-breadth dilemma also applies to the concept of validity itself. If we assume that the aim of diagnostics is to obtain as realistic as possible a picture not only of a person's symptoms but also of the patient's possibilities and limitations in their particular situation, then using several perspectives, including some that are less valid in terms of formal research criteria, is still the most appropriate choice.

Conclusions

Classification diagnoses such as syndrome diagnoses can be seen as an initial structuring framework that is meaningful and helpful. They bring order into complexity—the first goal of a diagnosis. These classification systems also provide a common language, which means that important concepts can be shared among the various stakeholders such as clinicians, patients, health insurers, and researchers. However, initial structuring frameworks are meaningless or even iatrogenically harmful if practitioners treat them as absolutes and think that with this initial structuring they are finished. Sometimes symptoms and syndromes are categorized without relating them to other aspects of the patient's functioning—the individual with his or her own context, history, and culture. This has a negative impact on the validity of the diagnosis and can even have iatrogenic effects. In principle the BPS approach provides effective guidelines to avoid this pitfall, but it requires considerably more from diagnosticians than having a good cookbook at their disposal. However, rather than being a good cook or diagnostician, what it is really about is a fundamental choice: the BPS approach is primarily about helping the individuals who are ill. This requires dialogue with the patient about what she regards as important in relation to illness and health. Patients usually attribute more value to enhancing their social functioning than to controlling their symptoms.

Tips and Tricks

Some practical lessons can be learned from this largely theoretical discussion. After all, this is a textbook for professionals in obstetrics and gynecology. Here they are:

1. It is important always to remain aware that diagnostic categories are only aids; their use is justified by whether or not they can help to structure and explain complex cases in clinical practice.
2. It is important to make a distinction between understanding and explaining on the one hand and predicting on the other. Although we can often classify certain symptoms or behavior in retrospect, it is and remains virtually impossible to predict possible future behavior and therefore to make a prognosis as regards the future course of symptoms, the effect of interventions, etc.
3. It is important to realize that this means we use the term "diagnosis" in only a small part of its original meaning.
4. If we are well aware of this, there is nothing against using a classification model, provided it can be shown that it is clinically helpful. This is actually rarely the case, if only because in practice comorbidity is often involved.
5. While many see comorbidity as a threat to the validity of the diagnostic process, it can also be seen as a source of inspiration for a more appropriate approach to illness, such as the BPS model.
6. Use the DSM as a kind of catalogue of psychiatric disorders. Like other aids such as checklists, it can help ensure competent and conscientious practice. But remember that having a recipe does not make someone a good cook.

Acknowledgment To a significant extent, this chapter was inspired by and is based on "Towards an Integral Psychiatry," a PhD thesis by O. R. J. Dellemann (Utrecht, The Netherlands: Universiteit voor Humanistiek; 2008).

References

1. Dellemann ORJ. Towards an integral psychiatry. PhD Thesis. Universiteit voor Humanistiek, Utrecht; 2008.
2. Korzybski A. A non-aristotelian system and its necessity for rigour in mathematics and physics. Sci Sanity. 1933;747–61.
3. Popper K. The tanner lecture on human values. Ann Arbor: University of Michigan; 1978.
4. Regier DA, First M. The American Psychiatric Association (APA) classification of mental disorders: strengths, limitations and perspectives. In: Maj M, Gaebel W, editors. Psychiatric Diagnosis and Classification. Chichester: John Wiley & Sons, Ltd; 2002.

Health Advocate: An Obstetrician in Doubt—Coping with Ethical Dilemmas and Moral Decisions

25

Harry B.M. van de Wiel, K. Marieke Paarlberg, and Sylvia M. Dermout

25.1 Introduction and Aims

All healthcare professionals are regularly faced with the following question: "What is the wisest course of action? What is the right thing to do in this case or with this patient?" An inherent part of this kind of dilemma is that it involves pros and cons that are difficult to weigh against each other; evidently there is a broad spectrum of *arguments*. These arguments refer to interests or values that are usually associated with rules for conduct and actions—what we call *standards*. Ethics is an area of study that can help those professionals deal with dilemmas of this kind and find answers to their questions regarding the right course of action and how to implement it.

In this chapter, a phased approach is advocated to manage this argumentation puzzle in real-life situations. According to the biopsychosocial (BPS) model, which is the theoretical basis for the psychosomatic approach and which is discussed elsewhere in detail in this book (see Chap. 22), the first step is to identify the relevance or *impact* of the various arguments so that an initial selection can be made. Impact means a combination of the scale and scope of the standards involved. When all the

H.B.M. van de Wiel (✉)
Wenckebach Institute, University of Groningen, University Medical Centre Groningen, Groningen, The Netherlands
e-mail: h.wiel@umcg.nl

K.M. Paarlberg
Department of Obstetrics and Gynecology, Gelre Hospitals, Apeldoorn Location, Apeldoorn, The Netherlands
e-mail: km.paarlberg@xs4all.nl

S.M. Dermout
Gynaecologist, Gynaecological Centre Dermout and Albicher, Alkmaar, The Netherlands
e-mail: sylvia@dermout.nl

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_25

relevant arguments have been identified, anything that clearly will have no impact can be eliminated. This usually simplifies the puzzle considerably. The remaining arguments must then be weighed up against each other. To do this, the following four generally accepted principles of medical ethics or kinds of *criteria* can be used: autonomy, nonmaleficence, beneficence, and justice. In order to provide adequate arguments for each choice, it is suggested to make an *impact matrix*, showing impact combined with kinds of criteria. If necessary this assessment can be made specific for target groups, since different considerations may apply for patients than for family or treating practitioners.

To illustrate this, this chapter will discuss the use of an impact matrix in the case of a common dilemma in obstetrics: whether or not to agree to a request from a healthy mother for a Cesarean section because she is afraid of damage to her pelvic floor, incontinence, or future prolapse. In succession the following topics will be discussed:

1. Medical ethics
2. The first selection: relevance
3. Applying the principles
4. Assessment
5. Decision-making
6. Discussion and final remarks
7. Tips and tricks

Case History

Marie-Anne Rose is a 28-year-old primigravida consulting you at 24 weeks of gestation. She has been referred to you by her midwife, since she is applying for an elective Cesarean section (CS). The midwife writes in her referral letter that Marie-Anne is healthy and has had an uneventful pregnancy thus far. Marie-Anne insisted on a Cesarean section during intake, and the midwife reports that she could not make her change her mind despite several discussions during the subsequent appointments she has had at her office. The midwife had discussed with her the options of a birth plan and epidural analgesia, but that was not the issue. Marie-Anne is an ambitious lawyer who does not want to run the risk of third-degree perineal tears, subsequent urinary and/or fecal incontinence, and future prolapse. Therefore, she insists on an elective Cesarean section.

She is referred to Gabriella Vermelho, an experienced obstetrician, brought up in the medical tradition of an old Portuguese family of doctors. Gabriella is well aware of the fact that the request of Marie-Anne will definitely not be a “black and white” discussion. Although an elective CS in primigravida women does indeed reduce the lifetime risk of pelvic organ prolapse and incontinence, there are many drawbacks to a CS on maternal request that definitely need to be to addressed as well.

In general one can say that a vaginal delivery is the safest option for the woman and the fetus, unless there are obstetric reasons to decide for a CS. Before Gabriella calls her in, she wonders how she should weigh all these arguments. These are all tumbling in her head asking for attention: What if Marie-Anne gets a third perineal tear with subsequent fecal incontinence if Gabriella and her team refuse to perform a CS? But what if she contracts a placenta previa with placenta percreta next time due to the previous CS? What if she contracts a pulmonary embolism postoperatively after an elective CS? And what is Gabriella's own opinion? She is personally convinced that women should only be operated on when there is an absolute medical reason for it. And according to her opinion, as well as according to the guidelines of her professional association, that is not the case when one wants to avoid some minor risks of a, usually safer, vaginal delivery at the expense of a CS, which is a major abdominal operation.

On the other hand, maybe this patient had a relative who has experiences with fecal incontinence, urine incontinence, pelvic floor problems with sexual consequences. What is wisdom, what is wrong or right, and what should be done?

25.2 Medical Ethics

This case shows that with a medical dilemma there are not only many factors to take into account but also different ways to assess those factors. The area of study concerned with answering the questions "What is the right thing to do?" and "How do we determine this?" is ethics. In recent decades the importance of ethics has increased considerably. Not only is there a growing number of choices, but the importance of accountability—being willing and obliged to account for one's professional actions—has risen significantly. After all, not everything that is possible is desirable, and what is good for one person is not by definition good for another. Something that helps today may have the opposite effect tomorrow. As we saw in the discussion of the BPS model (Chap. 22), medical action is always context dependent, and in principle a diagnosis is always temporary (a working diagnosis). Moreover, it is becoming increasingly clear that research results only provide concrete guidelines for the nonexistent "average" patient: Clinical practice always requires customization.

The domain of ethics that specifically focuses on medical dilemmas is medical ethics. A few examples of typical medical ethics issues relating to psychosomatic obstetrics and gynecology (POG) are:

- May surrogacy be used as a solution to involuntary childlessness or not?
- Will I be helping a woman with chronic abdominal complaints if I agree to her request for a hysterectomy?

- May genital surgery be used to solve aesthetic problems?
- Must I agree to a request for a Cesarean section when there are no obstetric reasons?

Ethics plays an important role in medicine for two reasons. The first is that medical actions, to a greater degree than most other forms of service, often have drastic consequences for the person involved—in this case the patient. The second is that medical actions are nearly always based on choices, and ethics provides arguments on which to base these choices and procedures for making them; these arguments can also be produced later to justify the choices made. In this sense the "what and how" of medicine is never noncommittal; it has, in fact, been discussed verbally and in writing ever since the "foundation" of medicine (see, e.g., Hippocrates). Two main forms of general ethics are distinguished:

- *Descriptive ethics* limits itself to identifying the values (what is considered important) and standards (the behavioral rules based on those values) in a particular population at a particular time.
- *Normative ethics* goes a step further, examining what the values and standards should be and providing practical guidelines; rather than descriptive, it is prescriptive. This chapter focuses on creating practical guidelines and is therefore in the realm of normative ethics, which is about learning to examine the pros and cons of a certain treatment in terms of values and standards. Normative ethics can again be divided into two streams:

- *Ontological ethics*: In the Platonic tradition, this form of ethics assumes the existence of an unassailable, fixed standard. This standard is often derived from a religious or ideological view, whether or not laid down in a written moral frame of reference. A well-known example of ontological reasoning is that abortion and euthanasia are forbidden because God, the Bible, or the Koran forbids them. The advantage is that you immediately know where you stand and that the focus is on the consequences of implementing or not implementing these procedures. The disadvantage of this approach is that any further reasoning or nuance is almost impossible.
- *Deontological ethics*: In the tradition of Aristotle, this form of ethics assumes that what is right is derived from the consideration of the arguments on which certain guidelines for action are based. Abortion and euthanasia can be carried out in well-defined circumstances, whether or not as a last resort, because otherwise the harm done to the person or persons in question is greater.

Although both forms of ethics are still found within medical ethics, over the past few decades in particular, ethics in medicine has made a major shift toward deontological ethics. Due to the growing influence of a science-based approach, often accompanied by the decline of an approach based on orthodox religion, medicine has become increasingly deontological. The basis of the scientific approach is that an event only has or gains meaning in a certain context. Moreover, in science

everything can, in principle, be discussed. Some say the original quote by Descartes was actually *Dubito ergo sum* ("I doubt, therefore I am"). An inherent part of issues of medical ethics is that the literature does not offer any clear-cut answers. What is right, and therefore what provides a guideline for the entire treatment, has become context dependent. This means that treatment must be customized, which makes the work interesting. However, it also means that, at most, ethical guidelines exist only at the meta-level. There are no ready-made answers to the primary question "What is the right thing to do?" What we do have are instructions to help answer the secondary question: "How can we determine what is right?"

Case History: Continued

Gabriella Vermelho (doctor) calls in Marie-Anne Rose (patient) who appears to be a tall and slender person and well dressed like she is just going to work. She tells Gabriella that her partner could not make it to the appointment due to his busy schedule at work. He is the CEO of a bank and regularly abroad. Furthermore, she says that she has decided to take the morning off from work, so there would be enough time today to arrange everything for the Cesarean section she desires.

Doctor: I have read the referral letter from your midwife. Do I understand correctly that you are assuming that we will get everything ready for a scheduled Cesarean today?

Patient: Yes, of course.

D: Well…. I can only decide on planning a Cesarean section, instead of awaiting a spontaneous delivery, after carefully balancing the pros and the cons. Therefore, I first would like to do an intake and assess exactly what your information is concerning the delivery and then try to find out together what will be the best plan concerning the delivery.

P: You say "delivery," but I think you mean "Cesarean," don't you?

D: I said "delivery" on purpose in order to keep open the outcome of the mode of delivery, if you don't mind.

P: Well, in fact, I do mind. I do not want a vaginal delivery, so it will be a Cesarean. We live in a free world and I can choose for myself which kind of delivery I am going to have, can't I? And I don't want a vaginal one—I don't want any damage to my vagina or pelvic floor.

D: We live in a free world indeed. And your independent choice is one of the factors we have to take into consideration, as is your fear of damaging your vagina and pelvic floor. However, there are additional issues that we have to address. I am your doctor. First of all, as an obstetrician, it is my duty to take care that your delivery will be managed in the safest possible way for you and for your baby. Secondly, I want to help you to perceive your pregnancy and delivery as positively as possible. I want you to experience the delivery as a rewarding experience that will be a defining moment in your life and that of your baby. And finally, you see, I am medically responsible for the

outcome. Scheduling an elective Cesarean may be one of the options, but I need your approval for a process in which we both can explore which arguments are most valid in order to make the best decision regarding the mode of your delivery. In fact, this will take more than one appointment.

P: Oh, uhm, I don't know what to say. So we have to first go "through a procedure" as you say? That's really disappointing for me. I was expecting to have it all settled today.

D: What strikes me is that you seem to be in such a hurry to plan a Cesarean section. We have time enough to discuss this. And you seem to speak very light heartedly about a Cesarean section. Allow me to tell you something about the implications of a Cesarean section. Did you know that a Cesarean section is an "emergency operation" surrounded with additional risks?

P: I thought nowadays a Cesarean is a piece of cake….

D: I wish that were true! A vaginal delivery isn't easy either, but compared to a C-section… (Silence!).

P: What could go wrong then?

D: There are a number of issues in fact, which can differ from person to person… (silence).

P: Such as what, in my particular case?

D: Well, things can go wrong in any case, but to explain the risks to you and especially in order to reach a good balancing of the pros and cons, we do have to go through a "procedure"… (silence).

P: So, it is not wise to choose a C-section right away….

D: Unfortunately no, because, while we would be ready quickly, you wouldn't be really grateful to me afterwards… (silence).

Gabriella repeats these kinds of sentences until Marie-Anne switches from "since you think this is necessary" toward "all right, let's try to find out together what the best solution is for me."

25.3 The First Selection: Relevance

25.3.1 Introduction

To arrive at an adequate assessment of ethical dilemmas of this kind, it is important to realize why the assessment is so complicated. The problem lies partly in the large number of potentially relevant factors, which is why an initial selection in terms of relevance is necessary. This is the only way to create the cognitive space required to weigh the remaining arguments against each other (see later section on *Assessment*).

Following the BPS model, first we zoom out so that we can assess the significance or relevance of certain values. To do this we identify the impact of the various pros and cons. In this context, impact means a combination of the scale and scope of the values and standards involved. The scale is about whether or not a certain

standard applies for every person or, for instance, only for patients or treating practitioners. The scope is about the relative force with which the standard applies, for instance, whether it is enshrined in law or is a matter of personal preference. Then the impact of the values and standards can be placed in a hierarchical order, which usually contains the following four levels:

- Level 1: General social ethical principles, laid down in laws that apply to everyone
- Level 2: More specific principles of medical ethics, laid down in laws that apply specifically to patients and medical practitioners
- Level 3: Even more specific principles of medical ethics, linked to membership of the specific groups of medical practitioners in question (in this case gynecologists, pediatricians, anesthetists, etc.) in connection with the exercise of their profession
- Level 4: Individual principles of medical ethics relating to personal exercise of the profession

25.3.2 Hierarchy

This is a normal hierarchical order of the kind used in many areas of society. The hierarchical structure means that if something is undesirable at a higher level—for instance, because it is prohibited by law—this takes precedence over the fact that something else may be desirable at a lower level, for instance, granting a patient their wish. It is only in very exceptional cases (e.g., with children of Jehovah's Witnesses in relation to blood transfusions) that medical practitioners can deviate from this rule. Constitutional standards take precedence over individual standards and all doctors and patients must obey the law. If there are any contradictions, they nearly always occur at the same level. In such cases a second classification mechanism is required: principles or criteria of medical ethics.

Case History: Continued

D: All right, with your consent, let's go for it. Given your background as a lawyer you must be used to reasoning in complex situations. However, when it's about your own health and baby, it's always different. How do you feel about that?

P: Yes, I am used to complexity all right, but now I am just afraid of being damaged.

D: Apparently so much that you don't mind being damaged abdominally and would willingly opt for a major abdominal operation? A CS could have negative consequences for you and for your baby as well.

P: But you just acknowledged that we live in a free country in which I may make my own choices, so what about that?

D: Well, I really appreciate your agreeing to discuss the matter systematically, which we will do first. I will call this the "initial discussion." When we have finished that, I as a doctor am interested in your opinion as a lawyer about all the aspects involved and whether or not you can overlook this as a patient. This will be a secondary discussion, in order to avoid confusion.

Initial Discussion

D: In this discussion, we have to start by addressing the individual aspects. This might be a bit sensitive. How shall I put it…. If you suffered a major or even a minor complication during CS, how would you react? The more elective a procedure is, the more severe it is psychologically when a complication occurs, since you could have chosen not to have this surgery. By the way, the same counts for a complication if we end up going for a vaginal delivery. You could blame me or my team for not having performed an elective CS. Either way, this might make it difficult. Your request is not an everyday request. As you notice, there are a lot of aspects to address and discuss. Although you as a lawyer are used to addressing issues in a rational order, it might be a complicating factor for me personally if something goes wrong in our decision-making process. I understand that you fear pelvic floor dysfunction after vaginal delivery, but what if something happens during or after the Cesarean section? What if you get severe deep venous thromboembolism? How will we deal with each other? We really need to clarify all risks and benefits of both ways of delivering.

P: Yeah, I see… didn't think of it like that. I do want to trust you in what you do. I am here as, and want to be, just a pregnant mother who is nervous about the consequences of vaginal birth. But I really appreciate the way you structure the process for me. I feel that I'm being taken seriously.

D: I am glad you say that. This is a mutual process, you see. Because, after having discussed the various aspects of the principles of medical ethics, you should also know what is advised by my National Society of Obstetrics and Gynecology. We have a guideline on this issue. And the last thing that I would like to address is that I also personally need to be comfortable with the outcome, since I need to take the responsibility for your health and your baby's health.

P: But I want you to be comfortable too. What if you are not comfortable with the outcome of our discussion?

D: I hope that we'll work through this together and come to a decision we both feel comfortable with. Otherwise, I'm afraid I'll have to hand you over to a colleague.

P: Hm, you are being quite frank with me, aren't you?

D: Well, I think I have to, in order to respect your autonomy on the one hand and "do good" on the other…. If you agree to go on, shall we schedule another appointment to discuss the hard facts and figures in order for you to get to know the risks and benefits of both modes of delivery?

P: All right, let's do that. I will do my best to bring my husband as well.

D: That would be great.

D: Since this is the end of my working day, we have some more time. As I have mentioned before, as an obstetrician I am interested in your professional expertise regarding legal and ethical issues. Do you have some time left?

P: Well, yes, it is interesting that you are interested in my professional opinion as well.

D: Let's discuss this systematically as well. Yes, we all have individual rights. A person is free to decide what, where, and how he or she leads his or her life. But when it comes to medical procedures, other values need to be weighed as well. You are still an autonomous person with the wish for an operative delivery. And you need to consent to every procedure I propose. However, if you propose a treatment, I have to weigh this professionally as well. I don't want to perform an operation that would do more harm than good.

P: But I have a baby to squeeze out through such a small canal! Isn't that reasonable enough?

D: Well, I wanted to show you that with a request like this the doctor has to go through a procedure. And that is what's happened with your request too. You need me, or if not me another obstetrician, to perform a CS. I cannot just stop at the first medical ethical consideration "autonomy" and do what you ask me to do.

P: All right, I get that, but which other considerations do you have to take into account?

D: The next one is "do no harm," or "nonmaleficence," which means that the outcome we arrive at together must not harm you or your baby. The third principle is "do good," or "beneficence," meaning that the mode of delivery we choose must seem to be the best way to go in terms of minimizing risk and achieving the best outcome for you and for your baby. This means that I have to inform you extensively about the risks and advantages of both CS and a vaginal delivery.

P: I see… are these the most important ones?

D: No, there is one left, this is more a general, societal, but also an important personal criterion. The last and fourth principle is "justice." This principle lets us weigh whether a procedure, say a CS, which is a more expensive delivery than a vaginal delivery, may weigh heavily on scarce healthcare funds.

P: Wait, I'm sorry but I really don't care. This is about me and my baby. I have paid my insurance for years. So do I now get to benefit from it or not?

D: As I said, this last principle partly addresses more a societal view. If all women were to deliver operatively, this would have a huge impact on both the costs and the organization of deliveries in our country. All women would need to be delivered by obstetricians in hospitals then.

P: Yes, I see, in general… all right, that is also an aspect of course. Well… yes…in my field it is usually more about balancing facts with each other. It is difficult for me to transfer that knowledge to this situation.

D: All right, it has been a long talk already. Please think about it and we will continue at the next appointment.

P: That's fine with me.

If individuals become patients or as a result of training and choice of profession they become medical practitioners, the focus shifts from the law that applies to civil society in general to medical principles. This change from level 1 to level 2 means that different kinds of principles and criteria become relevant. Whereas level 1 centers mainly on civil rights and values (freedom, equality, etc.), level 2 concentrates on the following four ethical principles:

- The principle of respect for autonomy, a principle derived from the level 1 value of freedom.
- The principle of nonmaleficence, also known as *primum non nocere*, meaning "first do no harm," based on the level 1 value of human life as the highest good.
- The principle of beneficence, which is the original basis of healthcare delivery in the general sense. The key values are solidarity, helpfulness, mercy, and compassion.
- The principle of justice, which relates to the level 1 value of equality.

These four principles constitute the core of medical ethics and therefore also the core of this discussion. Although in many cases the four criteria reinforce each other (autonomy and the freedom of choice that goes with it are usually "beneficent" and prevent harm), sometimes contradictions may arise among the four principles. In the case of a psychiatric patient who wants to harm himself or his environment, the principle of autonomy clashes with the principle of beneficence and even more violently with the principle of nonmaleficence. However, the likelihood of contradictions increases considerably if there are different parties who have completely or partly different interests. In the case of Cesarean section on maternal request, the patient's autonomy is limited not only by the autonomy of the doctor and the medical profession but also by the principle of nonmaleficence, risk of short- and long-term complications, and justice—should scarce and expensive healthcare resources be used to grant this wish if the woman has an 83% chance of a vaginal delivery, which is much cheaper?

It is precisely at this level that the interests of everyone involved in a specific situation must be considered with the greatest care, since it is at this level that the reasoning on which the medical treatment provided will be based. The rest of this chapter will in fact focus on this level, but before we examine it in greater detail, we will take a brief look at levels 3 and 4.

25.3.3 Levels 3 and 4

Although the arguments for or against medical action are mainly at level 2, this does not mean that levels 3 (usually formulated in guidelines for the specific discipline) and 4 (personal intuition, moral judgment, conscience) are unimportant. Level 3 is important because many clinical situations do not lend themselves to formal analysis. Often the consequences of certain procedures are unknown or there is no time to complete a formal analysis. In such cases the clinician must be guided by

standards and values covered by terms such as "best medical practice" or "the clinical eye." "Best medical practice" is based on experience, either of the doctor in question or gathered and passed on by the doctor's medical discipline, set out in guidelines and protocols. "The clinical eye" is a concept that largely circumvents analytical testing; it is comparable with the intuition developed in many professions over the years. Years of experience mean that skills and clinical assessments move from being "unconsciously incompetent" before medical training, during specialist training via "consciously incompetent," to "consciously competent," and eventually to "unconsciously competent." Although it is difficult to explain, particularly to people without medical training, in practice the clinical eye plays an indispensable role.

While arguments at this level may never lead to "random" decisions, including in cases of Cesarean section on maternal request, doctors' intuition and instinct may lead to a request being reassessed and possibly discussed in a wider context (reference group) before the procedure is carried out.

The same can be said about arguments at level 4. Whereas level 3 focuses mainly on considerations that, although difficult to formulate, are clearly medical, level 4 is about arguments at the personal moral level. Although in principle every obstetrician would be able to perform Cesarean section on maternal request of arguments at levels 1–3, this does not mean that every gynecologist actually does this. Personal values and standards play an important role in practice and certainly deserve to be made explicit. Often this scope for individual choice is also set out in official guidelines, for instance, in terms such as, "Given the particular nature of the procedure, its moral implications, and the interests of those involved, the treating practitioner/team will always be free to grant or not to grant a request for XYZ for their own reasons."

Conscientious objections play an interesting role in the domain of personal values and standards. For instance, on the grounds of conscientious objection, usually closely related to religious considerations (both at level 4), a female doctor may refuse to wear short sleeves or to have certain vaccinations even though these are highly desirable for reasons of hygiene (level 2, nonmaleficence) or to comply with the guidelines of the discipline. Level 4 considerations in particular are limited by considerations of a higher order. To determine the borderlines, other criteria play a role, such as [1]:

1. There must be a serious breach of a profound and sincere conviction of the treating practitioner: The individual must also act in the same spirit in other situations.
2. The objection must be consistent with relevant empirical facts: Homosexuality is not contagious, for example!
3. There must be a plausible moral or religious reason: The individual in question must be able to give grounds for departing from the rule.
4. The procedure or treatment in question may not be an essential component of the person's work: Core tasks or obligations associated with their job may not be refused. For example, conscientious objections to in vitro fertilization (IVF) may

not play a role at a fertility clinic; individuals who have such objections can be refused a job or, if they are already employed, can be dismissed.
5. The burden on the patient must be acceptable: The patient's well-being and safety may not be compromised.
6. The burden on colleagues and the institute must be acceptable: It may not be the case that due to an individual's different standards all the burden is passed on to colleagues or the team.

In short, there is only limited scope for different standards and values at level 4 in health care. This is reasonable, since health care has an important social function that can only be achieved by virtue of a certain consensus about what is right and uniformity regarding the conduct required from treating practitioners as a result.

Case History: Continued

Marie-Anne Rose and her husband Maurice (M) attend the next appointment together 1 week later. You have scheduled double time for this consultation.

D: Welcome, Ms. and Mr. Rose. I really appreciate it that, Mr. Rose, you could join your wife for this consultation. Are you both aware of the purpose of this appointment?

M: Thank you. Yes, I think so: We're going to discuss the pros and cons of a C-section, aren't we?

D: Exactly. Let's go right ahead. Last time I mentioned the different levels that we have to address. I will go through them briefly again, so we all know where we're at. I have a template to fill in for our convenience (Table 25.1) [2–11]. The first level consists of your and the unborn baby's basic rights, the second level the medical-ethical principles (autonomy, do no harm, do good and the last one, justice). Then we'll check our professional guidelines in this respect, and last but not least, we'll take into account how you, and finally, I, feel about the decision. We'll structure the pros and cons from the assumption that we are going to perform an elective Cesarean section.

Having written down all these issues on a paper, Marie-Anne sighs.

P: When I see it laid out like this, I must say that although there is an increased chance for prolapse and incontinence, I didn't realize that my baby would also be at risk from a CS. This neonatal intensive care unit admission didn't cross my mind. On the other hand, I certainly don't want to have a forceps delivery.

D: Well, it is very good that we have put all the risks on a spreadsheet. It seems to make it clearer, doesn't it?

P: Yes, it does.

M: Yes, it is also clearer for me.

P: So, my fear of suffering a prolapse…. There's a 2.2 % chance of this with a vaginal delivery, as compared to 0.2 % with a Cesarean.

D: Yes, that's right.

P: And the chance that my baby will end up in NICU is around 14 % as compared with around 6 % following a vaginal delivery.

D: Yes, it is.

P: So that is a much higher chance than my risk of a prolapse….

D: Yes, but it is about weighing things against each other.

P: I think—don't you, Maurice—reading this… I may go for a vaginal delivery, but I certainly don't want a forceps delivery. In such a case I would like to have a vacuum extraction or a Cesarean anyway.

Table 25.1 The pros and cons on Cesarean section on maternal request

		Pros on Cesarean section	Cons on Cesarean section
Level 1: Values by law		Freedom of autonomous choice for women who want to opt for elective Cesarean section (CS). Right to decide about own body	Given the professional autonomy of the medical professional there is no "freedom" as meant in level 1 as soon as somebody becomes a patient Full autonomy for patients may encourage commercial clinics that offer only CS on maternal requests, which is not desirable Allowing full freedom for maternal CS on request may give rise to socially unacceptable higher rates of CS in the population Contradiction or tension with other ethical principles addressed at level 2
Level 2: Medical ethical principles	Autonomy	Experience autonomy Women's birthing experience is important and goes along with women's satisfaction and experiences of care Do something, defending one's own interest, or even "rights" Desire of women to be able to decide for themselves	The health professional also has an autonomous choice in light of his/her professional standards Not delivering a baby by oneself but "being delivered by the doctor" Too strong a dependence on healthcare providers Once started, there is no way back Much more burden than expected Different delivery from most women Feelings of guilt, because this solution contributes to decreasing acceptance of vaginal delivery (VD) Feelings of guilt when complications occur

(continued)

Table 25.1 (continued)

		Pros on Cesarean section	Cons on Cesarean section
	Beneficence	1–4 % chance of third-degree perineal tear as compared to 0 % with CS [2] Long-term (20 years postpartum) problematic incontinence 11.2 % after VD versus 6.3 % after CS [3] Lifetime prolapse surgery is more frequent in women after VD (2.2 %) versus CS (0.2 %) [4] Forceps delivery gives the highest chance on lifetime prolapse surgery (14.3 %) [4] Levator defects have been found in 15.4 % of women with VD in history [5] Women with planned CS reported a higher satisfaction score regarding birth experience 2 days after birth compared with women having a planned vaginal birth and this effect remained 3 months postpartum [6] Potential short-term maternal benefit: less maternal hemorrhage [7]	Risk of fecal incontinence is not more prevalent in women after VD as compared to after CS (6 % in all women), except for women who underwent forceps delivery in which the risk for fecal incontinence doubled [8] After CS there is a 20 times higher chance of wound infection as compared to vaginal delivery [9] After CS a ten times higher risk of endometritis (8 % in CS versus 1–3 % for a vaginal delivery) [6] After CS, 2 times higher risk for deep venous thrombosis and pulmonary embolism (0.03 % in VD versus 0.06 % in CS), but in other study no difference was found [6] After CS 0.2–1.5 % versus almost 0 % uterine rupture in next pregnancy with 1.2 % chance for perinatal death in case of uterine rupture [10] After CS 0.65 % versus 0.26 % for subsequent placenta previa with 0.16–0.3 % versus 0.004–0.01 % risk for placenta accreta/increta/percreta in general. This condition increases the risk for postpartum hemorrhage, sometimes necessitating emergency hysterectomy with increased risk for severe maternal morbidity or sometimes mortality [10] More women who had a planned vaginal birth were breastfeeding at 3 months postpartum compared with women who had a planned CS. This finding was statistically significant [6]

Table 25.1 (continued)

		Pros on Cesarean section	Cons on Cesarean section
	Nonmaleficence	Good monitoring of the process from indication to operation, so the patient feels taken seriously and also feels the possibility to say "no," even under peer pressure Prevention of commercial practices in private clinics	Protection of people against themselves when they have insufficient notion of the risks to be expected in this medical or psychological area NICU admission more prevalent in CS (13.9 % versus 6.3 %) as compared with vaginal delivery [6] Patronizing, limiting autonomous choice Possibly going for a vaginal delivery that will cause harm to the mother, due to pelvic organ damage, third- or fourth-degree perineal tears with lifelong consequences CS inevitably leads to abdominal scarring, which increases the risk for hematomas, wound infections, neurinomas, and unaesthetic scarring that may need plastic surgery later in life
	Justice	Insurance fees have been paid, so the insurance has to pay for it Obstetricians have the professional right to decide what is right for their patient	Costs as calculated by the NHS: the costs of birth and "downstream" costs found that a planned vaginal birth was approximately £ 700 cheaper than a maternal request CS [6]

(continued)

Table 25.1 (continued)

		Pros on Cesarean section	Cons on Cesarean section
Level 3: Best medical practice (WHO 2015, NICE guideline 2011, ACOG committee opinion 2013)		When a woman requests a CS, explore, discuss, and record the specific reasons for the request [6] If a woman requests a CS when there is no other indication, discuss the overall risks and benefits of CS compared with vaginal birth and record that this discussion has taken place. Include a discussion with other members of the obstetric team (including the obstetrician, midwife, and anesthetist) if necessary to explore the reasons for the request and to ensure the woman has accurate information [6] For women requesting a CS, if after discussion and offer of support (including perinatal mental health support for women with anxiety about childbirth), a vaginal birth is still not an acceptable option, offer a planned CS [6]. An obstetrician unwilling to perform a CS should refer the woman to an obstetrician who will carry out the CS [6]. In cases in which CS on maternal request is planned, delivery should not be performed before a gestational age of 39 weeks [7]	CS are effective in saving maternal and infant lives, but only when they are required for medically indicated reasons [11] CS should ideally only be undertaken when medically necessary [7, 11] The effects of CS rates on other outcomes, such as maternal and perinatal morbidity, pediatric outcomes, and psychological or social well-being, are still unclear. More research is needed to understand the health effects of CS on immediate and future outcomes [11] Standard antibiotic treatment during CS is required, which may increase the already evolving threat of antibiotic resistance of bacteria If a woman requests a CS when there is no other indication, discuss the overall risks and benefits of CS compared with vaginal birth and record that this discussion has taken place. Include a discussion with other members of the obstetric team (including the obstetrician, midwife, and anesthetist) if necessary to explore the reasons for the request and to ensure the woman has accurate information [6] When a woman requests a CS because she has anxiety about childbirth, offer referral to a healthcare professional with expertise in providing perinatal mental health support to help her address her anxiety in a supportive manner [6] Ensure the healthcare professional providing perinatal mental health support has access to the planned place of birth during the antenatal period in order to provide care [6]

Table 25.1 (continued)

		Pros on Cesarean section	Cons on Cesarean section
Level 4: Doctor's own norms and values and norms		In general, there is more lifetime risk of prolapse and incontinence Third-degree perineal tears will not occur in CS	Absolute lifetime risks for prolapse surgery and incontinence are low and CS is not completely protective against prolapse and incontinence CS is more expensive and weighs more on scarce healthcare funds NICU admission more prevalent in CS

CS Cesarean section, *VD* vaginal delivery, *WHO* World Health Organization, *NICE* National Institute for Health and Care Excellence, *ACOG* American Congress of Obstetricians and Gynecologists, *NICU* neonatal intensive care unit, *NHS* National Health Service

D: I think that is a reasonable request. We can make a birth plan and put this in it, so the whole team knows where you stand. And I will record the issues we just have discussed.

P: All right. I think I am fine with this. It's a bit strange to change my opinion. But it has been very helpful to record the pros and cons systematically. Thanks!

D: You are very welcome! Let me summarize the process we have participated in. You entered my office with an explicit wish to deliver by Cesarean section. Together we've discussed the different aspects and pros and cons of a Cesarean for your personal situation. And together we've found out that the risks of a Cesarean in general are not outweighing the advantages of a vaginal delivery. Is that correct?

P: Yes…that's correct.

D: All right, whenever you or your husband has any questions or doubts, please let me know. We'll see how the rest of your pregnancy proceeds. In the end, most women deliver vaginally in good health.

P: I hope so….

D: We'll be taking care of you as much as we can to support you!

25.4 Applying the Principles

In this section we will apply the various principles of medical ethics to the dilemma of CS on request. The pros and cons of CS on maternal request are illustrated in Table 25.1 under level 2.

In this area the most important changes in arguments at ethical levels occur at levels 1 and 2, since some of the people involved do not perceive themselves as patients. They are not and do not feel ill and can usually function as full members of society (level 1) but are now being treated as "patients" at level 2 because the procedure involved is surgery. So why all this patronizing? The fact is that as

regards autonomy, a surgical procedure—and with it access to medical resources—inevitably entails stepping down from level 1 to level 2. This means that in general the limitation in autonomy as a result of, or for the purpose of, a CS on request is accepted and felt to be reasonable, in spite of the emotional objections it may evoke.

We will discuss the medical ethical principles in greater detail in the following sections.

25.4.1 Autonomy

Although the state exercises some control over people's behavior, in the Western world it is very reticent to do so. In terms of autonomy in relation to giving birth, it is important to notice that there is a difference between positive and negative liberty. Positive liberty is the freedom to fulfill one's owns wishes, e.g., to give birth in the way a woman wants. Negative liberty is the freedom from external restraint, e.g., a gynecologist who points out the dangers of a CS. Women who are going to give birth have to rely, for the fulfillment of their wishes, on one or more third parties, such as medical practitioners and health insurers. As soon as an individual turns to a gynecologist for medical treatment as a patient, that individual's autonomous position as a member of society (at level 1) lapses; they have now become a patient at level 2. In doing so they have "voluntarily" relinquished the core values at level 1 and must now comply with the frame of reference at level 2. The medical practitioner is now also in charge and the patient can no longer claim his or her rights as a consumer: "I ask; you do what I say" or, from the doctor's point of view, "Your wish is our command." Practitioners can certainly aim to retain level 1 rights as much as possible. The argumentation (both pros and cons) contains frequent references to level 1. However, once the doctor has become "the boss," he or she has a duty to respect the autonomy of everyone involved and is responsible for observing this respect with due regard for other ethical principles (including those at level 2). Since several parties are involved—mother and fetus, including, in the background, the medical discipline in question and civil society—this is no easy task. Safeguarding autonomy for all parties with due regard for other principles makes high demands in terms of time, energy, and communicative skills.

25.4.2 Beneficence

The intention of a CS on request is for it to contribute to the patient's well-being and that of her fetus or perhaps more accurately for it to remove an obstruction to well-being. It has been shown above that this view is too limited: the well-being of the patient's environment, society (including future patients), and treating practitioners, who may not be harmed either. It is only if this criterion is met that a practitioner can agree to a CS on request.

25.4.3 Nonmaleficence

The motto *primum non nocere* ("first do no harm") seems simple, but in fact it actually raises many problems. Another motto—*in dubio abstine* ("if in doubt, refrain")—is also apparently hard for many practitioners to adhere to. The term "interventionism" is sometimes used to refer to the idea that it is easier to do something than to do nothing and have nothing to offer. One of the factors involved here is that "doing nothing" can be interpreted in different ways. Whereas doctors and nurses ask if they can do anything for the patient, psychologists and chaplains ask how they can help. Different considerations have to be constantly weighed against each other to ensure the best outcome for the patient. This is why the role of the principal treating doctor is so important. He or she is in charge of the treatment process and usually also the person who, in the case of a CS on request, will be performing the actual procedure. The principal treating doctor is responsible both as a representative of the discipline and as the individual with the ultimate responsibility for carrying out the procedure. It is a good idea for the principal treating doctor to seek sound advice from the multidisciplinary team regarding nonmaleficence, as this is the best way to guarantee that opinions are formed with due care and that decisions regarding ethical dilemmas are evidence based and supported by society.

25.4.4 Justice

In many countries in the world, Cesarean sections on request are carried out on a large scale. Several arguments can be derived from the principle of justice for and against the standard introduction of an option for a CS on request.

In the past, if someone was pregnant, then—depending on the person's view of life—that was the will of God, a quirk of nature, or karma. This is an outdated view, given that semen processing, intracytoplasmic sperm injection (ICSI), tubal surgery, intrauterine insemination (IUI), in vitro fertilization (IVF), reconstructive surgery after sterilizations, egg donation, and in some countries high-tech surrogacy in certain conditions are used to fulfill people's desire for children. So why should a woman not be able to decide for herself how she wants her child to be born?

The UK National Institute for Health and Care Excellence (NICE) guideline on Cesarean section stipulates that a treatment team is always free, after extensive counseling about the pros and cons of a CS on request, to ultimately agree to a request for a CS [6].

25.5 Assessment

After identifying all possible values and standards and then selecting them according to relevance, the next question to answer is how to arrive at a balanced assessment on the basis of the remaining values and standards. A handy way to compare arguments is the two-column technique [12]. You make two columns on a sheet of

paper or a digital spreadsheet with the headings “advantages” and “disadvantages.” Then you fill these columns in with the values and standards remaining after your selection. If it turns out that in your first selection you forgot one or more arguments or wrongly discarded them, you can still add such arguments in your two columns at this point. Then you rate all the arguments, both pros and cons. This makes it clear where your focus must be in your ultimate assessment and what you can regard as “secondary” advantages or disadvantages. Secondary matters are not necessarily unimportant; they may play a decisive role if there is a “draw” as regards key issues. This results in a complex hierarchical framework in which the arguments (pros and cons) and their relative weights become apparent, including any tensions that may exist between them.

Pros and cons of CS on maternal request are illustrated on the different levels in Table 25.1 [2–11].

25.6 Decision-Making

When all the arguments have been identified and selected for true relevance and the pros and cons have been rated, the next step is to arrive at a rational final assessment. In an ideal situation, at least in terms of the Western Enlightenment tradition, a well-considered decision is made as follows:

- Clarify the nature of the dilemma: Give an explanation about the problem situation and the need to make a decision. In our case it is about performing or not performing a CS when there is no medical indication.
- Identify possible options: In principle this situation is about an elective CS as opposed to a normal vaginal delivery.
- Assess the options in terms of pros and cons.
- Make a final choice.
- Make arrangements for the implementation of the decision that has been made.

25.7 Discussion and Final Remarks

The multistep model discussed previously assumes that people can take time to make a choice or reach a decision and that they have all the information they need to do so. Reality is different, partly because the prior sketched-out model of well-considered decision-making, based on the Western Enlightenment tradition, is not always the dominant culture. Moreover, usually decisions are made on the basis of a limited amount of information and certainly not always after careful considerations of all the pros and cons. Furthermore, emotions often play a distorting or obstructive role that makes it difficult to weigh effectively. Interestingly enough this all may lead to a new kind of psychological coping mechanism: anticipatory prevention of remorse or regret [13].

Tips and Tricks

In order to help patients make their own decisions in a sound way, a few guiding principles should be kept in mind, such as:

- If you are a midwife and you are carrying out antenatal checks, it is important for you to pick up what a pregnant woman wants in good time. Then you can discuss this with a gynecologist you have a good working relationship with so that a referral can be given at a point when the gynecologist still has enough time to have the conversation with the pregnant woman.
- Decision-making is a process that often takes place collectively. Avoid being forced—for instance, through time pressure or emotional pressure—to act in a single moment. Take the time and make sure you have an adequate sounding board. This is why you should spread the decision-making across several consultations and ensure that information provision is a coordinated team activity.
- Solutions do not appear out of the blue. They are based on information from an analysis of the problem. Often these steps are intertwined. After an initial orientation, solutions are devised and choices considered. On the basis of these ideas you can gather new information for further analysis. Then you can reject some choices, modify solutions, or come up with new alternatives. For you this means that you have to take care that you are not deluged with information, but gather it carefully, guided by the questions you still have. In this way you can create time and space to get to the bottom of the dilemma and the need for a decision.
- Every decision is preceded by an assessment of the pros and cons of the possible solutions. Even if only one solution is left, because all the alternatives have been eliminated, you will still have to opt for this solution yourself.
- Remember that conditions are attached to every conclusion or choice. Sometimes, unfortunately, they only become visible when you know what you want, and sometimes that may lead to reconsideration.
- Once you have all the facts straight, in theory making a decision should be a piece of cake. If the patient and you have a clear pro or a clear con, it is obvious what she should do. If you end with a "draw," it is even easier: Apparently it does not matter what is chosen. Flipping a coin may be helpful.
- Another factor that sometimes makes it hard to decide is when there is a heterogeneous group of stakeholders. In principle you repeat everything set out above at a slightly higher aggregation level, with conclusions from the points of view of those involved (the patient, the individual treating practitioner, the discipline or disciplines in question, and the civil society) as the input.

Acknowledgment Based on the thesis of the third author: Dermout SM. De eerste logeerpartij, hoogtechnologisch draagmoederschap in Nederland. University of Groningen (RUG), The Netherlands; 2001.

References

1. Bolt I, van Dijk G. Ruimte voor gewetensbezwaren is beperkt. Medisch Contact. 2015;7:300–2.
2. Fernando RJ, Sultan AHH, Kettle C, Thakar R, Radley S. Methods of repair for obstetric anal sphincter injury. Cochrane Database Syst Rev. 2006;3:CD002866.
3. Gyhagen M, Bullarbo M, Nielsen TF, Milsom I. A comparison of the long-term consequences of vaginal delivery versus caesarean section on the prevalence, severity and bothersomeness of urinary incontinence subtypes: a national cohort study in primiparous women. BJOG. 2013;120(12):1548–55.
4. Leijonhufvud A, Lundholm C, Cnattingius S, Granath F, Andolf D. Risks of stress urinary incontinence and pelvic organ prolapse surgery in relation to mode of childbirth. Am J Obstet Gynecol. 2011;204(1):70.
5. Dietz HP, Steensma AB. The prevalence of major abnormalities of the levator ani in urogynaecological patients. BJOG. 2006;113:225–30.
6. Royal College of Obstetrics and Gynaecology (RCOG). UK National Institute for Health and Care Excellence (NICE) clinical guideline on Caesarean section (CG132). 2011. https://www.nice.org.uk/guidance/cg132.
7. ACOG Committee on obstetric practice. Cesarean delivery on maternal request. The American College of Obstetricians and Gynaecologists; 2013 Apr. Report No.: 559.
8. Macarthur C, Wilson D, Herbison P, Lancashire RJ, Hagen S, Toozs-Hobson P, ProLong study group, et al. Faecal incontinence persisting after childbirth: a 12 year longitudinal study. BJOG. 2013;120(2):169–78.
9. Smaill FM, Gyte GML. Antibiotic prophylaxis versus no prophylaxis for preventing infection after cesarean section. Cochrane Database Syst Rev. 2010;1:CD007482.
10. Dutch Association for Obstetrics and Gynaecology. Dutch Guideline on Pregnancy after previous Caesarean Section. 2010.
11. World Health Organization. WHO statement on caesarean section rates. Geneva: World Health Organization (WHO); 2015.
12. van de HB W, Wouda J. Communicatie in de palliatieve fase. Houten: The Netherlands: Bohn Stafleu Van Loghum; 1999.
13. Het imperatieve karakter van de medische technologie en de betekenis van geanticipeerde beslissingsspijt. Nederlands Tijdschrift voor Geneeskunde. 2015;131(26):1128–31.

Communicator: The Gynecologist Who Could Not Convince His Patients

26

Jan C. Wouda, Harry B.M. van de Wiel,
and K. Marieke Paarlberg

26.1 Introduction

The first meeting with a patient is usually devoted to identifying the patient's health problem or healthcare needs. The biopsychosocial (BPS) model works with a broad definition of "the problem." The gynecologist, midwife, etc.—for the sake of brevity, from this point on, we will use the term "health professional"—try to gain as complete as possible a picture of the reason why the patient has come, the medical problem (diagnosis), and any additional problems or issues the patient may have, whether they are physical, mental, or social. In other words, the health professional not only pays attention to the physical manifestations of a complaint but also assesses the patient's care request. On the basis of this assessment, the health professional maps out the mental and social components, causes, and consequences of the problem. In this chapter, we will focus exclusively on the educational information and guidance you give your patients in this context.

J.C. Wouda (✉)
Ahmas Foundation, Groningen, The Netherlands
e-mail: j.c.wouda@umcg.nl

H.B.M. van de Wiel
Wenckebach Institute, University of Groningen, University Medical Centre Groningen, Groningen, The Netherlands
e-mail: har.wiel@planet.nl

K.M. Paarlberg
Department of Obstetrics and Gynecology, Gelre Hospitals, Apeldoorn Location, Apeldoorn, The Netherlands
e-mail: km.paarlberg@xs4all.nl

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_26

Health professionals in the Western world give their patients a great deal of information[1]; they have a duty to adequately inform their patients about the state of their health, tests, the prognosis, the treatment options, etc. In most cases, this information is given to individual patients during a consultation at a surgery, a home visit, or a ward round, which is why the tips in this chapter are mainly about the information given to patients face to face in clinical practice. However, they can also be used in situations in which you provide information by telephone, e-mail, or online.

As discussed in Chap. 22, working according to the BPS model means examining complaints both in depth and in breadth. The health professional not only looks for a solution to the medical problem but also pays attention to the problems that arise from it and to the patient's psychological and social needs. This requires a broad definition of educational information for patients, such as Van den Borne's [1]:

"The use of educational methods, such as the provision of information, advice and behavior modification techniques, to influence the patient's knowledge, opinions, and health and illness behavior in order to ensure that the patient is able to co-operate effectively in deciding on the care which he receives and can make the best possible contribution to that care".

On the basis of this definition, a health professional may have several complementary goals in mind when providing educational information:

1. To help the patient understand the nature and consequences of his or her disorder, which additional tests may be useful, and what the treatment options are
2. To create an action plan in consultation with the patient
3. To reach agreements with the patient regarding the execution of this action plan (*informed consent*)
4. To support the patient with their role in the action plan, for instance, in regard to taking medication, doing exercises, or making lifestyle changes
5. To evaluate the action plan and if necessary to modify it, in consultation with the patient

In addition to these "primary goals," a consultation usually has secondary goals, which may also change during the consultation, depending on the health professional's insights or the patient's reactions. For instance, it may become clear during a consultation that a patient is quite worried about her disorder, in which case the most important thing is to reassure the patient as much as possible before discussing a plan of action. Or the patient may have already found a lot of information about her disorder online, but it may turn out this information is not all correct. In that case, you will need to correct the patient's inaccurate ideas before you can proceed

[1] *This manual concerns only the patient as a discussion partner. In clinical practice, especially if using the BPS model, a health professional will also have other discussion partners such as a patient's family members or other health professionals involved in a patient's care. To keep things simple, we will not continually refer to these other discussion partners.

to discussing the best approach. Or it may turn out that a patient cannot or is unwilling to follow your recommendations. In that case, you will have to discuss this "treatment noncompliance" with the patient if you want to be sure the agreed treatment is actually going to be effective. It should be clear that as a health professional, if you want to achieve the goals listed above, you will need to have conversational skills that go beyond being able to explain things well. The CELI model, discussed in the next section, divides these conversational skills into four sub-competences:

- Control and rapport
- Explaining
- Listening
- Influencing

However, before going into further detail, we will take a look at a number of consultation situations. Because giving educational information covers such a wide range of areas, this time we will follow a gynecologist in several different situations involving patient education.

Case History: Ms. Mustard

Dr. Garry White, a gynecologist working at a medium-sized hospital in the north of the Netherlands, has just performed an ultrasound scan on Ms. Mustard, a 29-year-old patient who is now 16 weeks pregnant. The scan shows a healthy fetus, and Dr. White congratulates his patient on the successful development of her pregnancy. He then casually asks her about her smoking and drinking. In one of the previous consultations, he had already asked her about her use of these substances, and she had told him that she was still smoking quite a lot and regularly having a glass of wine. At that point, Dr. White had given Ms. Mustard detailed information about the detrimental effects this would have on her baby's development, and he is now interested to hear whether she has heeded his advice. However, he realizes that his question has not gone down well at all.

Whereas she had talked quite openly about how the pregnancy was going, she is now clearly reluctant to answer this question. Yes, she is still smoking and still regularly drinks a glass of wine, but it's very difficult to stop given all the stress and changes in her life.

For a moment Dr. White considers explaining to her again how harmful her behavior is for her unborn child but decides not to do so, because he doesn't want to make the atmosphere even worse. Dispirited, he thinks to himself: "I explained it to her so clearly, but apparently she just doesn't want to understand what her unhealthy habits are doing to her baby. Oh well, it's her choice."

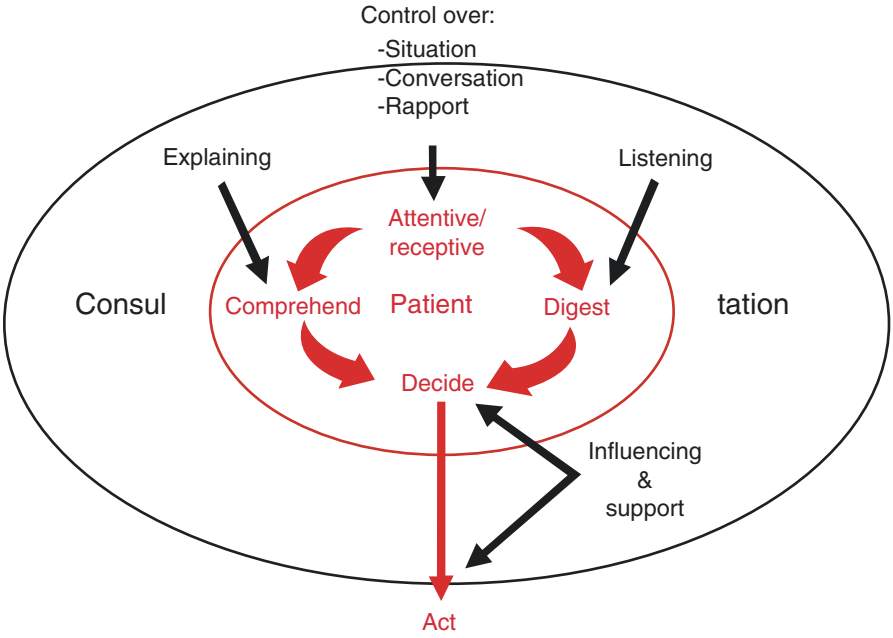


Fig. 26.1 The CELI model (Used with permission of Elsevier from Wouda et al. [2])

26.2 The CELI Model

To attain the educational goals listed earlier, the health professional must not only give the patient information but also help the patient to comprehend and assimilate this information and on the basis of the information to make a carefully considered decision about the required healthcare [2]. Then the health professional should help the patient to adapt her behavior and lifestyle accordingly. In doing this, the health professional must take into account the psychological processes that take place within the patient when this information is given. These processes are shown in the inner oval of Fig. 26.1 [2]:

- Being attentive and receptive
- Comprehend and store the information (cognitive level)
- Evaluate and digest (emotional level)
- Making decisions and adapting behavior (behavioral level)

The CELI model, which is derived from the Yale persuasion model [3], differentiates the communicative tasks a health professional must perform to ensure that the psychological processes listed above run smoothly. These tasks or sub-competences—control, explaining, listening, and influencing—are shown in the outer oval of Fig. 26.1 [2]. The following sections provide further clarification of these sub-competences. In the section titled *Tips and Tricks* in this chapter, an overview is

given of the patient education skills that go with these sub-competences. The limited scope of this chapter does not allow us to discuss all patient education skills in detail; we will examine only those aspects of patient education that are of particular importance to health professionals who work according to the BPS model.

Case History: Ms. Mustard Revisited

Even though it takes great effort, Dr. White asks Ms. Mustard to sit down again. "Sorry, I forgot something," he says.

Ms. Mustard sits down again, a bit surprised, but because of this Garry knows he has her full attention. "Last time we talked about things like smoking and drinking. I had the impression that that didn't really help you and I'd like to do something about that. I want you to know that in the first place my job is to care for you, regardless of what you do or don't do. At all times—even when you do things I'm personally not happy about. OK?"

Ms. Mustard looks at him with relief. "I'm glad to hear that, doctor, because the last time I felt just like a little girl being put in the naughty corner. And of course I know I should really stop smoking and drinking, but I just don't see how I can do it."

In the first instance, Garry feels inclined to talk to her about the importance of a healthy lifestyle for her unborn child. Fortunately he realizes just in time that this would be more of the same and would therefore be counterproductive. "People always act as though it's easy, but I think that right now it might be harder than ever to break certain habits that actually give you a kind of support."

Ms. Mustard nods and immediately agrees with him. "Exactly doctor, you do it almost without thinking about it. But if I don't light up a cigarette, it's as though the whole world is coming at me."

Garry now agrees with what she has said. "OK, so on the one hand it's extremely difficult to break habits like these, and on the other hand, we agree that you really should stop or at least smoke and drink as little as possible."

Ms. Mustard nods and shows that she has more self-knowledge than he had thought. "Perhaps I should talk to someone about the panic I suddenly feel sometimes, it's really not normal…."

26.2.1 Control and Rapport

Case History: Ms. Peach

"But doctor, it must be something. That pain comes back all the time!"

"Well, Ms. Peach, I don't think there's anything wrong. I couldn't feel anything abnormal during the internal examination, your blood test was OK, there were no abnormalities in your urine or feces, and there was nothing unusual in the ultrasound scan either. Everything looks fine. I think you

should just wait and see if your symptoms get any worse. Perhaps your pains have something to do with stress factors at home, and they'll go away if you get some rest." Garry should not have added those last few words.

Ms. Peach looks at him indignantly and protests fiercely. "Come on, doctor, do you think I'm pretending? Do you think I'm mad? I've had this awful abdominal pain for ages and all you can say is it's probably all in my mind. Great doctor you are! I'll find another one." With her face flushed with anger, Ms. Peach picks up her coat and leaves the surgery, leaving Garry White behind, dumbfounded.

Information can only sink in if the patient is ready and able to listen to the information and be open to it. The most important prerequisites for this are:

- The patient is aware of and agrees with the goals of the consultation.
- The patient's attention is not distracted during the consultation by external stimuli.
- The patient's emotions will not prevent them from taking in and processing the information.
- The patient feels at ease—as much as possible—during the consultation and has confidence in you.

To a large extent, these prerequisites will be met if you stay in control of the conversational flow and also make sure you have good rapport with the patient. Appropriate use of the other sub-competences will also have a positive effect on your control of the conversation and your rapport with the patient. It is important to be a good host in the contact with your patient; a medical consultation is not an ordinary conversation; it is a meeting with preset goals, and the health professional is primarily responsible for the attainment of these goals. The health professional must therefore control the conversational flow. However, control does not mean that the patient is a passive contributor to the consultation. On the contrary, good control entails the health professional inviting the patient to actively participate in the conversation [4]. The control task relates to three aspects of the consultation: (1) control over the situation to ensure the conversation is undisturbed and private; in Fig. 26.1, this control task is positioned *outside* the consultation oval since this task must be performed before the consultation starts; (2) guiding the conversation in order to reach the preset goals [5, 6]; and (3) fostering the relationship [4, 7]. Control includes activities such as initiating and ending the session, structuring the conversation, building and monitoring rapport, encouraging patient participation and collaboration, and using the available time efficiently. For instance, at the beginning of the consultation, you should give a brief summary of what has happened before the consultation and what the reason for and the goal and agenda of the consultation will be. When doing this, you must be sensitive to the patient's questions and wishes and make it clear what the patient can expect. Having this agenda will also help you to keep track of the topics that need to be covered. It means you can redirect the conversation if it starts to stray from the intended topics. In addition, during the

conversation, you can refer the patient to the agreed agenda if they dwell too long on one point or raise issues that are not really relevant.

Case History: Ms. Peach Revisited

"We saw each other a fortnight ago about your recurring abdominal pain. I examined you and I understood that you were worried about this pain. Last week you had some tests and I will discuss the results with you. I hope I can relieve your anxiety to some extent. After that I want to talk to you about what we can do about the pain. This will require some effort on your part, which is why I want to talk to you about it in more detail. But first I want to hear how the abdominal pain is now."

Ms. Peach reacts with relief, feeling that she is being taken seriously, and starts to talk.

Garry briefly summarizes what she has told him, stressing the partnership between them. "I think we have discussed the main issues. Your stomach pain is not a cause for concern, but if you want less trouble with it, you will need to be more careful about what you eat and drink. I've given you some recommendations and I hope you'll manage to follow them. And if you still have stomach pain, you can take antacids. We'll see each other again in 2 months to see if the recommendations have helped. Well, as far as I'm concerned, we are finished now, unless you have any questions."

Once all the topics on the agenda have been covered and the necessary arrangements have been made, you can end the consultation. It is helpful for the patient if you clearly mark this ending with a summary of the most important conclusions and arrangements and then give the patient an opportunity to respond to this. Obviously, you will respond to any questions the patient has. Then you should check that:

- You have given the patient any educational information you have promised.
- You have completed any documentation or forms for further appointments such as follow-up tests.
- The patient knows what to do directly after the consultation, for instance, making a new appointment at the reception desk.

Maintaining a good relationship entails:

- A friendly greeting at the beginning of the consultation and a friendly goodbye at the end
- Maintaining contact with the patient when you are doing other things such as typing in data, writing, or performing medical procedures
- Showing you are committed, painstaking, and knowledgeable

26.2.2 Explaining

Case History: Continued

"It doesn't get any easier," sighs Garry White, while having a coffee with a colleague.

"What do you mean, Garry?" asks his colleague.

"I mean explaining to a patient who's not that bright what the options are for artificial insemination. Just talking about IVF, ICSI, and IUI, all the acronyms were driving that woman mad."

His colleague thinks calmly about Garry's remark for a while. Then apparently he has had a eureka moment, because suddenly he starts talking enthusiastically. "You know, Garry, do you remember that British professor at the conference we went to in Berlin last year? I can't remember his name, but I can still remember him vividly. He gave a fantastic talk about preeclampsia. Not an easy topic, but his talk was absolutely clear. I finally understood how all those interactions work."

"Well, yes," sighs Garry, "it was a fantastic talk, but he was speaking to fellow doctors. I have to explain things to an ordinary woman who just really wants to get pregnant."

Garry's colleague is undaunted. "I don't know, Garry. I think you can still use a lot of the techniques he used when you're giving information to your patients. It's about structuring and presenting your material in such a way that your patients can follow it and understand it. And if you want to do that, I don't think it's such a good idea to bombard them with difficult terms like IVF, ICSI, and IUI."

The patient must be able to cognitively understand and remember the information you give. By paying attention to the structure, wording, and presentation of your explanation, you can make sure your patients can comprehend your explanation and also remember it.

In the first place, a comprehensible explanation must have a clear structure, with an introduction, body, and conclusion. The aim of the introduction is to connect the explanation to the patient's frame of reference. You should check what the patient already knows about the topic and what questions they have. In response to this, you can then provide an overview of what you are going to explain to the patient. The body of your explanation should obviously be well structured for your own sake but also for the patient's sake; the patient needs to be able to keep track. By dividing your explanation into core components (subtopics), you can present it to the patient in "bite-sized chunks." In the conclusion of your explanation, you should again stress the main points and check whether your patient has fully understood your explanation and whether the patient has any more questions. Finally, you can put your patient on a firm footing by being clear about what will happen next and giving them a brochure or showing them a website so that they can read your explanation again later and also show it to other people.

You can use the following techniques to formulate your explanation in such a way that it is as understandable as possible:

- Build on what the patient already knows and wants to know.
- Make sure there is an overview.
- Be clear and specific.
- Keep it as simple as possible.
- Take it step by step, repeat main points, and invite responses.
- Enliven your explanation by giving examples and connecting it with your patient's own experiences.
- Illustrate your explanation with a drawing from a brochure or a website.

Your presentation style can also ensure the patient understands your explanation properly and will remember it and accept it. You will need to find the right balance between calm and liveliness. Important elements are speaking style, tone of voice, eye contact, posture, and movements.

26.2.3 Listening

Case History: Ms. Taupe

"Well, Ms. Taupe, I understand very well that you want to get pregnant. And it's not your husband. His sperm has been examined and is of outstanding quality. I think the problem must be with you. As I told you the last time I saw you, I think your excess weight is the problem. Because of that you are not ovulating and therefore there is no chance of fertilization. There are various things we can do to try to induce ovulation, but if you don't lose weight, I don't expect that will do much good. Apart from that, being overweight could lead to all sorts of problems if you did get pregnant. So once again, I would really advise you to lose a lot of weight before we talk again about a possible pregnancy."

After this explanation, Dr. White leans back and waits for his patient's response. Ms. Taupe says nothing for a long time and Mr. Taupe also stares ahead in silence. "Ms. Taupe," says Dr. White cautiously, "what do you think of this suggestion?"

Now she looks at him and he sees tears rolling down her cheeks. "Doctor, I wish I could do that. We want a baby so badly, and I've really tried to lose weight, but I just can't do it. It makes me feel really desperate."

It is mainly Ms. Taupe's powerless tone of voice that immediately reminds Garry of another patient: Ms. Mustard. It takes some effort—it's not only patients who are creatures of habit—but he manages to switch to a nondirective style of giving advice. And it then soon becomes apparent that there are reasons why Ms. Taupe does what she does….

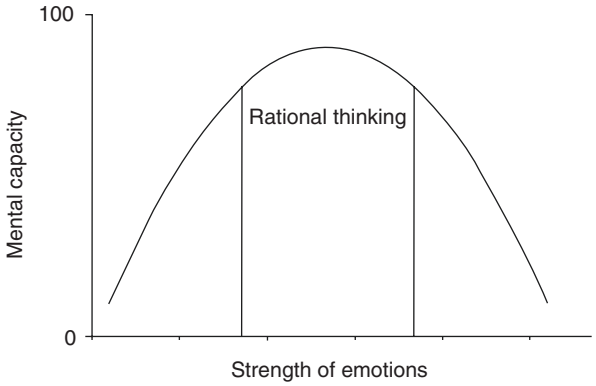


Fig. 26.2 Relationship between strength of emotions and mental capacity

The patient must be able to assess the value of the information provided by processing it emotionally and forming a judgment. This judgment may lead to acceptance of the information and experiencing support, but it may also lead to doubts about or even rejection of the information.

A certain degree of emotional tension is required to understand the information properly and be able to process it. When this tension is absent or too strong, this will take its toll on the patient's mental capacity. Figure 26.2 shows the relationship between the strength of emotions and the capacity to think clearly. If there is little or no emotional involvement (bottom left of the figure), little attention will be paid to the topic being discussed. As emotional involvement increases, so does the attention paid to the topic. The optimal ratio is in the middle of the curve. At this point the degree of tension and alertness is present that is required for optimal reception and processing of the information. The focus of a conversation of this kind is on the content, not on the patient's emotions. However, sometimes the emotions are so strong—as with Ms. Taupe who badly wants to get pregnant but sees her inability to lose weight as an insurmountable obstacle to fulfilling her desperate desire for a baby—that they draw attention away from the content. The person's attention is narrowed; information is either not heard or is strongly distorted, and there is no room for rational thinking.

Remember that while a lot of the information you give patients may have a "neutral" meaning for you, for the patient it can be highly emotionally charged, for instance, if you are discussing the need for a treatment, the postponement or an unexpected complication of a treatment, or a topic that is emotionally charged in itself. In conversations of this kind, you may be confronted with a patient's emotions, such as feelings of fear, sadness, anger, powerlessness, loneliness, or guilt. Emotions can also run high as a result of resistance to advice you have given a patient, when a patient feels unfairly treated, when you fail to respond to certain demands made by a patient, or when a mistake has been made with an intervention. Thus, if your explanation arouses emotions in your patient, you can help calm those emotions by active listening, so that the patient will be open to further explanation. Active listening

means that you invite the patient to express their views, wishes, and feelings and show the patient you have heard and understood them. At the same time, you gain an insight into the patient's comprehension, thoughts, feelings, and consent. Active listening also enhances rapport, because the patient feels heard, understood, and supported. Thus, active or attentive listening is regarded as an essential competence for health professionals [4, 8–11]. The main conversational skills needed for active listening are summarized later in the *Tips and Tricks* section of this chapter.

26.2.4 Influencing

Case History: Ms. Ivory

"Ms. Ivory, I've told you about the pros and cons of surgery now. We can see how it goes for a while longer and try to reduce your heavy bleeding with medication, or you can opt for this surgery. It's entirely up to you what you prefer."

Apparently this was not what Ms. Ivory had been hoping for, since she gives Dr. White a frightened look. "But doctor, I really don't know," she says timidly, "just tell me what's best."

Ultimately the patient, on the basis of the information provided, will have to arrive at a decision or an intention to do something or not to do it. Influencing means that the health professional helps the patient to reach a decision, such as consenting to a medical procedure or agreeing to change their behavior and to act accordingly [2, 12]. In many cases, the patient does not really have an option. On the basis of your knowledge, you advise the patient to have a certain test or undergo a treatment that proceeds according to a fixed protocol. Your "advice" then consists mainly of an explanation of the procedure and the outcome that can be expected. The patient can consent to this or not. Advice of this kind might be: "You've had vague stomach pains for quite some time now. I just examined you internally and didn't find anything unusual, but I still think we should do a few more tests to be sure there's nothing seriously wrong. Is that all right with you?"

This is known as directive advice. Sometimes you might also want to get the patient to change their behavior, as was the case with Ms. Mustard and Ms. Taupe. The patient has to do something herself, such as taking medication, doing exercises, or following certain lifestyle rules. Unfortunately, patients are not very good at following this kind of advice. For instance, 40 % of medication directions are not followed or not followed correctly, and approximately 80 % of recommendations about changing behavior or lifestyle (about stopping smoking, drinking alcohol, dietary recommendations, etc.) are not complied with [13, 14]. However, there are some guidelines for giving advice that significantly increase the chance that a patient will not only accept your advice but also actually follow it:

- Make sure your advice matches the patient's request for help, wishes, and experiences.
- Give clear and practical advice.
- Give acceptable advice.
- Discuss the effects that can be expected if your advice is followed.
- Monitor compliance with your advice.

26.3 Critical Reflection

In recent years the amount of information given to patients has risen sharply. Nevertheless, many patients still feel they have not really been able or allowed to choose for themselves. To some extent this is inevitable: Directive advice simply does not offer a patient much room to make a choice. This is not a bad thing in itself if the advice is indisputably the "best" option or in the case of an emergency. However, in many cases the patient does, in fact, have a choice, and you can help them to make a well-informed decision. The shared decision-making model is now seen as the most appropriate patient-focused form of consultation between a health professional and a patient [15]. This form of consultation means that both the health professional and the patient can make their own, unique contribution to the decision-making process—the health professional as a medical expert and the patient as an experiential expert. The key points to remember about shared decision-making are:

- Stay attuned to the patient's wishes and options.
- Offer choices. Let patients decide for themselves as much as possible.
- Help the patient to weigh up pros and cons.
- Give the patient time to reach a decision.
- Gain consent and check that you have it.

In some situations, the right choice depends not so much on medical considerations as on the patient's views, emotions, and personal situation. In situations like this, you can help patients to become aware of their views and emotions with the help of counseling. This means breaking down the decision-making process into a number of steps, starting with clarifying the problem and then identifying and weighing up the options in order to reach a final decision. In addition to the active listening skills required to clarify and discuss the patient's emotions, you can also use techniques to support patients, challenge them, and give them structure to help them make the decision. Sometimes a patient needs more time than one consultation affords to process the information provided, to comprehend the consequences, and to reach a carefully considered decision. You can help patients with this process by offering support after the consultation. This support may consist of:

- Making a step-by-step plan with the patient, including a contingency plan
- Providing decision aids
- Making a clear follow-up appointment
- Providing further professional support or contact with other patients with the same problems

Since the patient's change of behavior will only take place after the consultation, you should certainly make a follow-up appointment to evaluate the change in behavior and its results. If your educational information focused on including certain behaviors in your patient's lifestyle or even on completely changing that lifestyle, you will need several consultations to help the patient to internalize the new behavior. We refer to this as *supportive guidance*.

Tips and Tricks

Acquiring and applying communicative skills in connection with patient education are primarily a matter of learning from experience. A summary of commonly used conversational skills and techniques can be helpful. Below is a list of these skills and techniques classified on the basis of the CELI sub-competences.

C = Control and Rapport

- Friendly, invitational start of the consultation.
- Summarize previous history.
- Agree on the goals and topics of the consultation.
- Guide the course of the conversation, keeping to the prescribed structure.
- Monitor the patient's attention to the conversation.
- Monitor attention and participation of other interlocutors if present.
- Provide detailed summary when changing to a new topic or ending the consultation.
- Show genuineness, empathy, care, and competence, both verbally and nonverbally.
- Announce and explain activities, such as physical examination or writing.
- Reinforce patient behavior that benefits the conversation and relationship.
- Make social conversation to show interest in the patient and put the patient at ease.
- Conclude the consultation in a clear and friendly way.

E = Explaining

- Ensure contents of explanation are true and realistic.
- Use clear and comprehensible language (appropriate wording, short sentences).
- Make explanation concise and structured with an introduction, items, and short summaries.
- Be interactive, leave pauses for reaction, and proceed one step at a time, guided by response—emotional or otherwise.

- Fit in with the patient's frame of reference.
- Be convincing, use vivid examples, and tie in with patients' experiences.
- Repeat key points and illustrate them with visual aids.
- Check patient has understood.

L = Listen Actively

- Be verbally and nonverbally attentive; encourage patient to talk.
- Include periods of silence; give the patient the opportunity to reflect and digest.
- Paraphrase.
- Reflect patient's feelings and opinions.
- Ask appropriate open and closed questions to elicit facts, feelings, and opinions.
- Acquire relevant information.
- Make things specific.
- Explore inconsistencies and ambivalences.
- Summarize what the patient has said.

I = Influencing (= Instruction, Advice, Counseling, Shared Decision-Making, and Support)

- Offer suggestions (do not give orders); leave room for reflection.
- Useful and acceptable phrasing of instructions and advice.
- Reinforce patient's problem-solving behavior.
- Realistic presentation of advice, possibilities, promises, and limitations.
- Take the "bad news" nature of some information and advice into account.
- Counseling and assisting with difficult decisions.
- Constructive negotiation.
- Turn a problem into a shared problem by rephrasing it.
- Promote mutual acknowledgement of feelings and opinions.
- Phase the decision process and provide time for reflection.
- Reach clear agreements and make contingency plans.
- Check the patient's approval of suggestions, instructions, advice, decisions, and agreements.
- Offer educational material (leaflets, Internet links) and/or useful contact addresses.
- Provide personal support or professional help after the consultation.

References

1. Van den Borne HW. The patient from receiver of information to informed decision-maker. Patient Educ Couns. 1998;34:89–102.
2. Wouda JC, Zandbelt LC, Smets EMA, Van de Wiel HBM. Assessment of physician competency in patient education: reliability and validity of a model-based instrument. Patient Educ Couns. 2011;85:92–8.
3. Hovland CI, Janis IL, Kelly HH. Communication and persuasion. New Haven: Yale University Press; 1953.

4. Silverman J, Kurtz S, Draper J. Skills for communicating with patients (second edition). Oxford: Radcliff Medical Press; 2005.
5. Aspegren K, Lonberg-Madsen P. Which basic communication skills in medicine are learnt spontaneously and which need to be taught and trained? Med Teach. 2005;27:539–43.
6. Hulsman RL. Shifting goals in medical communication. Determinants of goal detection and response formation. Patient Educ Couns. 2009;74:302–8.
7. De Haes H, Bensing J. Endpoints in medical communication research, proposing a framework of functions and outcomes. Patient Educ Couns. 2009;74:287–94.
8. Boudreau JD, Cassell E, Fuks A. Preparing medical students to become attentive listeners. Med Teach. 2009;31:22–9.
9. Epstein RM, Street RL. Patient-centered communication in cancer care: promoting healing and reducing suffering. Bethesda: National Cancer Institute 2007; publ 07–6225.
10. Jagosh J, Boudreau JD, Steinert Y, MacDonald ME, Ingram L. The importance of physician listening from the patients' perspective: enhancing diagnosis, healing and the doctor-patient relationship. Patient Educ Couns. 2011;85:369–74.
11. Robertson K. Active listening: more than just paying attention. Aus Fam Physician. 2005;34:1053–5.
12. Bird J, Cohen-Cole SA. The three function model of the medical interview. In: Hale MS, editor. Methods in teaching consultation liaison-psychiatry. Basel: Adv Psychosom Med; 1990;20:65–88.
13. DiMatteo MR, Giordani PJ, Lepper HS, Croghan TW. Patient adherence and medical treatment outcomes: a meta-analysis. Med Care. 2002;40:794–811.
14. Van Dulmen S, Sluijs E, Van Dijk L, De Ridder D, Heerdink R, Bensing J. Patient adherence to medical treatment: a review of reviews. BMC Health Serv Res. 2007;7:55–68.
15. Makoul G, Clayman ML. An integrative model of shared decision-making in medical encounters. Patient Educ Couns. 2006;60:301–12.

Collaborator: A Midwife Who Had a Conflict with an Obstetrician—How to Transform "Contact Tics" into "Co Tactics"

27

Harry B.M. van de Wiel, K. Marieke Paarlberg, and Jan C. Wouda

27.1 Introduction

Although professional collaboration is nowadays recognized as of vital importance for the quality and safety of health care (organizations), this is especially the case in Psychosomatic Obstetrics and Gynecology (POG). As explained in detail elsewhere in this book (Chap. 22), the scientific fundament for the psychosomatic approach is the biopsychosocial (BPS) model. As the name indicates, the key characteristic of this model is the combination of insights from several disciplines, including biology, psychology, and sociology. This requires the ability to collaborate with colleagues with different backgrounds in order to establish true co-creation in highly reliable teams and organizations. Because mistakes are unavoidable, collaboration relies on correction mechanisms to transform "contact tics" into "co tactics." To do this, healthcare professionals must be willing and able to make their egos subservient to the treatment team. On the other hand, this ecosystem must be able to adapt to overarching cultural and scientific changes, which means that healthcare professionals must also create learning organizations by collaborating with each other. At the end of this chapter, we will discuss the learning organization concept in more detail. First we will focus on collaboration as defined in the CanMEDS approach.

H.B.M. van de Wiel (✉)
Wenckebach Institute, University of Groningen, University Medical Centre Groningen, Groningen, The Netherlands
e-mail: har.wiel@planet.nl

K.M. Paarlberg
Department of Obstetrics and Gynecology, Gelre Hospitals, Apeldoorn Location, Apeldoorn, The Netherlands
e-mail: km.paarlberg@xs4all.nl

J.C. Wouda
Ahmas Foundation, Groningen, The Netherlands
e-mail: j.c.wouda@umcg.nl

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_27

As collaborators, Ob/Gyn professionals work within a healthcare team to achieve optimal patient care. They should always work in partnership with others involved in the care of individuals or specific groups of patients.

Although its importance is widely endorsed, collaboration is rarely listed as an item on the agenda of professional teams unless there is an open conflict. If this occurs, it becomes clear that in this situation too, prevention is better than cure.

Therefore, the following topics will be discussed in this chapter:

1. Collaboration as a prerequisite
2. Collaboration as a targeted process
3. Feedback as interpersonal coordination
4. A learning organization
5. Conclusions
6. Tips and tricks

But first we will visit a perinatal audit in which gynecologists, obstetricians, and other people involved examine errors to discover substandard factors, with the aim of improving the quality and safety of their obstetric care.

Case History

Margareta Azul, an experienced and very compassionate midwife working at an antenatal clinic, found it difficult to take time off from her busy job to participate in the perinatal audit of the hospital she collaborates with.

The case to be debated is about Verda Green. Verda Green is a young, highly intelligent, and ambitious obstetrician, who tells her story in a flat and neutral tone. “It was busy on the ward. I was duty supervisor and could not get hold of my colleague who was on standby duty. Around 4 in the morning, things went wrong: uterine rupture, the baby was in a bad way and died a few days later. You can all find the medical details including the results of the section in the appendix.”

After giving this information, Verda remains silent. She does not comment on what happened or on her role in this drama. In fact, Margareta is most puzzled by the fact that Verda shows no emotional reaction at all. After a few seconds her amazement turns into anger.

27.2 Collaboration as a Prerequisite

When asked what makes working in health care exciting, many people say it is “the collaboration with other people.” When asked what sometimes makes life difficult, strangely enough the answer is often the same. Apparently collaboration is essential for human beings and it requires precision. Of course, this is not so strange, considering that no other animals are as weak as individuals and so strong collectively as

humans. Collaboration is in our genes and determines our mood to a significant extent. Given that over the past decades collaboration has also come to be one of the most common working models in health care, particularly in multidisciplinary consultations or integrated care arrangements, it has also become one of the most important quality indicators of health care.

The fact that collaboration is essential for healthcare professionals does not mean that it always goes well, quite the contrary in fact. Collaboration requires give and take and therefore room to maneuver. And at the moment room to maneuver happens to be a scarce commodity in health care, which is why things quite often go wrong. In spite of this, we pay relatively little attention to collaboration as a targeted process. One explanation for this rather unprofessional attitude is that as individuals we have limited influence on the final outcome. Except in typical leadership roles, such as chair or manager, the average healthcare professional more or less just lets collaboration run its course and certainly does not try to manage it. Although this is understandable, it is not a very professional approach, and it is everybody's moral responsibility to contribute to good collaboration.

Like communication and organization, collaboration is a "soft skill." Soft skills are not goals in themselves but are prerequisites for reaching higher goals such as healing and taking care of people. This subordinate position does not mean that collaboration is not an autonomous skill requiring a lot of knowledge and expertise. In collaboration it is always possible to distinguish two sides that are closely linked to each other. In addition to being a prerequisite for reaching higher goals, collaboration itself can be defined as a targeted process.

Case History: Continued

Margareta Azul tries to express her displeasure at the lack of any sign of emotional involvement from Verda as neutrally as possible. After all, one of the basic rules of the audit discussion is, and rightly so, "no fighting or name-calling." Everyone makes mistakes—the point is being willing to learn from them. And that is exactly what Margareta is missing.

"Sorry, Mr. Chairman, there's something I've got to say." It sounds reasonably neutral but as she continues her voice becomes sharper and sharper and by the time she has finished it sounds really scathing. "If we are just going to read out things that everyone can read at home, we don't need to waste our precious time on this meeting!"

27.3 Targeted Process

Collaboration has always been the ideal way to reach goals that individuals cannot reach alone. Now that health care is becoming increasingly complex, more and more frequently we are turning to different disciplines with a wide variety of qualities. Another reason for spreading tasks across several disciplines and job levels is

to control costs. First dividing the tasks and then combining them again have led to quite a lot of linguistic confusion in health care. However, a factor that has more impact is that each discipline tries to influence other disciplines. As soon as we consciously set out to provide health care together, unconsciously we will be engaged with each other at a personal level. In this process of interaction, we show each other how we influence each other by assuming a certain position in our contact. One leads; the other follows. One person is friendly toward us, another cool and aloof. We can plot positions like this using the Leary circle (Fig. 27.1).

The quadrants in this model represent several forms of cooperation or opposition that we can use professionally to steer others or even the group in the direction we want. For instance, if the person chairing a multidisciplinary meeting displays too much *leading* behavior, this will often evoke passivity in other people at the meeting: They become *followers* instead of participating actively and helping the group. This can manifest itself in different ways: Some people become passive-aggressive (*rebellious*), while others *withdraw*. At best, the chair will gain *followers* or *cooperators*. To entice other people at the meeting to really participate (*help*), the chair will therefore have to avoid being dominant all the time (*leading*) and sometimes show *following* behavior. Since in health care the health and well-being of the patient is the main focus (patient centeredness), we sometimes forget that

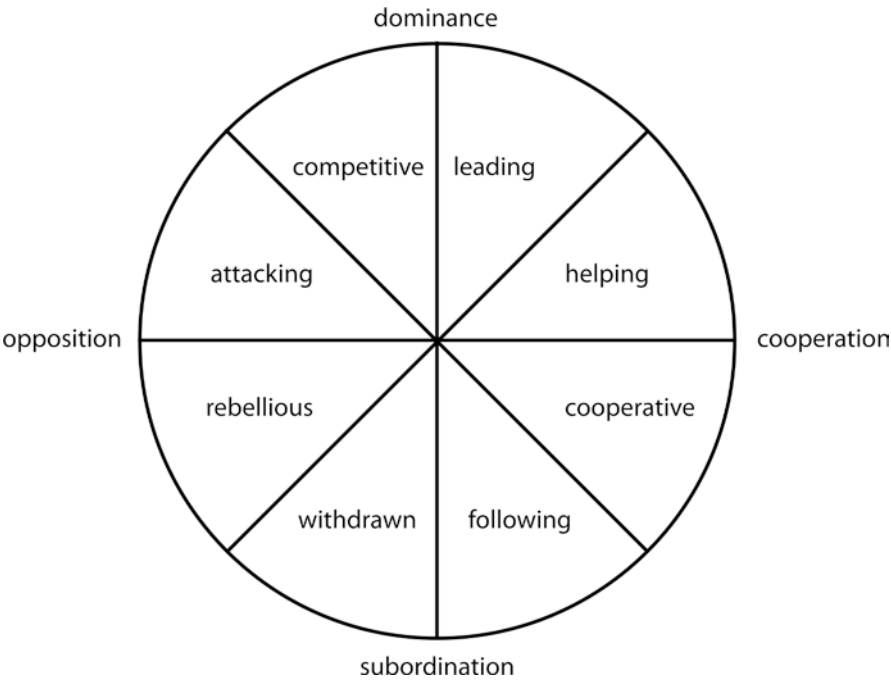


Fig. 27.1 The Leary circle (Adapted with permission of Wipf and Stock Publishers (www.wipfandstock.com) from Leary T. Interpersonal Diagnosis of Personality. New York: Ronald Press; 1957; republished 2004 by Wipf and Stock Publishers, New York.)

collaboration is a process that we ourselves must actively and consciously shape. This methodical approach to collaboration, known in contemporary jargon as *relations management*, requires numerous skills that go considerably further than having learned discussion techniques. Professional collaboration means that collaboration must be well organized, preferably in accordance with best practices and evidence from research. In short, good collaboration also requires good organization. This reciprocity applies to all the soft skills in models such as the CanMEDS roles and the "learning organization" concept.

27.4 Feedback as Interpersonal Coordination

If people are to react to each other adequately, they need to be able to influence each other. One of the most convenient ways to do this is to use *feedback*. Feedback is always and everywhere a crucial prerequisite for collaboration, but it can vary widely across different cultures. Gender, age, and, of course, personality and character also play a role: One person is a perfectionist who wants to have everything under control, another takes things as they come. Moreover, ingrained behavioral patterns play a role in giving and receiving feedback. This is certainly the case in teams who have known each other for a long time. Usually all these things result in familiarity with each other. They make our behavior predictable, and that is pleasant. We know where we stand and can focus on the content of the discussion. This does not alter the fact that feedback always requires sensitivity, especially if it involves criticism. However, it is also important to realize that feedback is a lot more than saying that we would like certain things to be different. We also use feedback to reward desirable behavior: Compliments are also feedback. Holding up a mirror so that the other person can improve their own behavior is also a form of feedback. Although the term feedback is in itself neutral, feedback itself nearly always has a certain tone. It is nearly always either an expression of *approval* or *rejection* or the absence of a reaction—ignoring someone is also a signal, and in fact often a very strong signal. If we ourselves are the subject of discussion, as Verda is in our case, the feedback is directly about us and may therefore be hard to take. Finally, it is important to realize that feedback also always reflects the opinion of the person giving it. This means that feedback always also says something about us, regardless of whether we are giving or receiving it. Particularly in situations in which people are vulnerable, it is important to be very careful about this personal aspect, whether it is about us or someone else.

Case History: Continued

After Margareta's fierce tirade, silence falls. Although everyone is aware of Margareta's commitment to her patients, people sense that a certain boundary has been crossed. The chair, the eloquent Carlos Amarillo, an obstetrician originating from Madrid in Spain, is also aware of this and wants to call Margareta

to order. Fortunately Carlos thinks again. He realizes that he has a responsibility not to make the same mistake as Margareta has just made. “Practique lo que predica!” Practice what you preach! To be effective, feedback must relate to behavior that can be changed, but what is even more important is that the other person must be able and willing to be helped by the feedback.

Carlos as an experienced chair knew better than anyone that the core of the problem was exactly this. Criticism of a person’s emotions, including the absence of emotions, is not helpful, because it is not acceptable. He decides to opt for a two-pronged approach: Be hard on the problem but soft on the person, and always start with this second aspect. “Margareta, we all know how committed you are to your patients and because of that you are certainly entitled to be surprised at certain things. You’re welcome even! But what exactly did you want to achieve with your comment?”

At this point Margareta doesn’t really feel criticized. “I just mean, I think if something like this happens to you, you should show that it affects you. Surely that’s the least you can do!”

Carlos remains calm and continues, “I have 2 questions for you: How do you know Verda is not affected, and—perhaps an even more important question—isn’t the purpose of this meeting for us to learn from the substance of what happened and to prevent it from happening again?”

A lightbulb goes on for Margareta, and she immediately apologizes to Verda and everyone else at the meeting. “Sorry, Carlos, you are absolutely right. We are not here to judge each other emotionally. I overreacted.”

27.5 The Learning Organization Revisited

To be able to adapt to the increasing pace of new developments, healthcare organizations must also innovate. Innovation means not only exploring unknown territory but also questioning the existing structure in the current organization. This is difficult to fit into everyday life in a hospital where people like fixed, predictable routines, preferably laid down in guidelines, protocols, and safety management systems. It is not for nothing that healthcare specialties are known as “disciplines!” To be able to learn in spite of this, informal processes are important, as are being open and communicative and being willing to help one another and to be vulnerable. In short, there must be a safe working and learning environment so that mistakes can be identified and discussed and people can put forward points for improvement and come to each other’s assistance. Katzenbach and Smith [1] defined the characteristics of a team as follows:

- The members are interdependent and are working toward a shared goal.
- The members have contact with each other.
- The members know who is and who is not a member.

- The members have specific roles and functions.
- People are members of the team for a specific period of time.

Apart from a clear definition of tasks and roles—the structure of the organization—the culture is also important: the set of core values and behavioral norms that governs the way people in an organization interact with each other [2–4]. Just as with psychosomatic disorders, the outer, visible behavioral layer and the normative inner layer are both important.

Conclusions

A common complaint within health care and outside of it is that there is less and less time for health care itself and that we are spending more and more time on work "surrounding" health care. Given the interdependence of collaboration, organization, communication, etc., this is perfectly reasonable. It makes it clear that we must be extremely cautious about making health care even more complex than it already is. Every extra specialty or even specialist places higher demands on all the core competences in the CanMEDS model. After all, collaboration is more than just finding solutions to specific situations where it would suffice for people to *pass on information* to each other clearly and in good time. As we have seen, collaboration also always entails influencing each other psychologically. This means that we must also pay attention to dealing with the messages we receive from each other—also emotionally—and accepting the consequences. This at least involves *consulting* each other. But because collaboration also influences relationships—who can make a decision and who determines that—it must be reshaped over and over again. This at least involves *participation*. In short, collaboration is much more than notifying each other and liking each other if we want to manage relations professionally, as is required for multidisciplinary teamwork or integrated care arrangements. We have to realize that this inevitably entails creating a huge amount of additional work!

Tips and Tricks (In Relation to Feedback)

1. First ask what the other person was trying to achieve with their approach. Then ask to what extent this purpose was achieved. This legitimizes your feedback and has the effect of opening the other person's ears. It also saves you from wasted effort. If the other person has, in their opinion, completely achieved their purpose, then you will no longer have any basis for your feedback.
2. If the other person has not achieved their purpose, that may be a reason for you to give feedback, but it does not yet mean you have the other person's consent. If feedback is to be effective, the other person must be hungry for feedback. You can increase this hunger by first asking the other person what they thought went well and only then what could have gone better. By this time you will be in conversation with the other person and tacitly working toward the same goal: improving the other person's behavior.

3. Ask if the other person is interested in your observations. Only start giving your feedback if this is the case, and in the first instance limit yourself to observations: "I noticed that…." Do not give advice until you notice signs of hunger for advice, such as "I'd like to hear how you would have approached this."
4. If you have gained the right to speak, first say what you think went well, what you are enthusiastic about. This may require some creative juggling. Limit yourself to things you are sincerely positive about. Then the other person will be more inclined to listen to the other things you have to say, because up to that point you have been a good discussion partner.
5. Always express your opinion in the first person. Start by mentioning specific behavior ("I noticed/heard…") and then give your opinion about this ("What I think about this is that…"). When expressing this opinion, build on the goals that have been formulated so that you have a common frame of reference.
6. State that it is not so easy to find a solution to the problem you have identified. This shows respect for the other person.
7. Ask if the other person would appreciate your help in finding a solution and if advice is welcome.
8. Wait until you have seen signs of hunger for advice before formulating options that might help the other person to achieve *their* goals (not yours!).
9. Often the other person will react with an explanation of the reasons for their behavior or defend themselves with an explanation of how they think their behavior comes across to other people. Be careful! If people defend themselves, they are not open to change. To put it more strongly, they evidently feel they are under attack. Take care not to enter into a discussion at that point!
10. Always respect the other person's opinion and do not try to convince them that you are right. Everyone is entitled to their own view, especially if it concerns their own behavior. Feedback means providing options, not giving orders!

Acknowledgment This chapter is based on and partly a translation of previously published works of the first and third authors: Wiel HBM van de, Wouda JC. Samen werken aan samenwerken (Working together on collaboration). Tijdschrift voor Verloskunde 2014; 2: 36–38; and Wiel HBM van de, Wouda JC, Wiel FS van de. Leren van fouten; omgaan met feedback, kritiek & klachten. Groningen, The Netherlands: The Ahmas Foundation; 2011.

References

1. Katzenbach JR, Smith DK. The wisdom of teams: creating the high-performance organization. Boston: Harvard Business School; 1993.
2. Senge P. The fifth discipline: the art and practice of the learning organization. New York: Doubleday; 1990.
3. van de Wiel HBM, Wouda JC. Samen werken aan samenwerken. (Working together on collaboration). Tijdschrift voor Verloskunde. 2014;2:36–8.
4. van de Wiel HBM, Wouda JC, van de Wiel FS. Leren van fouten; omgaan met feedback, kritiek & klachten. Groningen: The Ahmas Foundation; 2011.

Professional: A Sexologist Who Overstepped the Mark—How to Handle the Therapeutic Relationship in Psychosocial Care

28

Jan C. Wouda, Harry B.M. van de Wiel, and K. Marieke Paarlberg

28.1 Introduction and Aims

For therapists, who work according to the biopsychosocial model (BPS model), conversations with the patient are their main tool used for diagnostics and interventions. Other forms of communication—such as questionnaires, written information, and websites—can be used as supplementary material. To ensure that his or her conversations with a patient are effective and efficient, the therapist must build a good relationship with that patient. This chapter is about the characteristics of the care relationship generated by the biopsychosocial model. We will be focusing mainly on the characteristics of the therapeutic relationship. The care relationship as the basis for a diagnostic conversation will be discussed only in passing.

An effective therapeutic relationship places high demands on the therapist as a person. It requires personal characteristics such as capacity for empathy, respect, integrity, conscientiousness, and expertise. Moreover, in every therapeutic relationship, there is a certain tension between being involved enough to empathize with the patient and maintaining enough distance to keep a grip on the therapeutic process and the working relationship. If the balance between involvement and distance is not sufficiently safeguarded, this cannot only adversely affect the therapeutic

J.C. Wouda (✉)
Ahmas Foundation, Groningen, The Netherlands
e-mail: j.c.wouda@umcg.nl

H.B.M. van de Wiel
Wenckebach Institute, University of Groningen, University Medical Centre Groningen, Groningen, The Netherlands
e-mail: har.wiel@planet.nl

K.M. Paarlberg
Department of Obstetrics and Gynecology, Gelre Hospitals, Apeldoorn Location, Apeldoorn, The Netherlands
e-mail: km.paarlberg@xs4all.nl

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_28

process, but physical intimacy or other undesirable elements may appear in the care relationship, sometimes even with iatrogenic consequences. In short, it is important to create an effective therapeutic working relationship characterized by "maximum involvement while maintaining distance" [1]. In this chapter we will focus on the criteria that must be met if the relationship between practitioner and patient is to serve as a therapeutic tool. We therefore address the following topics:

1. A functional therapeutic contract
2. A professional attitude
3. The therapist's personal qualities
4. Maintaining boundaries
5. The therapeutic process
6. Conclusions
7. Tips to limit the risk of crossing boundaries
8. Literature

We will illustrate these topics with the help of a case report, presented in installments, about the care relationship between an eminent gynecologist-sexologist and an exceptional couple.

Case History

An Exceptional Request

Professor Albert Schwartz is a gynecologist and sexologist and a widely recognized authority on sexual disorders. He sees the vast majority of his patients at an outpatient clinic at a university medical center where he has been working for more than 30 years. There are a few patients who cannot or do not want to come to the outpatient clinic at the hospital, for instance, because of their social position. These patients he sees in the evening at his home. The patients in question appreciate this option very much, but it also gives him some welcome distraction in the evenings, which, since the death of his wife a few years previously, are often empty.

One day a fellow gynecologist asks him to make a discrete appointment with a couple called "V." The woman has been complaining for quite some time of dyspareunia, for which the other gynecologist can find no explanation. He has advised the couple to seek the help of a sexologist and has recommended his colleague, Professor Schwartz. With some reservations they have agreed to the referral. Since Mr. V is a minister in the current government, discretion is essential. As a rare exception, Schwartz is given Mr. V's private phone number and it is stressed that he should make the call personally. In connection with the minister's privacy, the consultation must take place at the doctor's consulting room at home. During the telephone conversation, Mr. V asks if his presence during the therapy is absolutely necessary, as he has a very full agenda and an appointment like this also requires extra security

measures as part of the so-called security profile. However, when Professor Schwartz says that with sexual problems, he prefers to work with both partners, they do manage to make an appointment reasonably soon.

At the end of the conversation, the minister says, "Professor Schwartz, I do hope you are as good as I've been told, because my wife really needs help urgently." Given the content, his tone is remarkably neutral, as though there is a minor practical problem that needs to be addressed.

Professor Schwartz feels slightly irritated and opts for a safe, if somewhat formal conclusion to the telephone conversation. "I appreciate your concern, but I suggest we leave it at this for now. I think it would be best to discuss the details of the case when your wife is also present. Is that OK?" Apparently it is, because after some unintelligible muttering the call is ended.

When putting the appointment in his calendar, Professor Schwartz notices that he feels some ambivalence. It flatters his ego that a minister has sought his help, but on the other hand, he also feels a bit caught off guard, particularly by the minister's attempt to present his wife as "the patient." If it is so clear that the wife is the patient, why has she not approached him herself? And what on earth is a security profile?

28.2 A Functional Therapeutic Contract

In principle, the patient contacts a therapist voluntarily and, largely, on his or her own initiative. Sometimes a patient is "sent" by someone in their direct environment, such as the patient in the case report. A patient who has been "sent" always requires additional attention from the therapist, because there are underlying motives that might significantly affect the therapeutic process. It is then the therapist's job to help the patient as effectively as possible, while acknowledging and respecting the patient's autonomy and staying within the boundaries of his or her own professional capacities. This professional focus on meeting the patient's needs does not mean that the therapist waits until a patient presents a clear request and then simply delivers what the patient has asked for. Therapy is based on the patient's complaints or problems. In conjunction with the patient, the therapist identifies these problems systematically (diagnostics). On the basis of his or her expertise and experience, the therapist then assesses the request or problem and formulates hypotheses about the factors that are perpetuating the problem and which might be amenable to therapy. Then the therapist draws up a treatment plan in consultation with the patient, keeps reports of his or her contacts with the patient, and records the results of the therapy. This means he or she can look back on the therapeutic process, account for it, and if necessary adapt his or her contact with the patient [2].

During this process a care relationship will develop between the patient and the therapist in which they each play their own role and make their own contribution.

This relationship is laid down in a kind of therapeutic contract. This is usually an oral, partly implicit, and generalized agreement in which both parties state what they can and may expect from each other and where the boundaries lie. Over the course of time, this contract may be modified in response to what is therapeutically functional. Functionality means that the practitioner formulates goals for the therapy to be given and works systematically and transparently toward achieving these goals.

Case History: Continued

An Exceptionally Charming Woman

When he receives the couple some time later at his home in the evening, once again the minister immediately presents his wife as the problem and the patient. His wife does not contradict him and Professor Schwartz therefore decides to concentrate, in the first instance, on the wife and her complaints. She confirms what he had already heard from his colleague. When asked, the woman herself cannot give any explanation for the pain she feels when having sex either.

"It just sneaked in somehow," she says in a soft, almost apologetic tone.

The husband responds in a slightly condescending tone, "So it would be nice if the professor could just get it to sneak out again."

Schwartz ignores the tone and examines the woman's background in more detail. Although she does not present herself very confidently, she is clearly not just anybody. She combined a university degree program with working as a model and is now successfully running her own business.

When asked what she expects from Professor Schwartz, she says in a despairing tone, "I just want it to be good between us in bed, like it was at first."

When Schwartz turns toward Mr. V and tries to say as neutrally as possible that a relationship requires effort from both parties, Mr. V's tone is again slightly patronizing. "If you say so, Professor, I'm sure you're right. So just tell me what to do."

Schwartz is surprised about all these sly digs, but is not sure how he should react at this stage—observe or intervene. The only thing he is wondering (almost out loud) is: What is such a charming woman doing with this self-satisfied windbag? Although he is still able to go ahead and ask the relevant diagnostic questions, Professor Schwartz is clearly not his normal self. He even forgets to round off this first session with a summary of the problems. There is no question of a clearly formulated joint objective with an accompanying proposal for follow-up appointments.

The minister is quick to take over the initiative. He observes that the professor and his wife undoubtedly have a lot to discuss without his presence being absolutely necessary. That is just as well, because he can then get on with looking after the interests of the country.

Although in the first instance healthcare practitioners concentrate on complaints and problems and ways to address them, this is not the only reason why people seek professional help. Often there are two presenting problems that are closely related. On the one hand, the patient wants to be freed from specific complaints or problems. However, patients usually also have an underlying need for help in overcoming their own powerlessness when it becomes clear that they are unable to solve the problems on their own. In other words, there is a request for help at the meta-level, which might be formulated as follows, "Restore my feeling of being competent enough to deal with the problems in my life." Within Psychosomatic Obstetrics and Gynecology (POG), this is a request to put an end to demoralization [3]. This request is often just as important as the request for a solution to the specific health issue, since the demoralization that has set in leads to a vicious circle. The inability to solve the problem leads to avoidance of activity, psychological effort, and social participation. In this way people avoid disappointments, but they also miss out on positive experiences of their own self-efficacy. The problems or complaints persist and fear of failure and demoralization only increase, as do apathy and social isolation.

The therapeutic relationship plays an important role in meeting both these requests, but it is not identical for the two requests. To solve the actual problem, the therapist and the patient examine it together, and the therapist offers treatment and/or insights and skills to solve the problem. To a significant extent this is also a psycho-educational process. The therapeutic relationship provides a safe social framework for this. In addition, the therapist and the patient work together to overcome the powerlessness that prevents the patient from navigating the change process successfully. In this case the therapeutic relationship also functions—much more than with information provision and psycho-education—as a tool to effect change. It is in fact a working alliance [4, 5]. This working alliance mainly revolves around the emotional bond of closeness and trust between patient and practitioner, which enables therapeutic change in the patient.

The distinction between the educational forms of care and psychotherapeutic care is certainly not clear-cut. Usually there is a sliding scale from information provision and psycho-education to counseling and psychotherapy. Within Psychosomatic Obstetrics and Gynecology, there are forms of information provision and education that tend toward psychotherapy, while the psychotherapeutic approach to sexual problems, for example, includes many educational elements [6–8]. Chapter 26 about the CELI model discusses the communication skills required to meet a patient's educational needs to deal with the medical and psychosocial problems at hand (the psycho-educational process).

Case History: Continued

An Exceptionally Attractive Secretary

Mrs. V does, in fact, come to the next appointment alone, which makes contact considerably easier. She tells her story calmly and confidently and from the outset makes a much more lively impression than when her husband

was there. Her complaints had started at a time when her business was going through a rough patch. Facing the threat of bankruptcy, she had been forced to dismiss several highly valued employees, including her own secretary. Her husband showed practically no interest in her concerns, let alone for her business. However, he had "taken on" her secretary, an exceptionally attractive woman with whom he still regularly goes on work trips.

Schwartz asks her what hurt the most: his lack of interest in her or his excessive interest in the secretary. "What hurts the most is that he doesn't want to talk about anything. He's too busy with other things! Though…of course, he's working night and day, even when he's at home. So in a way I can understand that he spends a lot of time with his secretary and doesn't show much interest in my work." The depressive undertone can be heard again in this last sentence.

"If I understand you correctly, on the one hand you feel you are not being taken seriously and truly respected, but on the other hand you also have some understanding for your husband given his position. And this makes you feel sad and helpless."

Mrs. V gives a little nod and then continues in a whisper, "Since that time I haven't really felt like having sex at all, but I suppose it's part and parcel of things… So yes."

Key Points

Basic principles for psychosomatic obstetrics and gynecology (POG) therapists are as follows:

- The service provided is based on a therapy contract between patient and therapist, entered into voluntarily.
- The POG therapist has the required professional qualities and adheres to the professional standards.
- The therapist takes a functional approach. He or she sets goals, works toward them systematically and transparently, and keeps records of interventions and results.
- There are two sides to therapy: On the one hand, the educational process of change in the way the patient thinks, feels, and acts, and on the other, the therapeutic process, in which the therapist helps the patient to counteract his or her feelings of powerlessness and demoralization in relation to the health problem or issue.

28.3 A Professional Attitude

Research has shown that several factors that are not characteristic of a specific form of psychotherapy have a beneficial effect on the course and outcome of psychotherapeutic interventions [9–12]. These are known as "nonspecific factors." In relation to these nonspecific factors, the literature offers a rich palette of recommendations for behavior and personal qualities in therapists [2, 13, 14]. They are designated by terms such as "involvement," "empathy," "openness," "transparency," "providing safety," "inspiring confidence," "positivity," "unconditional acceptance," "respect," "caring attitude," "reassurance," "providing support," "offering hope," "critical reflection," and "maintaining boundaries." While it may be possible to define each of these recommended behaviors and personal qualities, it is difficult to indicate how these qualities in a therapist determine the quality of the therapeutic relationship. This is why the term "professional approach" or even just "professionalism" is used to group all the behaviors and qualities listed above together as a single cluster that guarantees a good therapeutic relationship. In the following section we will discuss the main general qualities.

Apart from these, there are ethical, normative, and legal frames of reference that also entail requirements regarding a therapist's behavior toward his/her patients. These requirements have to do with matters such as due care in therapeutic actions, confidentiality, and patients' right to access their own file. In connection with this, there are also media contact rules for the protection of patients' privacy. It has also been stipulated that therapists must respect their patients' physical and mental integrity and boundaries, and the law and the professional code of conduct both explicitly provide that a therapist must refrain from sexual behavior and sexual advances toward his or her patients.

28.4 A Therapist's Personal Qualities

In the introduction it was stated that an effective therapeutic relationship not only requires the therapist to have good communication skills but also certain personal qualities. The main personal qualities referred to in the literature are empathy, respect, integrity, conscientiousness, expertise, and the ability to maintain boundaries.

Case History: Continued

An Exceptional Click

Initially, Mrs. V still occasionally tried to have sex to keep the peace, but it soon became so painful that she started to avoid her husband in bed. Given his working hours this was not so very difficult, and the last few months he has not taken any initiative either. Rather than providing relief, as she had hoped, this mainly caused feelings of guilt and jealousy when he was away.

After a few difficult conversations with her husband about the absence of sex in their marriage, she got her general practitioner (GP) to refer her to the gynecologist in the hope that he would be able to cure her dyspareunia with an ointment or something like that. This turned out not to be the case, which was why the other gynecologist had referred her to Professor Schwartz.

"But you probably think I'm a just a boring whiner."

To counteract her self-criticism, but also because he sincerely thinks she is a captivating and charming woman, Schwartz decides to give her a bigger compliment than he normally would. "Mrs. V, I certainly don't think you're a whiner. On the contrary, you're an engaging and attractive woman and when I hear your story about your marriage and particularly about the lack of contact with your husband, I can well imagine that you are not very keen on having sex. What is it that still makes your marriage to your husband worthwhile?"

As the conversation continues, they are soon discussing fundamental human values such as fidelity, integrity, and not abandoning someone as soon as things are not going so well. It gradually becomes apparent that Professor Schwartz and Mrs. V are mentally very much on the same wavelength, and sometimes even physically, since their postures match completely. The depressive undertone has disappeared completely. In fact, they hit it off so well that in spite of the sometimes grave topics of discussion there is a lot of laughter. At first Schwartz is just glad he has managed to strike the right chord to get her out of her lethargy. It is a little harder than otherwise to say goodbye: It is as though they never have enough time to talk.

When he is alone again in his now conspicuously empty consulting room, he realizes he is already looking forward to the next appointment. For a moment he considers making a note of his feeling; after all, personal emotions are always serious points of concern for a sex therapist. But just as he is sitting down at his desk, one of his children rings and after that he just does not get around to it.

28.4.1 Empathy

Empathy has been defined as the capacity to put oneself in another person's shoes so as to be able to understand what the other person is experiencing and also to show this understanding to the other person [14, 15]. The term "involvement" is defined in a similar way. The influence of empathy on the effect of the treatment has been examined extensively. The research has shown that the expression of empathy by the treating practitioner, as experienced by the patient, has a positive correlation with the outcome of the therapy [11, 14, 15]. The important point is the empathy perceived by the patient rather than the empathy felt by the therapist [11]; in fact, the latter shows practically no correlation with the outcome of the treatment. Therapists must therefore actively check whether their patients feel understood by them.

Empathy or involvement does not mean that a therapist should simply accept that everything a patient says is true. If the therapist observes the patient's nonverbal behavior and listens to the feelings expressed by the patient's story, it will become clear whether or not the patient's story can be believed. If it seems this is not the case, then a certain distance is required to confront the patient in a constructive but clear way with any inaccuracies or inconsistencies in their story. Too much empathy or involvement can also be a trap for a therapist. We will come back to this. A patient who expects a lot of empathy can also be a stumbling block. Nearly every healthcare practitioner is familiar with the situation in which a colleague, friend, or family member turns to them with a health issue or problem. In this kind of situation, because the practitioner does not have enough distance, it is generally not recommended for them to tackle the problem themselves but to refer the person to someone else.

28.4.2 Showing Respect

In the first place respect means that the therapist should accept the patient's views, feelings, and behavior for what they are. Respect also means that the therapist should acknowledge patients' autonomy with regard to the way they deal with their problems, even if the therapist, on the basis of his or her expertise and views, regards this as problematic. The important thing is to show patients that the therapist has confidence in their capacity to find a solution to their problem. Showing respect is particularly difficult when strong emotions appear or when a patient expresses views, for instance, about certain sexual preferences or their lifestyle, which are at odds with the therapist's views. It shows professionalism if a therapist can make space for such emotions and views, realizing that showing respect is a functional approach in therapy. Not only does it enable valuable information to emerge about the way the patient experiences the world, but in terms of the relationship, it means the therapist is also giving a strong signal that he or she is not afraid of confronting intense feelings or extreme views.

28.4.3 Integrity

Integrity or authenticity on the therapist's part determines to a large extent the trust a patient will have in the therapist and the success of the therapy. Integrity mainly has to do with finding the balance between a dynamic and a more reflective way of acting: spontaneity as well as self-discipline, being both serious and playful, openness as well as reticence and creativity, as well as predictability [16]. A therapist with integrity is sincere in his or her intentions, is aware of his or her feelings during a session, and expresses these feelings in a constructive way but only if that is helpful in the therapeutic process. Numerous authors stress the value of self-disclosure by the therapist [16, 17]. Patients want to see "something human" in their therapists to be able to trust the alliance and to bare their own souls. However, Schnarch warns

about openness regarding personal matters and stresses that it is the therapist's integrity that is the basis of the patient's trust [4]. Apparently self-disclosure is no panacea.

28.4.4 Conscientiousness

The fact that a therapist is conscientious in the way he or she works and approaches the patient also contributes to the patient's confidence. In the first place conscientiousness means that the therapist is transparent and enters into a therapy contract with the patient. Clear agreements should be reached about the goal and methods of the therapy; about the duration, frequency, and payment of the sessions; and also about a few rules of conduct in health care, such as confidentiality, safeguarding privacy, and not crossing personal boundaries. Given the unequal relationship and patients' vulnerability in the therapeutic process, a therapist must guard against errors such as giving the patient insufficient information, departing from or failing to comply with agreements, or making decisions without consulting the patient. Conscientiousness also means that therapists must maintain both their own and the patient's boundaries.

28.4.5 Expertise

The therapist's expertise is probably the most essential factor in determining the confidence a patient has in the therapist and the therapist's approach. A professional therapist is assumed to have sufficient knowledge in his or her field and to be competent. The required expertise relates both to the diagnostic and therapeutic interventions the therapist uses and to the therapist's ability to present these interventions in such a way that the patient understands them and cooperates with them with confidence.

A great deal of empirical knowledge has now been accumulated about the effectiveness of psychotherapeutic interventions such as cognitive behavior therapy and rational emotive therapy [9, 10]. Therapists can show their expertise in their field by basing their therapeutic interventions on these insights, in other words by following evidence-based practices and by adhering to the treatment protocols and guidelines that apply to effective therapy. This does not alter the fact that each case has its unique characteristics and context and that therapists should certainly not simply follow guidelines unquestioningly. Critical reflection on one's own actions is always necessary.

In addition, a therapist must have educational expertise. In the first place the therapist must be able to give the patient adequate information about the treatment options. This should entail not only talking about the results that can be expected from a treatment but also about the nature of the treatment (with medication, with surgery, with psychotherapy, or with a combination of these), the best and most desirable form of treatment (individual, with partner, or in a group),

and about the time and intensity of the treatment. Then the patient will know what to expect and on that basis will be able to decide to undergo the proposed treatment. Then, during the treatment, the therapist must be able to convey his or her insights and interventions to the patient in such a way that the patient can understand them cognitively, deal with them emotionally, and incorporate them into their behavioral repertoire. Educational expertise also includes the ability and willingness to check whether the ideas and tips have come across to the patient. This evaluating approach is crucial if the therapist is to identify any blocks that may occur during the treatment. Many therapists give "homework," in which case evaluation is actually part of the treatment, since in the next session the therapist will check whether and how the patient has done the homework and any misunderstandings and emotional resistance or problems in carrying out the tasks are discussed.

In relational terms the therapist's position as an expert with educational skills means that for the patient the therapist can play the role of a "master." Not only is the therapist an expert in their field and in relation to the process, he or she is also able to translate this expertise into comprehensible, acceptable, and applicable insights and tips. In terms of the relationship, a certain dilemma is involved. If the treatment is to have results, the patient must gain and maintain confidence in both the approach and in the therapist personally. This requires a bond, which also makes the patient dependent. On the other hand, the patient must also be able to use the acquired insights and skills outside the therapeutic relationship. Patients must learn to stand on their own feet again and be able to apply what they have learned in their own lives, without the presence and support of the therapist. Dependence is needed to achieve independence. In the first stage of therapy, the therapist focuses on strengthening the bond with the patient to give a helping hand and to induce the patient to accept and use the therapist's insights and interventions as much as possible. In the course of the therapy, the therapist should start working toward weakening this bond, in order to strengthen the patient's autonomy. The transition from the therapeutic situation to everyday life is facilitated by various motivational and autonomy-enhancing techniques described in the literature [3, 9–12, 14]. We will not discuss these techniques any further.

Key Points

- If the patient perceives empathy or involvement, this has a positive effect on the outcome of the therapy.
- If therapists respect their patients' autonomy and integrity and are themselves honest and conscientious, this encourages the patient to be open and provides a basis for the patient's confidence in the therapist.
- In addition to evidence-based expertise in the field, the POG therapist is also expected to have the educational expertise required to convey his or her insights to the patient in a comprehensible and acceptable way. The

therapist should help the patient to deal with these insights—including emotionally—and use them to solve his or her health problems.
- The therapist should evaluate how effective his or her educational work is and if necessary modify the therapy on the basis of this evaluation.
- In the first instance the therapist has an educational role as a teacher or coach, with the patient being dependent on the therapist's expertise. In the course of the therapy, the roles change as the patient's autonomy increases, so that ultimately the patient is able to tackle his or her problems without the support of the therapist.

28.5 Maintaining Boundaries

Case History: Continued

An Exceptional Rapport

Just 2 days after they had parted so cordially, there is a turning point. Late in the evening Professor Schwartz receives a panic-stricken text message. "Don't know what to do! Tried to talk to V about his lack of respect and messing around with that woman. It got completely out of hand! Need to see you, quickly!!!"

To his relief he has nothing on his calendar for the next evening. When he opens the door for her, what he sees cuts him to the quick. In spite of her still beautiful and charming appearance, not much of her lively personality is left. Even before she has taken a seat, she bursts into tears. For a moment Schwartz is at a loss, because during his training it had always been stressed that he should be extremely cautious with regard to physical contact. But it feels very inappropriate to just stand there without doing anything. After some hesitation, he puts his arm around her encouragingly, while trying otherwise to have as little bodily contact as possible with her.

When Mrs. V stops sobbing after a while and sits down on the sofa, he almost automatically sits down beside her instead of opposite her. The message is clear: I'm at your side! Because they are both bending forward, their heads are close together. Soon she is no longer talking about the recent argument but about the impossibility of living with that man, and gradually the conversation turns to a possible divorce.

When Schwartz asks her what he can do to help her in this respect, she looks at him gratefully. "Whatever would I do without you?"

When she has calmed down and leaves again after a few hours, the two parting kisses she gives him feel completely normal. Schwartz does not even record them in his case notes, which he otherwise updates so meticulously, particularly about matters such as transference and countertransference.

However important empathy, respect, and trust may be, they should never determine the relationship to such an extent that they impede a critical view of the patient's utterances and actions or the therapeutic process. Maintaining distance in therapeutic contact is necessary for therapists to keep a grip on their own emotions. Any disruptions in the contact should be identified in good time and handled appropriately. An important "disruptive" factor in psychotherapy is the phenomenon known as "transference." This term means that on the basis of experiences with significant others in the past, such as parents, patients experience similar expectations, attitudes, and feelings toward their therapist, without checking whether these experiences correspond with reality [18, 19]. These transference feelings may be positive toward the therapist, such as falling in love or wanting intimacy, but they may also be negative, such as mistrust, anger, or even aversion. The therapist's emotional reaction to the patient's transference feelings in particular can obstruct the therapeutic process. This reaction is known as "countertransference." The therapist becomes so involved with a patient that the patient's views and feelings arouse feelings in the therapist that disrupt the intended therapeutic process and result. Due to this excessive emotional involvement, the therapist loses sight of the functionality of the therapy. We will explain this with the help of the "involvement spiral" (Fig. 28.1) [20, 21].

The boxed part of Fig. 28.1 is the part that is relevant when it comes to professional counseling. People go to a therapist to solve a problem they cannot solve on their own. If there is only involvement and good communication but no problem-solving or collaboration, the working relationship is inadequate. However, if the patient arouses such strong positive or negative emotions in the therapist that the relationship does not remain limited to problem-solving, then there is excessive emotional involvement. An unmanageable intimacy comes into being, sometimes also erotically charged. For instance, a therapist asks (out of curiosity) about sexual details, even though this is not going to lead to a better understanding or more effective approach to the problems. In doing this, the therapist is violating the patient's privacy. Another example is the overinvolvement that may arise when the therapist is working with a couple, as is regularly the case in sex therapy. The therapist then ends up in a "love triangle" with the two patients and starts to act as a lightning rod for the tensions in the relationship between the two patients [4].

Talking about intimate matters sometimes creates a form of intimacy that in everyday life goes with erotic contact. In therapy, sexuality and intimacy as topics of conversation can easily lead to crossing boundaries, showing behavior that deviates

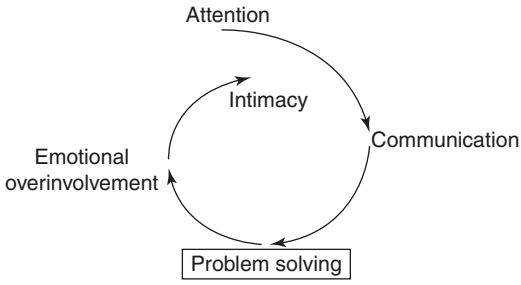


Fig. 28.1 The involvement spiral (based on data in References [20, 21])

from what is regarded as normal, proper, or predictable. In spite of the clear position of all professional associations and of statutory provisions that sexual contact between the therapist and patient is *always* absolutely prohibited, it still occurs frequently, and many examples have been described, particularly in the reports of disciplinary proceedings, of therapists drastically overstepping boundaries. It is not a new phenomenon either. However, interest in it has increased in recent decades. A review by Wilbers et al. showed that 5-10 % of male doctors had had sexual contact with a patient once or more often [20]. Leusink arrived at a figure of 4 % among Dutch GPs [22]. Pope found a similar percentage for male psychologists and social workers in the United States [23]. Sexual contact between female therapists and their patients is considerably less frequent, with figures ranging from 0.5-1.5 %. Various studies have also shown that actual sexual contact with patients is only the tip of the iceberg. Feeling sexually attracted to and having sexual fantasies about patients are very much more common. Almost 80 % of male therapists sometimes feel sexually attracted to a patient, and over half of them also have sexual fantasies [20, 22, 23]. For these parameters the percentages for female therapists are again significantly lower. Approximately a third of them sometimes feel sexually attracted to a patient. On the basis of research, official reports, and case histories, Pope [23] described a few scenarios that increase the chance of violating sexual boundaries, such as:

- The therapist becomes a "patient" and the focus in the therapeutic relationship shifts to the therapist's emotional and sometimes sexual needs.
- The therapist takes on the role of protector: He or she arranges everything for the patient, playing the role of the great "carer," but at the same time starts to tell the patient how to feel and act. As a result, the therapeutic relationship provides a false security, which blocks the patient's therapeutic growth.

Key Points

- Therapists should safeguard their own boundaries by remaining critical and maintaining sufficient emotional distance from the patient's experience and person. Overinvolvement and overstepping professional boundaries can pose a serious threat to the therapeutic relationship.
- The guidelines and statutory provisions relating to these matters are very clear: A therapist may not have a private relationship and may certainly not embark on a sexual relationship with a patient.

28.6 The Therapeutic Process

The pillars of the bridge to the patient's own competence and problem-solving capacity are safety, challenge, and empowerment—safety as a prerequisite to being able to achieve change, challenge as a vehicle of this change, and empowerment as a lever for change. Roughly speaking there are three kinds of interventions available to

provide patients with safety, challenge, and empowerment: support, structuring, and confrontation. Support creates safety and is also a strong source of empowerment. Confrontation leads the patient to accept the challenge. Structuring not only provides a solid footing and control and therefore safety but also a frame of reference for implementing and empowering changes in thinking, feeling, and acting [24–26].

28.6.1 The Therapeutic Relationship as a Safe Haven and Playing Field

Cormier and Hackney distinguish four basic functions of the therapeutic relationship [27]. In the first place, the therapeutic relationship provides a safe situation in which patients can express themselves and be vulnerable. In the second place, the therapeutic relationship is a medium for arousing strong feelings in the patient and helping the patient to deal with these feelings and gain control of them. Arousing strong feelings and ensuring they are expressed are often necessary to initiate a process of change, but the patient must feel protected, understood, and respected in this situation if he or she is to be able to accept this challenge. This also applies strongly, for example, to the loss of sexual functions after gynecological cancer treatment or to memories of sexual abuse. In the third place, the therapeutic relationship can have a significant empowering and motivating function for the patient. The feeling of no longer having to face the problems alone can often mean a breakthrough. In the fourth place, the therapeutic relationship can function as a model. The patient can see how pleasant and helpful an interpersonal relationship can be if it is possible to work constructively on solving problems within such a relationship. The therapeutic relationship also provides a "playing field" where the patient can practice certain skills before applying them in real life. With respect to communication in particular, the therapist can serve as a role model and the therapeutic relationship as a practice situation which can be very valuable. However, a prerequisite is that everyone involved is fully aware that this is, in fact, a practice situation that is completely separate from the rest of ordinary life. If this is not the case, then it is only a short step from providing safety and sharing intense emotions to boundary-crossing behavior.

Case History: Continued

An Exceptional Night

One stormy evening Professor Schwartz has just gone to bed when the telephone rings. Somewhat disorientated, he hears her now familiar voice. Obviously that evening emotions had been running high at the Vs' place, since Mrs. V—now known as Linda to Professor Schwartz—tells him, sobbing, that she is in the car and is not sure where she is. After another heated argument she had run out of the house, furious, and gotten into her car. She had driven around aimlessly for a while and is now parked in a car park, at her wits' end.

"I'm not going back, I'd rather jump in front of a train," she says desperately.

Schwartz tries to calm her down and after a few more expressions of anger, she seems to calm down. "I think I'm not far away from your place now. Would you mind very much if I came to see you, because I don't know what else to do. I just ran away. I haven't got anything with me and I can't really turn up at a girlfriend's place like this."

Before thinking about all the implications, Schwartz agrees. "Of course you're welcome here. I was still awake anyway." Fortunately he does have a moment of reflection. "Linda, you can stay in the guest room, but please let your husband know you're with me."

When Linda turns up at his door a short time later, she doesn't look very happy, but she has calmed down again. Schwartz has quickly put some clothes on and invites her into his consulting room. Over a cup of tea they talk about what happened at the Vs' place. Schwartz doesn't want to talk for long, because by now he is very tired and tomorrow his patients at the outpatient clinic will be waiting for him. He does ask Linda if she has let her husband know where she is. Linda is a bit vague about this. Yes, she had intended to, but she does not want to talk to him on the phone now. She will send him a text message.

Schwartz shows her where the guest room and the bathroom are and then goes to his own bedroom for a few hours of sleep. It is now 2.30 a.m. and at 6.30 the alarm will go off.

In sex therapy there are significant advantages to working with couples rather than with individuals. In the first place the therapist can gain a better understanding of both the nature and the consequences of the complaints or problems. This is important, because problems can be not only both cause and consequence but also a solution. Sometimes patients, but sometimes also both partners, perpetuate problems. In the second place, it is easier to make the transfer from the therapy situation to the everyday private situation. For the couple, the therapist is mainly a catalyst for having positive experiences of communication and coping with problems so that they can build on these experiences in their daily lives. Moreover, it prevents the boundaries of professional involvement from being crossed and undesirable intimacy from entering into the therapeutic process, with all the damaging effects that can have [23]. The therapy situation itself is not always suitable for exercises or assignments. For instance, sexual assignments should be done in the patient's private life.

28.6.2 Therapeutic Power

There are many possible reasons why a therapist's interventions do not sink in with the patient or why the patient fails to follow them up. All such disruptions in a patient's attention, capacity to comprehend, and ability to change emotions and behavior are covered by the term "noncompliance." Noncompliance certainly does

not necessarily mean active rejection of the therapist's insights and interventions. Following Lange, we can distinguish between processes such as habituation, other concerns, lack of attention, or forgetting that result in failure to follow therapeutic suggestions and the more active opposition arising from intrapsychic or interactional motives that conflict with the stated therapeutic goals or methods [28]. This active form of therapy noncompliance is referred to as "resistance." It may involve unconscious processes, but it may also entail an open refusal to follow certain instructions or to continue therapy.

Case History: Continued

An Exceptional Morning

The next morning Schwartz feels fairly exhausted and also ambivalent about Linda staying the night. There is still no sound from the guest room, and while drinking his first cup of coffee, he thinks about what has happened. It dawns on him that he is very captivated by Linda and that he has not felt such a strong connection and need for intimacy with a woman since the death of his wife. On the other hand, he is also very much aware of the delicate situation that has now arisen. Not only for himself but certainly also for Linda, the therapist–patient relationship is shifting toward friendship and even toward a relationship with erotic overtones.

Schwartz resolves to put forward Linda's treatment as a case in his peer supervision group, no matter how painful that will probably be for his ego. Just then the telephone rings. "Hello, this is Schwartz."

"Professor Schwartz, this is V, is it true my wife is with you?" Mr. V's voice is still fairly neutral, but after Schwartz answers in the affirmative, he starts to sound undeniably angry. That he had had to hear from the security officer responsible for his and his family's safety that his wife had stayed the night with Schwartz. And whether it was customary for Schwartz to let his female patients sleep at his home and if so what the health inspector thought about that. And that Schwartz was to stop this so-called treatment of his wife immediately, because otherwise he could expect a complaint to be lodged with the medical disciplinary tribunal.

The connection is broken before Schwartz can respond. Although considerably confused, Schwartz realizes perfectly well that the V case could have far-reaching consequences for his professional life and especially for his reputation as a sexologist if he fails to take action at once.

Schwartz knocks a few times on the door of the guest room and hears Linda call, "Come in." He opens the door and sees a sleepy face with tousled hair in the bed that immediately melts his heart.

"Keep your distance," Schwartz thinks to himself, and he remains at the door. "Linda, will you please get up? Your husband just rang, and, to put it very mildly, he was 'not amused.'" So I would like to talk to you about what should happen now."

Linda looks surprised and says timidly, "OK, I'll be right with you, I'll just have a shower."

Schwartz then rings the clinic to say he will be coming later and that a colleague or a trainee will have to take over from him at the outpatient clinic that morning. He sets the breakfast table, has another cup of coffee, and thinks about his strategy. The triangle that has arisen between him, Linda, and Mr. V has to be broken. In the first place this will require a lot of diplomacy toward Mr. V. An apology is certainly in order, but it is not very likely that Mr. V will still be prepared to accept Schwartz's position as a therapist and thus his own position as a co-client along with his wife. In addition, his relationship with Linda will have to change. Ultimately she will have to accept that he can no longer be her therapist now that he has become her friend and confidant. She will therefore have to look elsewhere for professional help in solving her marital problems.

Of course, for the therapeutic relationship it makes a difference whether noncompliance is the result of passive processes or active resistance. In the first case, the therapeutic power of the therapist and thus also of the therapeutic relationship is evidently insufficient to neutralize the effect of the passive processes. By "therapeutic power" Lange means "the non-specific factor which ensures that the many passive processes which may cancel out therapeutic effectiveness are overcome" [29]. Therapeutic power can be strengthened in various ways, for instance, by formulating specific realistic treatment goals, by defining the duration and intensity of the therapy, and by reaching clear agreements about the effort required from the patient.

28.6.3 Resistance

Resistance on the part of an individual patient or a couple is a common phenomenon in therapy and it is sometimes difficult to deal with. Resistance can be expressed openly, but often it exists beneath the surface of the therapeutic process. When a therapist works with couples, it is an illusion to think both are equally motivated for the therapy. A certain degree of resistance is normal and is nothing to be worried about. Resistance also has a positive side: It shows that the patient has a critical attitude to the therapist's approach and will not simply accept all interventions. However, it is really difficult if a therapist continually meets opposition in response to his or her questions and interventions. In a situation like this there is usually no point in persisting with ardent efforts to help the patient with his or her complaint or problem. It is more helpful to put the actual problem on hold and to make the resistance an interim goal of the therapy and thus also the topic of conversation. Just as with the actual problem, the therapist should work systematically and transparently in tackling resistance. In the first stage, focused on understanding the problem, the therapist should investigate the source of the resistance and the factors maintaining it. It is important

to check at which level the resistance is taking place. Is there a conflict relating to the actual problem because the patient does not agree with the definition of the problem and the insights into it presented by the therapist? Is the resistance directed at the way the therapist is approaching the problem? Does the patient feel uncomfortable with certain exercises or assignments? Is the resistance at the level of the patient-therapist relationship and is the opposition directed at the way the therapist behaves toward the patient? Or has resistance arisen because the loyalty within the patient relationship has come under pressure through the interventions?

The literature offers a wide spectrum of techniques for dealing with resistance that is directed toward the actual problem or the therapeutic process [15, 30]. We will not discuss these techniques here but will focus on what can be done if the resistance is directed at the therapeutic relationship itself. The first step in restoring the therapeutic relationship is for the therapist to examine what has gone wrong. Which of the three pillars—safety, challenge, and empowerment—is too weak to give the patient enough confidence to collaborate with the therapist? To solve this problem, the therapist needs the patient's collaboration. The therapist has to ask the patient a difficult question, which contains a paradoxical element, "Will you work with me to find a way to work together again?"

The paradoxical nature of the question necessitates a cautious, staged approach. The therapist's first step is to examine the basis of the therapeutic relationship. What were the patient's (or in the case of a couple, the two patients') motives and expectations when starting therapy and what are they now? What has led to the patient having insufficient confidence in the relationship? Is it mainly the feeling of powerlessness that is putting pressure on the collaboration, or are other transference feelings also playing a role? Critical self-examination is certainly appropriate in this context [29]. The therapist may also have expectations or even feelings of resistance that make the therapeutic relationship less solid than it should be. After diagnosing the relational problem, the therapist and patient will have to arrive at a basic agreement, "Are we going to carry on with therapy or do we have so little confidence in each other that there is no point in continuing?" It is only when an explicit decision has been made to continue together that there is any point in redefining the relationship in such a way that it will no longer lead to resistance or at least that it will lead to much less resistance than previously [5].

Case History: Continued

An Exceptional Parting

When Linda sits down at the breakfast table a short time later, Schwartz starts at once, on the principle that bad news should be told immediately and clearly. "Linda, I am in a very tricky situation and I urgently need your help to get out of it. Will you help me?"

He sees her hesitating, but eventually she nods her consent.

"Well, a few problems have arisen because as a therapist I have not maintained my boundaries properly. In the first place, your husband is pretty angry

because you spent the night here without his knowledge. I did ask you to tell him, but evidently I was not insistent enough. And now he is threatening to sue me."

Schwartz pauses for a moment to give Linda a chance to react, which she does. "What a bastard, it's always the same with him. If he doesn't get what he wants, he gets really mean and tries to break you down."

Schwartz allows Linda to let off steam but then takes control of the conversation again. "I understand that you don't expect anything good from your husband any more, we've talked about that before. You say you want to divorce him, but that doesn't solve the problem that has arisen now. There is no doubt that his threat is partly due to the fact that the relationship between us has become more than a normal therapeutic relationship and I think your husband is well aware of the fact that we are on very friendly terms with each other. I can imagine he thinks we are conspiring against him and for a number of reasons that is not good. The 2 of you came to me as a married couple because of problems with having sex. Your husband withdrew from therapy almost immediately and I went on with you alone. In retrospect that was probably not wise, but it happened. In the course of our conversations we drew closer to one another and I became your confidant and friend rather than your therapist. I let that happen, because, to be frank, it made me feel really good. I think you are a very charming woman and I feel attracted to you. But that should not have happened either. Now you've stayed here the night and your husband has made that angry telephone call. I certainly can't help you with your marital problems any more. You will have to turn elsewhere for help. Do you understand?"

Linda stares at him, amazed. "Do you mean I'm not allowed to visit you anymore? That from now on I'll just have to resolve the conflicts with my husband on my own? That you're leaving me in the lurch? Just because my husband threatened you? What a coward!"

Schwartz sees her eyes fill with tears and he would like to put his arm around her to console her. But the only thing he can say is, "Yes, as a therapist I'm leaving you in the lurch and that is certainly not just because your husband threatened me. Our relationship has become too friendly and as a friend and confidant I would like to continue to support you, but for the time being that's impossible. First I need to straighten things out with your husband and you need to make arrangements for your divorce."

He can see that Linda is struggling to keep back her tears and he too has a lump in his throat. They look into each other's eyes and then Linda stands up and picks up her things. Schwartz sees her to the door and she gives him a parting kiss on the cheek.

"I'll be in touch," she says as she goes out the door.

Key Points

- The transition from education to therapy is made by shifting attention from the health problem to the patient's feeling of powerlessness in relation to the problem.
- Combating this powerlessness and working on the patient's capacity to solve problems rest on three pillars: safety, challenge, and empowerment.
- Roughly speaking, therapists have three kinds of intervention at their disposal: giving support, providing structure, and confronting the patient.
- The therapeutic relationship should be a safe haven where patients can express themselves and deal with experiences and the feelings they cause, self-images, and expectations, but it should also be a playing field where the patient can experiment with new skills and gain new, positive experiences.
- Sexual or intimacy exercises do not belong in the therapeutic relationship.
- In spite of a good relationship, sometimes the desired therapeutic effect is not achieved because there is insufficient therapeutic power in the relationship or because of the patient's resistance to change.
- Tackling resistance requires a cautious approach. A certain degree of resistance is useful, for instance, in connection with the patient taking a critical look at the therapist and his or her approach. However, resistance becomes a problem when it systematically blocks progress in the therapeutic process.
- The therapist should determine at which level the resistance is taking place. The resistance is an obstacle to further progress, and before any more work can be done on the patient's original problem, it must be dealt with by making it a topic of discussion.

Conclusion

One of the most valuable aspects of working with the biopsychosocial model is that the therapist also gets to know the patient as a human being. This human interest creates a pleasant, noninstrumental working atmosphere. If all goes well it also provides professionals with opportunities to get to know themselves better and to grow as human beings. It is not for nothing that many professionals say they learn a lot from their patients. We hope we have made it clear in this chapter that this form of role inversion—the patient helps the treating practitioner—and the synergy that goes with it also involves risks. This is certainly the case when sexual feelings arise, but it is actually true of every form of countertransference. The tips that follow to prevent or limit boundary-crossing behavior can be applied in numerous similar situations.

Tips to Limit the Risk of Crossing Boundaries

- Be aware of your own inner experience. In the work context, does the professional see a woman or man primarily as a colleague, as a student, as a patient—in which case crossing boundaries is absolutely prohibited—or primarily as a potential sexual partner?
- Be aware of the sexual feelings, suggestions, and behaviors of patients. It is not unusual for patients to have sexual feelings for their therapist. It is important to recognize these feelings and then to deal with them adequately.
- Recognize patterns. When certain types of patients regularly fall in love with a doctor or therapist, the doctor or therapist should examine to what extent his or her behavior contributes to arousing and/or perpetuating sexual feelings.
- Be aware of the risk factors that can lead to crossing boundaries and to the rationalization of such behavior. Examples are nonfunctional self-disclosure, particularly about the therapist's own sexual life, accepting gifts (whether or not inappropriate), sharing one's own sexual or relationship problems, and private contact with the patient outside the therapy setting.
- Therapists should continuously take care of their own personal, sexual, and intimate lives and relationships and ensure that they are sufficient. Nurturing these should help guard against the risk of crossing boundaries, and developing them should mean that their quality is high enough to safeguard against temptations in professional life.
- Be aware of the law and the ethical standards of your own profession and act in accordance.
- Participate in a peer supervision group in which it is natural if you feel sexually attracted to a patient—or confused by this attraction—to talk about it.

Acknowledgment This chapter is an adaptation of Wouda JC, Van de Wiel HBM, Gijs L. The sexological care relationship (De seksuologische hulpverleningsrelatie). In: Gijs L, Gianoten W, Vanwesenbeeck I, Weijenborg Ph (editors). Seksuologie (2nd edition). Houten, The Netherlands: Bohn Stafleu Van Loghum 2009; Chapter 13:311–31.

References

1. Rümke HC. Psychiatry, volume 1 (Psychiatrie, Deel 1). Amsterdam: Scheltema & Holkema; 1954.
2. Beutler LE, et al. Therapist variables. In: Lambert MJ, editor. Bergin and Garfield's handbook of psychotherapy and behavior change. 5th ed. New York: Wiley; 2003. p. 227–306.
3. Frank JD, Frank JB. Persuasion and healing. A comparative study of psychotherapy. Baltimore/London: The John Hopkins University Press; 1991.
4. Schnarch DM. Constructing the sexual crucible. An integration of sexual and marital therapy. New York/London: Norton & Company, Inc; 1991.
5. Trijsburg RW, Knaevelsrud C, Vervaeke GAC. The therapeutic relationship and the working alliance (De therapeutische relatie en de werkalliantie). In: Trijsburg W, Colijn S, Collumbien E, Lietaer G, editors. Handboek integratieve psychotherapie. Leusden: De Tijdstroom; 1998a: Vol I, Chap. 2.3.

6. IJff M. Sex counseling in psychosocial care (Sekscounseling in de psychosociale hulpverlening). Assen: Van Gorcum; 2002.
7. Kleinplatz PJ, editor. New directions in sex therapy: innovations and alternatives. Philadelphia: Brunner-Routledge; 2001.
8. Perez DM, DeBord KA, Bieschke KJ. Handbook of counseling and psychotherapy with lesbian, gay and bisexual clients. Washington, DC: American Psychological Association; 2000.
9. Lambert MJ, Ogles BM. The efficacy and effectiveness of psychotherapy. In: Bergin AE, Garfield SL, editors. Handbook of psychotherapy and behavior change. 5th ed. New York: Wiley; 2003. p. 139–93.
10. Nathan PE, Gorman JM, editors. A guide to treatments that work. 3rd ed. Oxford: Oxford University Press; 2007.
11. Orlinsky DE, Ronnestad MH, Willutzki U. Fifty years of psychotherapy process- and outcome research: continuity and change. In: Bergin AE, Garfield SL, editors. Handbook of psychotherapy and behavior change. 5th ed. New York: Wiley; 2003. p. 307–89.
12. Trijsburg W. Taxonomy of therapeutic factors and interventions (Taxonomie van therapeutische factoren en interventies). In: Trijsburg W, Colijn S, Collumbien E, Lietaer G (red). Handboek integratieve psychotherapie. Leusden: De Tijdstroom;1998b: Vol I, Chap. 4.1.
13. Norcross JC, Beutler LE, Levant RF, editors. Evidence-based practices in mental health: Debate and dialogue on the fundamental questions. Washington, DC: American Psychological Association; 2006: xv, 435.
14. Castonguay LG, Beutler LE, editors. Principles of therapeutic change that work. Oxford: Oxford University Press; 2006.
15. Norcross JC. Psychotherapy relationships that work: therapist contributions and responsiveness to patients. Oxford: Oxford University Press; 2002.
16. Leijsen M. The therapist (De therapeut). In: Trijsburg W, Colijn S, Collumbien E, Lietaer G, editors. Handboek integratieve psychotherapie. Leusden: De Tijdstroom; 1998: Vol 1, Chap. 2.1.
17. Hill CE, Knox S. Self-disclosure. In: Norcross JC, editor. Psychotherapy relationships that work: therapist contributions and responsiveness to patients. Oxford: Oxford University Press; 2002. p. 255–65.
18. Andersen SM, Chen S. The relational self: an interpersonal cognitive theory. Psychol Rev. 2002;109:619–45.
19. Verhaeghe P. About normalcy and other deviations (Over normaliteit en andere afwijkingen). Leuven: Acco; 2002.
20. Wilbers D, Weijmar Schultz WCM, van de Wiel HBM. Sexual contacts in the patient-physician relationship (Seksuele contacten in de arts-patient relatie). In: Lens P, Kahn P, editors. Over de schreef. Utrecht: Van der Wees; 2001. p. 99–118.
21. Wynne LC. The epigenesis of relational systems: a model for understanding family development. Fam Process. 1984;23:297–318.
22. Leusink PM, Mokkink HGA. Sexual contact between general practitioners and patients: prevalence and risk factors (Seksueel contact tussen huisartsen en patiënten: prevalentie en risicofactoren). Ned Tijdschr Geneeskunde. 2004;148:778–82.
23. Pope KS. Therapists' sexual feelings and behaviors: research, trends and quandaries. In: Szuchman LT, Muscarella F, editors. Psychological perspective on human sexuality. New York: Wiley; 1999. p. 603–58.
24. Bouwkamp R. Interpersonal interventions (Interpersoonlijke interventies). In: Trijsburg W, Colijn S, Collumbien E, Lietaer G, editors. Handboek integratieve psychotherapie. Leusden: De Tijdstroom 1998:Vol I, Chap. 4.5.
25. Depestele F, Hermans D. Exposure in psychotherapy (Blootstelling in psychotherapie). In: Trijsburg W, Colijn S, Collumbien E, Lietaer G, editors. Handboek integratieve psychotherapie. Leusden: De Tijdstroom; 1998: Vol I, Chap. 3.1.
26. Nicolai N. Supporting and structuring in psychotherapy (Steunen en structureren in psychotherapie). In: Trijsburg W, Colijn S, Collumbien E, Lietaer G, editors. Handboek integratieve psychotherapie. Leusden: De Tijdstroom; 1998: Vol I, Chap. 4.3.

27. Cormier LS, Hackney H. The professional counselor. Boston: Allyn and Bacon; 1993: Chap. 3.
28. Lange A. Strategies in directive therapy (Strategieën in directieve therapie). Deventer: Van Loghum Slaterus; 1987.
29. Lange A. Behavioral change in families (Gedragsverandering in gezinnen). Groningen: Wolters-Noordhoff; 1994.
30. Hawton K. Sex therapy: a practical guide. 2nd ed. Oxford: Oxford Medical Publcations; 1990.

Leader: A Proof of Leadership, Dealing with and Learning from Work-Related Psychotrauma

29

Harry B.M. van de Wiel and K. Marieke Paarlberg

29.1 Introduction and Aims

Healthcare professionals in action are always in danger of causing harm to others and thereby often also to themselves. Although not intended as such, these critical incidents are theoretically speaking "golden" opportunities to demonstrate leadership and to grow in terms of professionalism. We say theoretically because transforming incidents and accidents into mental growth not only requires personal courage but also extensive counseling or therapeutic treatment. In this chapter this treatment is described to illustrate the cognitive and emotional turmoil that is characteristic for the adaptation process after traumatic experiences. Although less dramatic and intense, the adaptation process itself is representative for fundamental learning experiences of professionals: basic cognitive schemes—ideas about the world, life, and oneself—are replaced or modified by others. Examples of such invasive but also instructive experiences are medical complications, medical errors, or, as is most commonly the case, unforeseen combinations of events with severe results. Although this causes a lot of emotional pain, in the end more realistic schemes are internalized, reflecting a higher level of professionalism. The aim of this chapter is to give insight into this often confusing aspect of professional life by drawing parallels between the experiences of so-called first and second victims. In order to highlight these parallel lines, the case, in which a gynecologist is treated by a psychotherapist, is more than just an illustration. The case and especially the

H.B.M. van de Wiel (✉)
Wenckebach Institute, University of Groningen, University Medical Centre Groningen, Groningen, The Netherlands
e-mail: har.wiel@planet.nl

K.M. Paarlberg
Department of Obstetrics and Gynecology, Gelre Hospitals, Apeldoorn Location, Apeldoorn, The Netherlands
e-mail: km.paarlberg@xs4all.nl

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_29

explanation of the treatment process are prominent parts of the text, also serving to illustrate a number of key communicative strategies. All in all, these aspects give this chapter a slightly different structure than other chapters. In succession, the following topics will be discussed:

- Psychotrauma
- A guideline for treatment
- Needs assessment
- Rationale of the intervention
- The step-by-step plan
- Conclusions and final remarks

29.2 Psychotrauma

Alongside the patient as the primary victim in the context of medical complications, errors, etc., there are often also secondary victims: the caregivers. They are also referred to in international publications as *second victims*. It is characteristic of these second victims that they not only suffer a disruption of their normal coping process, but this disruption is also closely related to their position as a "medical professional." The likelihood of their suffering from complex grief and post-traumatic stress disorder (PTSD) is increased due to their special position and the role they played in the events. One of the characteristics of PTSD is that the disruption of normal psychological functioning one would normally expect is postponed from between a few weeks to a month. Instead, the individual either recovers remarkably quickly, appearing to be unaffected by the event and continuing immediately with their daily tasks, or else they drown themselves in feelings of inadequacy, call in sick, and slip further into depression. The characteristic pattern of healthy coping behavior—involving going back and forth between reliving and repressing the traumatic event, whereby the intensity of the relevant emotions slowly decreases (Fig. 29.1)—is absent.

The problems—and PTSD—are often recognized only after a considerable period of time has passed, meaning that the individual is often only referred to a specialist for cognitive therapeutic treatment much later and/or only after the case has been deliberated at length. The objectives of such interventions are:

- Reduction of the complaints associated with the trauma
- Reduced consumption of medical services and sick leave
- Prevention of errors and subsequent incidents

The intervention proposed here has the additional secondary goals of being:

- Transparent and effective
- Transferrable to other healthcare professionals and generalizable to other target groups and/or similar situations

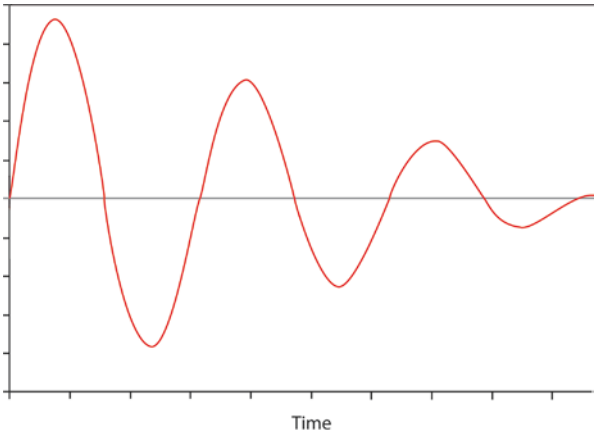


Fig. 29.1 The characteristic oscillating and decreasing pattern of psychological coping, with alternating reliving (intrusion) and repression (denial) of the event in time

29.3 A Guideline for Treatment

This chapter can be used as a guideline for carrying out this intervention. Before the description of the intervention itself, the terms that occur regularly in this chapter are defined below:

- The *target group* of the intervention consists of second victims—in this case healthcare professionals. These may be physicians as general practitioners (GP) or obstetricians (Ob), nurses, paramedics, and others who can be held individually liable in a legal and/or moral sense.
- The *nature of the complaint* concerns complex grief following a psychotraumatic event. Complex grief is diagnosed if the duration and/or intensity of the normal reactions, such as intrusion and denial and the associated thoughts and feelings, is disproportionate.
- The *cause* is normally a traumatic event at the workplace. In some cases this may be a series of minor incidents. These incidents may be characterized by major negative consequences to others caused by the professional's actions, for example, in the case of individual error. The complaints may also occur even if no error has been made, but severe injuries or death ensue during or despite the treatment provided by the professional. Another form of incident may involve the professionals themselves being a victim, for example, in the case of aggression directed at them or a colleague, a complaint submitted by a patient, or a disciplinary case against them.
- The *complaints or symptoms* of complex grief—the complaints associated with coping with the incident—can be diverse in nature and intensity, varying from clearly recognizable emotional problems to less visible problems such as vague somatic complaints, fatigue, lack of concentration, insomnia, and depression.

The intervention described here is theoretically underpinned by cognitive behavioral principles and emotional processing theories [1, 2]. The intervention itself,

however, is primarily described in terms of *communicative strategies* as widely applied in directive psychotherapy and previously described by us [3].

This intervention is *structured* as follows:

1. Needs assessment: complaints, reactions, and expertise
2. Rationale of the intervention
3. The step-by-step plan, with the following phases:
   A. Making acquaintance and providing structure
   B. Venting thoughts and feelings
   C. Explicating ambivalence
   D. Reformulating in positive terms
   E. Homework: written assignment
   F. Assignment with guaranteed success
   G. Challenging irrational thoughts
   H. Doubting success
   I. End of therapy with multiuse ticket
4. Contraindications and required expertise
5. Final remarks

29.3.1 Note

- We use a case study throughout to illustrate the intervention. This case study is primarily intended to illustrate a number of key communicative strategies.
- The subjects are healthcare professionals who have become "clients" themselves following incidents with their "patients."

Case History

Verda Green (VG) is an archetypal modern medical specialist: young, highly intelligent, and ambitious. She has just turned 33, she graduated from her medical program with distinction, and she has been working at the gynecology department of a university medical center for the past 6 months. As if that were not enough, she also became the mother of two children during her combined degree PhD program. In short, an illustrious career would appear to be guaranteed. Until that one birth goes wrong.

29.3.2 Needs Assessment

An interim analysis of a survey of gynecologists that is currently underway has not yet produced exact figures, but it has revealed that problems with coping with a work-related psychotraumatic incident are by no means rare [4]. The individuals involved are referred to as *second victims*. Insiders in the world of obstetrics, where the occurrence of second victims is relatively high, indicate that there is probably a

case of an iceberg phenomenon here. The main reason for this iceberg phenomenon, alongside a closed institutional culture and a mentality of looking forward rather than backward, is that the symptoms are hard to interpret. Trauma-related coping problems are sometimes difficult to recognize as such due to:

- *The nature of the complaints or symptoms*: Psychotraumatic incidents often result in preverbal symptoms. The client feels generally out of sorts and has vague physical symptoms but cannot explain their complaint precisely in words. Only after an extended period of time and/or professional help will the client fully understand what is wrong with them and that this is related to the incident.
- *The course of the symptoms*: The client needs to come to terms with the incident before they can process what happened. The problem with work-related incidents is that the work has to go on regardless of what happened. It is well known that incidents at work are often not processed until holidays, because only then is there enough time and rest to really take stock and confront the incident. The complaints are initially strong, which is logical as the incident is still fresh. The complaints often then diminish, giving rise to the hope that the client has successfully coped with the incident and will return to business as usual. Unfortunately, the worst is yet to come, but this is typically contrary to the expectations of the client and their family, friends, colleagues, and other people in their social support network. This makes it all the more difficult to link the complaints to the incident.
- *The response to the complaints*: All the parties involved (the client, their partner, colleagues, etc.) find it difficult to accept that the client has not been able to resume their normal work activities after all the efforts that have been made. This implies that if the client is still visibly suffering from complaints after a certain period, these are seen as complaints *against*—that is, a poor reflection on—their own resilience and their social network. Social support (perspective) soon degenerates into social resistance (trivialization), and then the safest course is often to deny the problems.

Case History: Continued

It is an excessively busy night and to top it all off, Verda is completely on her own as the duty supervisor. Her colleague on standby duty cannot be reached for some reason. It will be revealed later on that she had accidentally turned her phone off.

Verda makes a misjudgment during her shift. She fails to notice the signs of an impending uterine rupture. At the end of her shift, by now exhausted and irritated, she realizes that the uterus must have ruptured and performs an emergency cesarean.

Although the baby is still alive when she retrieves it, it appears to be severely asphyxiated and the prognosis looks bad. The boy suffers a whole range of complications and is admitted to a neonatal intensive care unit and

kept cool. However, the prognosis fails to improve. After he is warmed up, the physicians decide to refrain from further intervention, and the boy dies in his parents' arms 3 days after his birth.

The contact with the parents is initially good, given the circumstances. Verda freely admits she made an error and patiently answers all their questions. She also accounts for her actions during the handover meeting. She maintains daily contact with the parents. A team meeting is convened, during which she shows her vulnerability and answers all the questions from her colleagues and the nursing staff.

After one-and-a-half months, just when everybody is starting to think the worst is over, Verda starts regressing. She has been sleeping poorly for some time and notices that she finds it more and more difficult to concentrate. She has also become terribly afraid of making mistakes. She is irritable and even manages to antagonize her closest colleagues. After a few months, she is completely exhausted and has to stop work altogether and report to the occupational health physician, who diagnoses "fatigue."

29.3.3 Rationale of the Intervention

Although there are obviously many differences in the positions of first and second victims, the psychological coping process is identical. In order to understand the client's coping process, we will now briefly explain a normal and an abnormal grief or coping process following a traumatic event, based on the work of De Keijser [1]. This "coping with shock theory" also forms the basis of the treatment and as such is necessary to be able to understand the rationale of the intervention:

- According to the latest insights on abnormal grief, the key issue is that the client is faced with a dilemma that is so huge that cognitive integration of the incident is impossible. On the one hand, the client realizes they have experienced a traumatic event and that it is normal that this is accompanied by intensely painful emotions and extremely disturbing thoughts. Emotions and cognitions hereby form two sides of the same coin. On the other hand, the client cannot endure these painful emotions nor accept the disturbing thoughts. An event has taken place that is so inconceivable that a number of existential foundations are in danger of being swept away.
- Such existential crises can be seen as information processing problems, whereby the autobiographical memory is compromised, but they also involve a confrontation with existential questions and can damage the subject's world view. If an event does not agree with our world view, if something truly *inconceivable* happens, then the subject is faced with two options: either they must change their perception of the event or they must change their world view. The more shocking the event, the more far-reaching the necessary change and hence the greater the stress experienced.

- What becomes painfully clear here is that, after events like these, the basic assumption that "the world is good" is replaced by the assumption that "the world is extremely dangerous." The people involved in such an event suffer from extreme anxiety, feel hounded, and indicate that they have "lost touch with themselves."
- A third way of examining such a case involves emphasizing the victim's context. For the first victim, the patient, this is typically the partner or family. For the second victim, the client (the healthcare professional), this will be the workplace, the team, and their direct colleagues. The Melbourne Family Grief Studies [2] demonstrate that there are roughly three types of social context:
  - *Supportive and conflict solving*. There is open communication and a joint effort to find a solution or acceptance.
  - *The in-between group*. Communication is initially poorer and some victims will withdraw into isolation. However, after some time the victim will find a new balance, either on their own or with some support.
  - *Stiff and hostile families or work situations*. Communication is poor, the victim holds others at a distance, and hence there is a significant risk of complex grief developing.
- What many people only realize after they have had a traumatic experience is that we tend to foster a positive illusion under normal conditions, namely, that the world is meaningful, fair, and predictable. The confrontation with the incident makes it clear that those very important assumptions have only very limited validity.
- In psychological terms, there is a significant degree of ambivalence so that the emotions required for coping with the incident are suppressed and the coping process stagnates.
- The rationale of the intervention is to rebuild the positive illusions. But old assumptions, such as "everybody makes mistakes except for me," have to be buried first. In communicative terms, this concerns the reappraisal of the following contextual cognitive schemata in the following order:
- The subject believes that life (or in any case their own life) is meaningful, fair, and predictable.
- An event takes place that destroys these assumptions.
  - The subject now feels that life is utterly meaningless, unpredictable, and unfair.
  - Their initial response is "there must be something wrong with this feeling," but in fact they are absolutely right: Life is, in and of itself, amoral and has no inherent meaning. This is confusing, but the good news is that this demonstrates that there is nothing wrong with the subject's thoughts and feelings. In fact, the healthcare professional is actually having the "right" thoughts and feelings for the first time. This process is wonderfully expressed in the phrase "sadder but wiser."
  - This is a painful process, but actually highly beneficial for healthcare professionals, because with this new knowledge they will become more capable of helping others.
  - With the wisdom that this helping brings, life becomes meaningful, predictable, etc. again (despite or thanks to the foregoing events).

The main objective of the intervention is to facilitate the acceptance of the most fundamental and thus most painful emotions and cognitions. This is achieved by creating a framework that allows the ambivalence to be converted from two simultaneous contradictory contexts into two sequential contradictory contexts. A kind of "interim putting into perspective" of the initial starting points must take place so that an acceptable final conclusion can be reached. Schematically:

- *Simultaneous*
- "I do my best but still it all goes wrong." → "There is something wrong with me!"
- *Sequential*
  1. "I do my best."
     Interim perspective: "That's good, but it does not guarantee success."
  2. "It still goes wrong." → "It could happen to anybody!"

The latter statement allows both contexts to be true: "I do my best but it still goes wrong, but this does not imply that there is something wrong with me." A methodical approach is required to convert this ambivalence into "ambiguity," and its success depends for a large part on the working relationship between the therapist and the client. Extremely intense emotional support is required if the client is to successfully confront such painful emotions. Please note: this support, and particularly the intimacy that ensues from transference and countertransference, cannot normally be provided by nonprofessionals!

Case History: Continued

When Verda visits her GP and, following a short examination, hears that she appears to be in good health, it suddenly all becomes too much for her. She had expected to be relieved that at the very least nothing was seriously wrong, but after a few seconds she starts to cry. She even berates the GP, where normally she is always very polite to her colleagues.

"Well? What do you mean well? It's not going well at all!"

Thankfully, the GP understands that the anger is not directed at him and recognizes the impotence in Verda's voice. His response is short and to the point, "What's not going well?" After which he deliberately remains silent to give Verda the opportunity to consider her reply.

Smiling shyly, she gradually pulls herself back together. "I… I don't know. Of course I'm glad there are no somatic problems, but… I'm so tired… everything seems to be going wrong. I feel incapable of doing anything…"

29.3.4 The Step-By-Step Plan

We have chosen to describe the intervention as a number of phased steps toward a solution. This is the most effective approach for the communicative strategies and the underlying directive psychotherapy framework.

29.3.4.1 Making Acquaintances and Providing Structure

As well as making each other's acquaintance, the aim of the first meeting is to build a working relationship with the client. The best way to achieve this is to:

- Provide a structure (in the procedural sense) by briefly describing the aim of the first meeting. During this meeting, the client must be made aware, as much as possible, that they are the one in control.
- The painful episode, described in the client's own words, must be the principle theme of the talks. As painful as it is, this is the client's own story and the one they are the most comfortable with.
- The therapist's responses should mainly serve to summarize the client's words and provide supportive and sensitive reflection.

Case History: Continued

Verda Green (VG) is referred by her general practitioner to a psychotherapist (PSY). After introducing themselves the following conversation ensues:

PSY: Well, Ms Green, I have to admit I know very little about you. I know you are a gynecologist and that an incident occurred at your work that has had a considerable effect on you. Your GP explained that you are having difficulties and he thought it would be a good idea if you were to talk to me about them. Is that right?

VG: Yes, that's right. I have never seen a psychotherapist before so I'm not sure, but my general practitioner did indeed think I should talk with you… yes…

PSY: Okay, maybe it would be a good idea to start by looking at what happened during the incident and the period that followed. That will help us find out exactly where the problems lie. Of course I am unable to say in advance whether I will be able to help you. That will depend on what is actually wrong, which I do not know yet. But I can say one thing in advance: If, after this talk, I think I have nothing to offer you, then I will tell you this honestly. And likewise, I will tell you if I think you would be better off seeing somebody else. If I do think I can help you then I will tell you so, but you do not have to say yes or no immediately. If I think I can help you I will explain my reasons why, and then you must take the time to consider what this will mean for you and whether or not you want this. Do you agree?

VG: Yes… umm… okay.

PSY: Do you have any questions before we start?

VG: No, I'll see how it goes first…

PSY: Good… my first question is: can you tell me exactly what happened?

29.3.4.2 Venting Thoughts and Feelings

The patient's account of their experience of the incident will always involve various visible and less visible emotions. If these feelings (typically in the realm of helplessness and loneliness) are adequately reflected, the client will respond with more

open, sometimes even strong, emotions such as crying, anger, or maybe the determined avoidance of tears. Here are some milestones of the process:

- Allow some time for these emotions to vent and then ask what is so painful.
- The client is now no longer hindered by encouragement, trivialization, or other well-intentioned responses and can relate their story.
- As the client vents their feelings, they notice that they are not being "judged" and that they are allowed to be themselves, complete with any confusing, strong, or unpleasant emotions that crop up. For the first time, they are able to really let go. Many pent-up feelings will be released, and normally, after some initial pain, this will provide them with much relief.
- The therapist's response should be supportive and affirmative, but then only very subtly, for example, through small and gentle encouragements. This is because excessively strong or open support of either of the aspects of the ambivalence could easily diminish the other. If the therapist is capable of openly describing and respecting both of the client's emotional opposites, then this will foster a high degree of intimacy and closeness, the basis of a strong working relationship.

Case History: Continued

VG: It was extremely busy on the ward, and even though I was duty supervisor, I was rushed off my feet running from one problem to the next. I was trying to get through to my colleague who was on standby duty, but couldn't reach her. It turned out she had turned off her phone by mistake. Sometime around four in the morning, when I was dead tired and quite pissed off that I couldn't reach my colleague, it went wrong. I failed to detect a uterine rupture… even though the mother practically pointed it out to me herself. How could I be so stupid! So anyway, the couple was terribly upset of course. The baby was in a bad way… So stupid of me… So, of course, I got home exhausted and couldn't sleep. And I was still furious with my colleague; I was full of adrenaline… and then it turned out she had turned her phone off by accident. And she really is a very nice colleague; so what can you do? And so the first weeks were full-on of course; I talked with the parents regularly. The baby could not be saved and they were able to let him pass away peacefully in the end. So sad! I picked up again afterwards. Life goes on and I thought to myself: If I can make it to my holiday then I'll be okay; I can catch up on sleep then. But now here I am.

PSY: Okay, we'll get back to exactly what happened shortly. So I understand that in the weeks after the incident it was a question of gritting your teeth and getting on with it; looking ahead and making it through to your holiday? This worked, more or less, but then things took a turn for the worse. What happened?

DG: I started doing the shopping a few days before my holiday and then I slept terribly the night before we left… I was still tense… and then off to

France with two kids in tow. I didn't want to spoil everything for the others so… in the car I told stories, played CDs… but I was completely worn out… and that's pretty much how I stayed.

PSY: It was finally time to relax, you thought you could put the events behind you and get back to your normal self, but that didn't happen at all?

DG: Exactly, and it didn't get any better. I felt so worn out and empty and I was sleeping badly. That birth kept on going through my head… and those grieving parents… so I never really found any rest. But still, I couldn't let my husband and children down… We had all sorts of plans for the holiday… And usually I'm the one to drag the rest along, but now… Some days I couldn't recognize myself anymore; I got up and wanted to go straight back to bed.

PSY: Did you talk about this with your husband? Ask if he could do more? If he could take the kids on trips so that you could rest, for example?

DG: No, that wouldn't have made any difference, and he had been working really hard in the past months. He has his own business and because of the crisis it's really hard work. So yes, I was glad that he found the time to recuperate a bit and enjoy the holiday. But then it really went downhill. I had hoped to return from holiday well rested, but instead I was even more tired than before we left. I started doing less and less. I tried just doing daytime shifts for a while, but that didn't work either. So then I tried working fewer hours; first a day less, then I tried going home earlier every day… but I was always exhausted when I got home… in the end it was just work, sleep, work, sleep…

PSY: You mention that the change started on the first day of your holiday, that until then you have still been functioning fairly normally, despite everything that had happened. And then the holidays… instead of a fun trip with the family it turned into a lonely and helpless time away…

DG: [her eyes become moist, but no real tears yet] I was exhausted… I was ready to fall asleep and never wake up again, but you have to go on, don't you…

29.3.4.3 Explicating Ambivalence

If the venting process has been successful, a healthy relationship will have been built up with the client that will make it possible, in time, to start working toward a change. However, before this can happen, certain matters have to be dealt with in a Socratic manner, and the client needs to be confronted with certain idiosyncrasies. The latter is necessary in order to get to the core of the dilemma: ambivalence toward fundamental values. On the one hand, there are the "appropriate" feelings of sadness, anger, etc., and on the other hand, there is the conflicting tendency to be "strong," "hide your feelings from others," and "solve your own problems." It is important that the therapist recognizes this, but even more important is that they help the client to see it. The therapist can start by asking questions about the nature

and the extent of the problematic emotions and/or behavior to get a clear picture of the problem for himself or herself. The problems can then be made clear to the client by recounting their statements back to them in a "magnified" form.

Case History: Continued
PSY: You were dead tired but you went on holiday anyway. At the same time, you also had to play the ideal mother and wife.

VG: Everyone was so looking forward to the holiday; what choice did I have…?

PSY: You present it as a fact, but it is also a question. On the one hand you say: I was completely exhausted, while on the other you say: I had to make sure my children and husband had a good holiday. Did you wash all the cars at the campsite while you were at it?

This will often result in a—hopefully light-hearted—discharge of the tension that is inherent in this ambivalent stance.

Case History: Continued
VG: [now with tears in her eyes] Actually it was mad… I should have said that we would leave a day later or organized something with my husband when we arrived, but you know how it is… you don't want to be…

The therapist can then build on this with subtle references to the underlying conflict. For example:

Case History: Continued
PSY: On the one hand you were exhausted and wanted to go to bed, on the other you didn't want to be a complainer or weakling. You are the doctor, not the patient…

Or:

Case History: Continued
PSY: After that incident, you thought: If I can only make it through to the holiday then I'll be okay. In that sense it was not so much a holiday as a kind of farewell to an awful episode. But as the farewell party progressed, you realized that the story was still far from over, that you still had stuff to deal with in your head…

After having clarified the internal dialogue in the client's head, it is time to focus on the role of the client's colleagues, all the more because the incident was work related.

Case History: Continued

PSY: How did your colleagues react when you returned to work after the holiday?

VG: They didn't, really. Only: How were your holidays? It's great you're back because we're rushed off our feet… Back to the grindstone!

PSY: Has the colleague who was meant to be on standby been in touch?

VG: No, but what could she do?

PSY: As I understand it she was part of the problem… Shouldn't she be part of the solution?

VG: [quietly] No, I haven't heard from her…

Following recognition, reinterpretation, paraphrasing, and confirmation of the problem, it can often be summarized again using variants of "on the one hand… on the other hand… and these two feelings conflict with each other." Talk about fundamental issues and doubts and especially complex emotions such as:

- Furious at the other: "Why couldn't I reach you?"
- Angry with oneself: "How could I have been so stupid?"
- A paralyzing fear of making the same mistake again.
- Shame about the fact that "This happened to ME of all people, me who is always the first to consider patient safety! I'm afraid to go to the handover, let alone ever dare to open my mouth there again."
- And finally, an all-consuming feeling of guilt: "I actually killed a child by failing to pay proper attention and I've ruined the parents' lives. I cannot bear it."

It is important to describe the various types of emotions separately, even though the same psychological mechanism lies behind them all: it is inconceivable and yet it really happened. Normally the full range of fundamental emotions will present itself: sorrow, anger (at the other, at oneself), fear, disgust, guilt, shame, helplessness, and loneliness. The latter emotion will often be the first time that the subject is moved to share their story with others. It is terrible to suffer, but even worse to suffer alone and in silence!

29.3.4.4 Positive Labeling

After the most conflicting ambivalences have been identified, it is time to work on bringing about a change. It is important to realize that people do not hold on to their problem-solving methods for no reason; however unproductive these have been so far. They may have had to be big and strong for their whole life already, and this has always worked for them and even brought them much success.

Moreover, decisiveness is an important selection criterion for doctors, and this is then further cultivated during their career. If the therapist were to undermine this perception in this phase, it would simultaneously undermine the client as a person: "Apparently I've been an absolute fool my whole life!" In order to avoid this even greater conflict, it is important to point out the positive points of both sides of this ambivalence.

Case History: Continued

PSY: There have been advantages to putting on a brave face. You tried to do the best you could for the parents. You forced yourself to get through a terrible period. How else would you have been able to ensure that the holiday turned out well for your family? You're obviously a persevering type and you have a strong sense of responsibility. These are good characteristics for a doctor, and I would not recommend simply putting these qualities aside.

On the other hand, feelings of sadness, anger, guilt, shame, etc., are all part of the healing process. You find that you have by no means returned to your normal self and you even wonder if you ever will. You have realized that your husband only has limited scope to help you, as much as he commiserates with you. Nor do your colleagues seem able to offer you much warmth… In short, there are plenty of reasons to be angry, sad, and much more. In this sense, the fact that you are struggling now is actually a good sign. Your emotions are working fine and the healing process has started. You could compare it with a broken leg that is healing. After a while the wound starts to itch. And that's not pleasant. And then trying to stick a knitting needle through the plaster to get to it… but it is actually a sign that you are on the mend. You could even say that the worse it feels, the better it's going…

While on the one hand it's incredibly painful… and it's not like you to be angry and sad… but by always putting on a brave face you're burying the emotions and stopping the healing. Moreover, by taking it all on yourself you find yourself in an extremely lonely position, and you could say that you are keeping out those who could offer a little help… What you really need to do is to try to find a balance between the 2, because they're both important. On the one hand, being strong; well you've proven you can do that because you've been doing it your whole life. And on the other hand, learning to share with others, being able to lean back and let others shoulder a bit more of the load… that would be good…

VG: [laughing cautiously] Yes, that would be good…

29.3.4.5 Homework: Written Assignment

Because the client is so used to dealing with life differently from what the current situation demands of them, it will often take quite an effort to bring about the change described above. Often, different variations on the same theme are required to clearly describe the underlying theme. This will typically take place at the rational

level first: the client recognizes themselves in the therapist's narrative. The next step is the most difficult: the client recognizes that their way of solving the problem is only partially successful and that they "still have a lot to learn," i.e., complementary methods of solving problems, which will typically involve letting go rather than maintaining control. The more the client is able to accept this way of reasoning, the easier it will be to move on to the next stage: drawing up a work plan to help the client learn the coping skills they have failed to develop to date or in fact have tried to avoid. The strong types have to learn how to let go (including allowing themselves to cry), the quiet types have to learn to talk (and scream), the anxious types have to learn how to confront, etc.

Conversely, complete acceptance is only rarely achievable nor is it strictly necessary. As long as the client is sufficiently motivated to do something about it, their actions will generally be affirmed so quickly that this motivation will grow of itself. In the end, the best way to learn is through experience. This learning process has been initiated during the first few therapy sessions, and a useful way to ensure that it can also be practiced outside of the therapy is to give the client a written assignment.

Case History: Continued

PSY: What I would like to ask you to do is this: In the coming week, I would like you to spend 5 min every day—no more, no less—writing down how this incident has affected you. Not financially, but what positive things you have lost because of it… so in your case it could be energy, or maybe your carefree approach to life, or your spontaneity, etc. It is important to write every day, but you must not write for longer than 5 min. So set an egg timer and when the 5 min is up stop and go and do something else. Go out of the house, have a chat with someone, etc. It sounds simple but it's actually difficult. You will find that it takes quite an effort…

A writing assignment such as this, within the relatively safe context of the client's own notebook, allows them to vent their ambivalent and hence "dangerous" emotions and provides them with insight into which emotions keep coming back and are thus important, which underlying aspects play a role, etc. Although this certainly may differ from individual to individual, the client will normally build up from the external toward the internal context: from sorrow for others, anger at others, shame and guilt in the eyes of others, to anger at themselves. They think, "This could have happened to anyone… but not ME!"

In addition, and easily just as important, the instruction to write for only a clearly defined period (using an egg timer) helps the client to learn that they can turn emotions "on and off," i.e., they can control their emotions and so do not have to be afraid of being overwhelmed by them. If the client is not able to do the writing assignment, this is an indication that the memories of the incident are so painful that the client cannot confront them alone or that there may be contraindications for continuing this intervention.

29.3.4.6 Assignment with Guaranteed Success

If the client succeeds in doing the written assignments, the next step is to confront the emotions in real-life social situations. One of the best ways to reduce fears is to confront the situations in which they occur. In this case, the client could:

- Talk to their partner about their reactive behavior and tell them what they need.
- Likewise, talk to the colleague who should have been on standby and/or their supervisor.

However, there is a risk of failure here. If this risk is better avoided and then special measures will need to be taken, such as giving an *assignment with guaranteed success*. In Verda's case, the therapist could ask her to bring up the matter during the next staff meeting by calling attention to the current working conditions on the ward. After all, with the current working environment, where it's always "rush, rush, rush" and there is no time to step back and consider the situation, it was an accident waiting to happen. Putting the working environment on the agenda is a congruent and fitting course of action in the search for a solution to this problem. Carrying on in silence, as she has done to date, is actually paradoxical. Because it is likely that she will not dare to press her point during the meeting, and also in order to boost her self-confidence and self-esteem, a second, paradoxical assignment is required. For example, "If you find that you are unable to confront your supervisors after all, then that's fine. You surely have very good reasons for this, and this is actually a unique opportunity to gain a much better understanding of what's going on. I want you to write down exactly what you think and feel when you feel yourself blocking up." So combining a congruent and a paradoxical assignment can have the following results:

- The assignment is successful and the client is a step closer to a solution to the contextual problem (congruent success).
- The assignment is unsuccessful, but the failure provides insight into the nature of the emotional block. This insight can be used during therapy as a vehicle for personal growth (paradoxical success, "the worse the better").

The advantage of an "assignment with guaranteed success" is that the result is always a form of therapeutic progress so that the client can be complimented for their efforts and the results.

29.3.4.7 Challenging Irrational Thoughts

If the client succeeds in making progress on their own, then the therapist can continue with the work plan. If the client has an emotional block, then their report will provide insight into the nature of the block, which will often concern extreme forms of unrealistic expectations. Cognitive behavioral therapy in general and rational emotive therapy (RET) in particular may be excellent means of changing these expectations and, if this is successful, continuing with the intervention. RET involves asking Socratic questions and/or confrontations such as:

- "You were afraid to admit you were tired and ask your partner for help. You were afraid of disappointing your children. You were afraid your colleagues would think you are a weakling. This is interesting. If I were one of your colleagues, I would think that I could work out my own thought about anyone, including you."
- "You say that you mustn't complain about your problem. Who says you mustn't complain? Have your partner or your colleagues ever told you to stop complaining? If they haven't, then who has? If they have, well that's a friendly bunch of colleagues you have; when you're in trouble they tell you to stop complaining!"
- And at a more fundamental level: "Thousands of errors are made in hospitals every year. Why should you be the one person to never make an error?"

This is mainly useful for bringing fantasies of omnipotence to light: "I must be able to cope with anything," "I must never…," etc.

29.3.4.8 Doubting Success

If the client by now seems to have recovered, it is important not to be too enthusiastic. Not only will this immediately give rise to tension (after all, the initial ambivalences were not there for no reason at all), but it may also provoke a fear of failure and, if things go wrong later, a feeling of having completely failed. It is wiser to emphasize that it is good that the client is feeling better, but that life can sometimes be disappointing, a combination of events can lead to a change for the worse, etc., so hard times may yet follow. This provides support when times are tougher and also gives the client more feeling of control, because they were warned of the relapse beforehand: It's all part of the healing process, don't panic!

29.3.4.9 End of Therapy with Multiuse Ticket

If the treatment has been followed through to a successful completion, then the therapist and the client can part ways for good. This is difficult for many clients. Many of them have built up a highly supportive relationship for the first time in their lives, and this relationship must now end. There is a high likelihood of a relapse. A multiuse ticket is an ideal way to ease the end of the therapy while still leaving the client in control. At the end of the treatment, the client is given a ticket for three sessions to use whenever they feel the need. But there is no coming back after all the sessions have been used up!

29.3.5 Contraindications

Although this intervention works well in nearly all situations, thanks to its simultaneously congruent and paradoxical design, there are also limitations. The intervention focuses on coping behavior. This implies that the crisis itself, in this case an incident that results in a fatality, must now be over. Furthermore, we can only refer to abnormal grief if the normal coping process has failed. Therefore, contraindications are:

- An incident that took place less than 4 weeks ago, which means that normal coping must be given a chance. Much has to be done during this period: the work has to go on regardless of what happened. The client has to talk to the patients; the management has to be consulted, possibly the inspectorate too; the nurses and colleagues all require an explanation; etc. The second victim needs to take a proactive and open stance to this communication. Relating the events several times helps to complete the puzzle. This leads to understanding, and understanding helps the coping process. The emotions are tempered and it will usually become clear that there is more than one "truth" or one "story." The colleague who did not answer the phone has their own truth; there is the story of the tired but tireless doctor and finally the story that ends in "I am only human." The black-and-white world view of right and wrong is nuanced to become a subtle interplay of factors in which coincidence also has a role to play, despite the righteous intention to make no mistakes.
- Ongoing legal proceedings with regard to incapacity for work or an inter-collegial conflict. Legal proceedings relating to the situation of the first victim (the patient) are often so painful that they overshadow the incident itself and so impede the client's coping process. Such proceedings also make it hard for the client to put the incident behind them, and they are, in effect, forced to act strategically: after all, spontaneous and emotional responses could be used against them in the proceedings.
- A manifest psychiatric history that is so painful in and of itself that the intervention could lead to escalation.
- The experience of previous traumas often makes it impossible for the client to separate the experiences of the latest incident and the related emotions from other difficult situations. This makes short-term treatment very difficult. The latest incident in any case reveals that the client's foundations have been rocked, which requires more intensive and thus longer term treatment. This will require major changes in the client's work responsibilities and could even lead them to deliberately leaving the profession or no longer visiting a specific work location.
- Lack of a common language that both the therapist and the client speak to a suitably high level. Although the intervention could in principle be carried out through an interpreter, it has been demonstrated that this severely inhibits the therapeutic process. The same applies to differences in cultural background between the therapist and the client, because even though the coping process is in principle universal, the ways of dealing with emotions differ widely (both showing emotions and offering support). There is a strong likelihood that, if the therapist is insufficiently familiar with the emotional behavior typical of the client's culture, they will miss certain important signals.

29.4 Conclusions and Final Remarks

Although the intervention is described in sufficient detail that it could be used by others in similar situations, it is also important to voice a number of reservations in connection with the success story described here. These reservations are partly

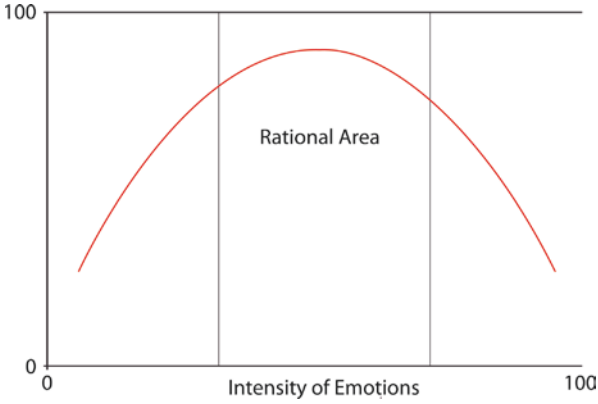


Fig. 29.2 Relationship between "intensity of emotions" and the "ability to think rationally" (in the middle: "rational area")

related to the preconditions that must be met (Box 29.1), but also to the phenomenon of the success story itself (or even better, in the myth of the "fallen hero"). People too often assume a *complicated* rather than a *complex* context in medical practice. Not only does this lead to overestimation of the subject's decisiveness, including the tendency toward interventionism, but even worse to the identification of black sheep and scapegoats, in this case the "fallen hero." This tendency is reinforced in situations where the emotions of other involved parties (colleagues, managers, patients) are aroused, because emotions simplify judgments, turning situations into good or bad and black or white. In short, a person is as intelligent as their emotions allow them to be (Fig. 29.2).

As well as being aware of the risk of "blaming the victim," it is also important to be aware of the system as a whole, such as a working environment in which there is no time for thorough meetings and regular risk analyses. Learning individuals can only exist in a learning organization!

Case History: Continued

Closure

Verda is doing well. She is happy again, is able to take on a reasonable workload, and is positive about her future. However, she also realizes that she needs to spend her time and energy carefully and that an all-nighter will come at a high price. She appears to be much more aware of the nonverbal signals of patients and colleagues, such as feelings of guilt, shame, etc., that are normally not openly expressed. She was always very knowledgeable; now she seems to have gained wisdom too. In that sense, she is certainly not her old self… but she is, in her own words, a very good new self. Sadder but wiser!

Box 29.1 Preconditions

Of course, the expertise of the therapist will to some extent determine whether he or she is to recognize coping problems, regardless of this mechanism. This rather specific psychotherapeutic expertise is typically lacking in primary care providers. This is inevitable in light of the current degree of specialization in healthcare. However, it does imply that therapists who do have this expertise will need to be on the treatment or support team following traumatic incidents. The identification of such traumas on the other hand is a task and responsibility for many if not everybody. If peers and other colleagues can recognize that there is a problem, and if there is no stigma attached to seeking help, then unnecessary traumatization, delay, aggravation of complaints, and postponement of help can be prevented. Therapists are advised to join peer discussion groups because feelings of transferral and counter transferral play an important role in such problems.

The intervention described here is designed as a short-term therapy of a maximum of 10–12 sessions. If possible, the sessions should follow each other relatively quickly. A frequency of once per week is ideal to start off with, but the intervening period can be lengthened as the treatment progresses. Experience indicates that about seven sessions are sufficient, with an intervening period of some 6–8 weeks between the last two of these. At the end of the therapy, the client can use their multiuse ticket as they see fit to contact the therapist again. Experience so far reveals that this option is rarely used.

We recommend keeping a record of the client's complaints and functioning during the course of the intervention, preferably including the situation upon registration (and prior to treatment), at the end of the treatment, and one or two follow-ups (3 and 6 months after the end of the therapy, respectively). Alongside the commonly used generic questionnaires (Short Form Health Survey [SF-36], Symptom Checklist-90 [SCL-90], etc.), we highly recommended identifying a number of specific matters with personalized tests. For example, the client could record their main complaints themselves in a diary using visual analogue scales.

Acknowledgments This chapter is based on an earlier publication in Dutch by HBM van de Wiel and C. Linden van den Heuvell, Kortdurende oncologische psychotherapie (short-term oncological psychotherapy). In: Psychologische patiëntenzorg in de oncologie (Psychological care of oncology patients). Haes JCJM de, Gualtherie van Weezel LM, Sanderman R, Wiel HBM van de (eds.). Assen, The Netherlands; Van Gorcum: 170–174.

References

1. Keijser J de. Diagnostiek en behandeling van complexe rouw. Oratie RUG; 2014.
2. Kissane DW, Bloch S, Dowe S, Dowe DL, Snyder RD, Onghena P, McKenzie DP, Walllace CS. The Melbourne family grief study, I: perceptions of family functioning in bereavement. Am J Psychiatry. 1996;153(5):650–8.
3. Van de Wiel HBM, Linden van den Heuvell C. Kortdurende oncologische psychotherapie (Short-term oncological psychotherapy). In: de Haes JC, Gualtherie van Weezel LM, Sanderman R, van de Wiel HB, editors. Psychologische patiëntenzorg in de oncologie (Psychological care of oncology patients). Assen: Van Gorcum; 2009. p. 170–4.
4. Van Pampus MG, Evers R, Stramrood CAI, Baas MAM. Care after stressful life events in the workplace. 2014. http://www.medischcontact.nl/web/file?uuid=78175ca1-f607-44ee-96b9-a20883249c50&owner=8fffb8d4-dd7e-4e3e-8072-49b131fb7392.

30 Medical Expert: The Resident Who Passed the Ultimate Test—The Integration of Roles During the Gynecological Examination

K. Marieke Paarlberg and Harry B.M. van de Wiel

30.1 Introduction

The gynecologist (in training) and health care practitioners (HCPs), in this chapter referred to as *examiners*, who perform a gynecological examination need to integrate all CanMEDS competences to perform an effective examination. Effective here means an interaction between the HCP and patient, in which the woman feels acknowledged, respected, well treated, and well diagnosed. As such the gynecological examination is an excellent illustration of "the final test" in terms of competency-based learning. If there is one moment to demonstrate medical expertise, that is during a woman's *first* gynecological examination. For many women, such as with the menarche and deflowering, this is a rite de passage; it is a step toward maturity and a reference point for similar experiences in the future. Therefore, above all traumatic experiences should be prevented and, if possible, she should look back on a positive and instructive encounter with her ObGyn professional. This is a challenging target for the patient as well as for the examiner.

What the examination as a test for medical expertise illustrates is that each aspect of the CanMEDS model is a *conditional fractal*; every role is conditional for all the other roles. Communication has to be organized; organization has to be communicated. Everything is connected to everything and that makes it so hard to grasp in the beginning. The *medical expert* is able to integrate all roles as *intrinsic roles* [1].

In this chapter, we therefore address the different CanMEDS competences that play a role during a gynecological examination. Many aspects already have been

K.M. Paarlberg (✉)
Department of Obstetrics and Gynecology, Gelre Hospitals, Apeldoorn Location, Apeldoorn, The Netherlands
e-mail: km.paarlberg@xs4all.nl

H.B.M. van de Wiel
Wenckebach Institute, University of Groningen, University Medical Centre Groningen, Groningen, The Netherlands

K.M. Paarlberg, H.B.M. van de Wiel (eds.), *Bio-Psycho-Social Obstetrics and Gynecology*, DOI 10.1007/978-3-319-40404-2_30

addressed in this book, and we will refer to these chapters for more background information.

The following CanMEDS competences are addressed:

1. *Communicator*: The examiner needs to explain the gynecological examination well before the procedure is performed and needs to listen to possible problems that might be encountered. During the examination the reactions of the patient need to be noticed and properly addressed. After the examination the findings need to be explained in a clear and understandable manner.
2. *Collaborator*: The examiner needs to collaborate with the patient closely, even when the patient is anxious or tense. This requires collaborating skills to find ways to operate truly as a team. Being a participant (instead of an object) during the process ensures optimal control by the patient, which reduces distress. Only then can all the information needed be exchanged, both in terms of diagnostic as educational requirements.
3. *Leader*: Although the examiner and the patient should operate as a team, the examiner needs to guide the patient through the examination process and has to determine which examinations need to be carried out given the aims set and discussed with the patient. This is not only to correctly diagnose or refute a certain diagnosis, but also with regard to making the examination as an experience "worthwhile" from a patient's educational perspective. Moreover cost-effective analyses play a role; if a condition can be established by the naked eye, it is not "cost-efficient" (in terms of money but also of distress) to perform a full gynecological examination.
4. *Health advocate*: The examiner needs to be aware of the patient's context and preferences and should tailor examinations to these circumstances. After that, the examiner has to recognize what the boundaries of the ObGyn discipline are in respect to which examinations can or should be carried out.
5. *Scholar*: The examiner needs to be up to date about the latest developments on diagnosing and examining gynecological diseases.
6. *Professional*: The examiner needs to realize how to deal with personal and professional boundaries between the patient and the examiner, in this way preventing sexual or physical harassment during a gynecological examination.

Case History

Jean LeBlanc has just started his residency in Obstetrics and Gynecology. Today he is working at the gynecological outpatient clinic. His first new patient of the day is Gina, 17 years old. Gina enters his room with red cheeks. He thinks to himself, "What a young girl and all alone. She must be quite nervous."

At that time he realizes that he himself is quite nervous too, being confronted with such a young patient and having so little experience as a gynecologist. He decides to try to imitate one of his supervisors who told him "to

stick closely to the medical procedures when in doubt." He starts taking the history in a very structured way and doing so he feels more and more comfortable.

Gina tells him that she has had an irregular menstrual cycle since her menarche at age 13 and asks his advice. He asks her some general diagnostic questions, which Gina kindly but softly answers. However, when he asks whether she has "coitus," Gina becomes silent and gazes at him while her face looks confused.

Fortunately Jean realizes that he was using a typical medical term and rephrases his question, "Do you have a boyfriend with whom you have intercourse? Do you make love with somebody?"

Her cheeks turn red again when Gina tells him in a soft tone that she has a boyfriend with whom she has had sex for a few months. With her eyes looking at the table, she tells him that they have been using condoms so far, but she would like to have a higher guarantee of avoiding pregnancy.

Maybe taking the pill would help stop her irregular cycle. Jean just had training on contraception and starts to discuss the pros and cons of the different methods. Gina just listens; she does not ask any questions. In the end Jean advises her to use second-generation contraceptive pills in order to prevent pregnancy but also to regulate her menstrual cycle. In order to prevent sexually transmitted diseases, he advises her to continue using condoms for some more months as well. At the end of the consultation Jean feels quite comfortable, especially when she repeats his advice in her own words. Apparently his message was clear and acceptable.

However, while he thinks he is making some final notes in her patient file, Gina surprises him. "Doctor, is it normal that I nearly always lose some blood after having sex?" This simple question, pointing out a fundamental diagnostic omission, makes it clear that he was not such a good doctor after all by deviating from the normal scientifically based routines. When he looks at the clock, he also realizes that he has a lot to learn about time management during consultations.

In this chapter, we focus on the task of constantly changing roles and using different perspectives during consultations and examinations. Especially for young residents like Jean LeBlanc, this integration and balancing between competences is difficult and often time consuming. Because expertise can only become visible through acting and the gynecological examination is a typical kind of action, we use this as didactical vehicle. We will restrict ourselves to the issue: the contents of the physical gynecological examination. Routine additional examinations, such as transvaginal ultrasound examinations or other examinations carried out by radiologists, will not be addressed in this chapter. For those examinations, we ask you to refer to the appropriate textbooks.

30.2 From Multifunctionality to Emergence

In a gynecological examination, different aspects need to be addressed. In order to provide effective and respectful care, it is important to consider each gynecological examination as a configuration of meaningful events, such as:

- A *medical examination* in order to inspect the medical status of the patient, i.e., to diagnose diseases, to screen for diseases, such as cervical dysplasia, or to refute diseases.
- An *educational event* in which the woman is exploring her own genitalia under the guidance of the examiner.
- An opportunity to demonstrate *leadership* by keeping one's head cool in "stressful situations" as a professional one may serve as a role model for the patient.
- *An organizational* challenge in terms of process management. A gynecological examination requires thorough preparation (logistics, time, etc.), standardization (according to the protocols of the profession), and also improvisation because not everything can be foreseen, and every woman is different as an individual.
- A test for *professionalism,* feelings of doubt, embarrassment, disgust, sexual attraction, sympathy, etc., may and do all occur during the job. All these human feelings have to be dealt with in such a way that not only the patient but also the professional is not "harmed."
- All this well-intended behavior must be *communicated* in such a way that the patient feels supported and invited to join forces with us, to *collaborate* in a team.

Next to balancing *within* these metacompetences, a gynecological examination requires balancing *among* them. One moment the communication with the patient requires attention; the next moment another role stands on the foreground—like different kinds of fruit in a slot machine. And if this is not enough, there is interaction between the roles. When something goes wrong in one domain, all the others are jeopardized. This refers to a phenomenon that occurs in all complex adaptive systems (like human beings): emergence (Fig. 30.1) [2].

A well-known example of negative and even dangerous medical emergence comes from our daily practice: polypharmacy. Interactions between different kinds of medicines are a well-known phenomenon; however, they are hard to tackle. Some interactions between two kinds of medicine are well known, but what happens when they are combined with a third medicine is difficult to know. Many elderly patients have more than ten different types of medications.

The same emergence occurs due to interactions between metacompetences or roles. The combination of an ideal communicator with a bad organizer creates a completely different situation than the opposite. Each combination has its own unique characteristics.

Because it is impossible to describe let alone control all combinations, here we will stick to one golden rule of thumb: each role or metacompetency has the ability to hinder/help the others! The destiny of the gynecological examination as a

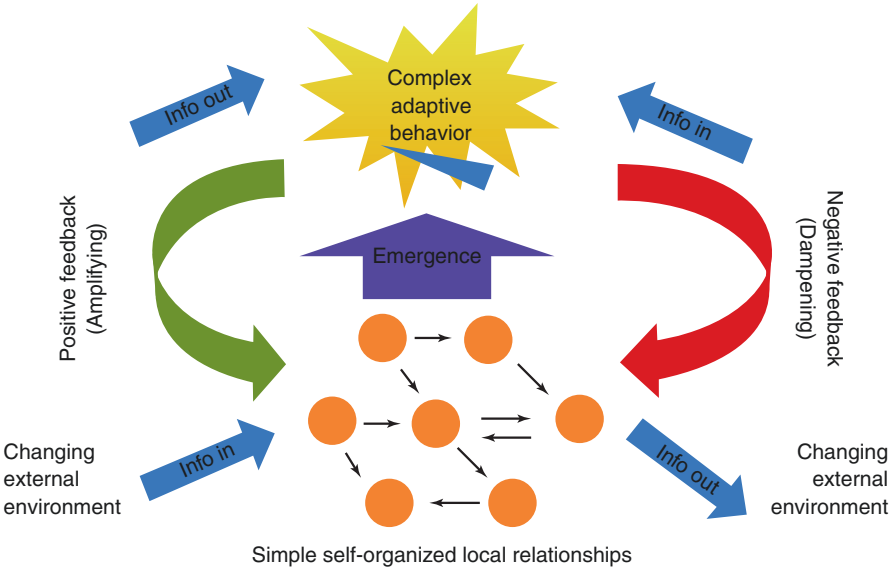


Fig. 30.1 Complex adaptive systems (Used with permission from Hakimi A. The new world of emergent architecture and complex adaptive systems. http://blogs.msdn.com/b/zen/archive/2010/08/10/the-new-world-of-emergent-architecture-and-complex-adaptive-systems.aspx)

"whole experience" is in the hand of the user/professional. Or to put it simply: It is up to you!

30.3 Educative Aspects of the Gynecological Examination

One of the educational tasks of HCPs is the normalization of perceived "abnormalities" in anatomy and/or bodily functions. As has been described in Chap. 8, body image plays an important role in women's lives. Social comparison is a prerequisite to build up a realistic way of looking at oneself. Because comparing genitals is hardly possible in our culture, this feedback process is hampered. Especially in young girls, this may lead to "perceived pathology." This is especially the case in an era in which the selection of models and photo altering are even more disturbing to the already fragile normal feedback processes, e.g., the (non)verbal reactions of peers.

In order to meet this educational task, it is important to know what the worries are. After that, an "educational gynecological examination" (EGE) can be very instructive for women of all ages. This EGE is carried out by using a hand mirror for the woman while the health care professional (HCP) can explain to her what he/she sees and what the function of the different vulvar structures are. In addition to giving information, this investigation should also be used for gathering information. Think of the woman's ideas about the physical aspects of sexual functioning, but also

information relating to questions about what is normal, to reduce a possible negative body image and correction of myths. Such an examination is performed only after consent of the patient and should take place in an atmosphere of maximum security. Because partners, especially young male ones, often also lack this kind of knowledge, it is desirable, but not necessary and only if desired by the patient (!), that the partner is present at the investigation. Using the functionality of the examination as a basis, one needs to discuss these kinds of circumstances in advance. In the end, it is the woman who decides with whom and how in nonmedical terms. Of course, the investigation itself is basically painless. However, because this cannot be fully guaranteed, it is important to agree upon a "verbal fuse," e.g., stop is stop!

There is not always a medical reason to perform the full gynecological examination, especially not when it is the first time. Such an EGE provides a good opportunity to give realistic information about the appearance and function of the genitalia. When a vaginistic reaction is found, this can be addressed and discussed in light of a possible reaction during coitus. This may prevent a future negative spiral of anxiety and pain. Although perhaps the impression has been created that this approach to the patient is only possible after much practice and mastery of technical feats, this is not the case. Of course, "practice makes perfect," but what really matters is to express a certain attitude, namely, an attitude of genuine interest and empathy for the woman and the willingness to solve the problem together. Empathy is described in Chap. 28 as "the ability to put oneself into the position of the other." Or to put it in biblical terms, do not do to others what you would not like to be done to you!

30.4 Professional Aspects of the Gynecological Examination

As has been described in Chap. 26, it is important for physicians and HCPs to balance between "maximal approach while keeping distance." In order to be able to do so, as an examiner one needs to maintain a professional attitude and that is exactly what is lacking in inexperienced HCPs. Especially students often have all kinds of emotionally upsetting connotations with a gynecological examination, including sexual ones. Therefore, one of the most challenging aspects of the gynecological examination is to find a way to professionally handle one's own emotional and sexual feelings and associations. Only then may one serve as a guide to the women who are being examined and who are struggling with a wide variety of "mixed feelings" themselves. Although the latter probably holds for all women, this is especially the case for women with negative sexual experiences in the past.

HCPs have to learn to deal with situations in which they can feel strongly emotionally involved with their patient. This may lead to "overinvolvement" and "countertransference," endangering the professional distance between the health care professional and the patient. This phenomenon and the way one should deal with it are described in detail in Chap. 26.

When the HCP is capable of neutralizing the situation and thereby "desexualizing" it, both participants obtain complementary positions in the encounter. For the woman it stays a unique situation, possibly loaded with all kinds of (sexual) associations and

fear. For the HCP it becomes a procedural examination, which gets rid of a confusing, possibly sexual connotation. When the HCP is not aware of this kind of emotional turmoil, his or her own (sexual) associations could evoke compensatory behavior, such as the tendency to objectify the woman in an exaggerated way as "a vagina with discharge"; asking how is "the vagina" doing; and choosing a distinctive, superior, and arrogant attitude. Such reactions may evoke a feeling of humiliation in the woman.

When the HCP wants to fulfill the role of a neutralizing person, acknowledgement and recognition of a wide variety of emotions and associations including sexual aspects is a prerequisite. If this does not happen, the HCP's attitude will be insensibly influenced by his or her own experience with sexuality in general and his or her expectations regarding this experience.

30.5 Communicative Aspects of the Gynecological Examination

30.5.1 Before the Examination

Clarifying to a woman (under the circumstances of a gynecological examination) why you are going to examine, what you are going to examine, what you are not going to examine, and how you are going to do this: these are educational aspects that require a high level of professional communication. Before the actual examination, when the woman still is dressed, for instance, a tranquil conversation is always necessary. This conversation, preferably about how the woman feels at that moment, her expectations about the examination, etc., can determine the atmosphere in which the examination will be carried out, and it gives the HCP the possibility of finding out how the woman will be looking upon the examination. The explanation about what is going to happen, about the procedures to be followed, is tailored to the needs of the woman to be examined. She will have the possibility to ask questions. Frequently the woman has had a gynecological examination before. Therefore, it is important to ask for previous experiences and take notice of these aspects. The language used should be clear, understandable, and acceptable to the woman. Difficult formulations should be avoided in order to prevent misunderstanding. The examiner is constantly checking whether or not the information given is being understood by the woman. During the conversation, the examiner should check whether it is appropriate to use a nonstandard type of speculum.

30.5.2 During the Examination

The examiner tries to involve the woman in the examination as much as possible and gives her as much control as possible. She has been told that she can stop the examination at any time if she experiences too much pain or discomfort, and the examiner keeps his or her promise. The woman is offered a mirror and is invited to look into the mirror in order to view the examination if she wishes. The examiner

keeps eye contact with the woman and looks at her as much as possible, especially at the moments when each one is speaking. Take care that the information provided relates only to the findings. Every step is first announced and, only then, performed. Simultaneous explanation and performance are avoided as much as possible, as are rude and sudden movements during the examination.

30.5.3 After the Examination

After the patient is dressed and seated again, the first impressions (caution!) and results of the examination are communicated in a structured way. This means that the aims of the examination are repeated, the results in terms of the aims are shared, and if necessary further explained. And of course, given the educational aims, the patient gets ample opportunity to ask questions and provide feedback.

30.6 Collaborative Aspects of the Gynecological Examination

The gynecological examination could be perceived as an encounter between two different individuals, each with a different role and a different reaction to what takes place. At the same time, they are mutually dependent on each other in order to reach the final goal: bringing the gynecological examination to a good conclusion. However, this good conclusion encompasses more than just an encounter between two people. The personal background of the HCP and the woman and both their expectations are influencing the way they experience this encounter. Previous experiences, for instance, about sexuality and power(lessness) may influence the signals, answers, and reactions that become apparent in the interaction. Negative sexual experiences in the past, e.g., violation and rape or even sexual abuse during childhood, may hinder collaboration. The inability to trust the other, especially someone who represents authority, may negatively influence the course of a gynecological examination, which is frequently not recognized as such. Although usually in less far-reaching terms, the same may hold for fear of sexually transmitted disease, extramarital affairs, etc. By being aware of the "abnormal" (including sexual) aspects of a gynecological examination, the examiner is capable to avoid obstructions in the collaboration. When there seems to exist an atmosphere of tension and potential conflict of power, HCPs can avoid this by simply pointing out to the woman that she is the one who ultimately can control the situation.

30.7 Organization of the Gynecological Examination

First of all, it is important to define which aspects of the gynecological examination need to be carried out and which do not need to be carried out. These aims determine which procedures and thereby which instruments, etc., will most likely be

used. We say "most likely" because sometimes one may encounter unexpected problems. In order to avoid instantaneous logistical problems, plan abundantly. Better to be safe than sorry!

30.7.1 Instruments and Material

Take notice that the instruments and material, such as the material necessary for taking a Pap smear, are within reach. The examination lamp also has to be close, in order to focus it over the shoulder on the vulva and the vagina during the examination.

There are different kinds of specula. The models designed by Seyffert have large handles (pistol grip); the Cusco specula have small handles. When the Seyffert speculum is opened, the circumference at the base, at the introitus vulvae, becomes larger. A Cusco speculum hinges in such a way that the circumference of the introitus does not increase. A Seyffert speculum allows the examiner more room for performing procedures, such as taking a Pap smear. When the vaginal introitus is narrow, this speculum is less suitable. The so-called virgo speculum by Seyffert is just as wide at the vaginal introitus as the normal variant and therefore not suitable for women with a narrow vaginal introitus, as is frequent in virgins. However, this speculum is suitable in postmenopausal women in whom the vaginal introitus usually is wide enough, but the vagina may be narrower toward the end because of atrophy. Therefore, "postmenopausal speculum" is a better name than "virgo speculum." Among the Cusco specula, there are a few with small blades that are suitable for examination in case of a tight vaginal introitus. In most cases, one can use a standard speculum, Seyffert or Cusco. Except for virgins and postmenopausal women, there are more indications in which a nonstandard speculum needs to be used, such as in women with vulvar dystrophy or women who have undergone pelvic radiation.

30.7.1.1 Hand Mirror

A hand mirror should be at hand. This can be an ordinary, inexpensive hand mirror.

30.7.1.2 Gloves

There is much debate on the number of gloves to use during the examination and when they should be used. The current practice is mainly influenced by the risk of bacterial or viral contamination. Although this risk is not great, there remains a risk, especially in menstruating women. Therefore one should always work with two gloves, one for each hand.

30.7.2 Conditions for a Gynecological Examination

To obtain optimal quality of the examination, it is important that certain conditions are fulfilled in order for the woman to be relaxed, but also for the examiner to be able to work as comfortably as possible.

30.7.2.1 Toilet Visit

Being examined with a full bladder is awkward for the woman and makes the examination not reliable. Therefore, before the examination, the examiner asks the woman when she last voided.

30.7.2.2 Undressing

The woman has to undress herself in privacy, after it has been explained to her which clothing has to be removed and which clothing does not have to be removed. For this examination, she has to be undressed from umbilicus until the knees.

30.7.2.3 Positioning at the Gynecological Chair

The examiner does not stand in front of the patient, but next to her and helps her assume the best position. The woman has to place her buttocks at the edge of the chair. The position of the stirrups and the position of the back of the chair have to be checked. A half-sitting position is usually perceived as the most comfortable; in this position the woman can see what is happening. A pillow below the head may add extra comfort for the woman.

30.7.2.4 Position of the Patient and the Examiner

Vulvar inspection and speculum examination are performed in the sitting position. Required are a good stool at a good working height and a bright light appropriately positioned. The light is well focused onto the speculum, over the shoulder. An eventual third person (such as the partner or a medical student) may be able to look over the shoulder. Vaginal palpation is usually performed in standing position. One can also choose to stand beside the patient in order to have a position more equal to the patient instead of standing between her legs.

30.7.2.5 Relaxation

During the examination the woman needs to lie as relaxed as possible. Quiet, deep breathing in which the abdomen is involved is important. Furthermore, "relaxation" means that the adductor and pelvic muscles are relaxed. It is advisable to ask a (tense) woman to tighten these muscles first and then relax, in order to let her feel the difference between tension and relaxation. Some women rotate their pelvic area, which means they lie on the chair with lordosis and tense buttocks. It is better to position the back flat on the examination chair and to control this position by putting a hand underneath the back of the woman.

Case History: Continued

Since Gina is losing blood following sexual intercourse, Jean realizes that there is a clear indication for a gynecological examination. He is thinking, "Since she is so young, cervical dysplasia will not be the reason. However, she might have contracted chlamydia, or she might have a vulnerable cervical ectropion."

This will be Gina's first gynecological examination. Therefore, Jean discusses with her that he would like to inspect her vulva, vagina, and cervix. In order to be able to do that, he will need to use a speculum to view the cervix. He explains the procedure to her. She agrees to it, but says that it is also embarrassing to have such an examination. He reassures her that he understands that such an examination might feel embarrassing. He is a little hesitant to go on.

He asks her, "Is there anything that I can do to diminish these feelings? Are there things I should do or, on the contrary, should not do? You know you can always ask me to stop by raising your hand or by just saying STOP."

Gina nods her head, relaxes a bit, and says, "What must be done must be done."

He prepares his materials for PCR-swab in order to test for any sexually transmitted disease (STD), a cervix brush for a Pap smear, and a container for it. He proceeds much slower than he is used to doing. He is remembering his lessons on "The first gynecological examination" and "How to involve a woman during a gynecological examination." He hands over a hand mirror to Gina and asks whether she is lying all right now. She relaxes and nods.

With a wetted cotton swab he starts to point out the anatomy of her vulva and the vaginal introitus. She is following him now, a bit anxious, however also with interest. She says she did not know that her hymen was there and where exactly the mouth of her urethra was.

Then it is time for the speculum examination. He explains every step before performing it: "Now I am going to rest the speculum at the entrance of your vagina…when you push a little, I am going to insert the speculum slowly inside your vagina… now you can stop pushing… now I am going to open the speculum a little to be able to look at your cervix… now I am looking at your cervix… can you see it in the mirror?"

He notices that she has a vulnerable ectropion indeed, but no abnormal vaginal discharge. To rule out dysplasia he decides to perform a Pap smear and to perform a PCR on chlamydia and gonorrhea. Then he continues, "You can see that there is some redness at your cervix, which is very common in women of your age. Now I am going to take a Pap smear, which might feel a little awkward, but when you continue breathing, it should be all right… all right… see, it is bleeding a little easily, which might also happen during intercourse… and now I am taking a swab culture with this cotton swab which you should not feel very much… OK, nearly finished. You are doing a great job!"

When Jean has finished his examination, Gina says that she is relieved that her first examination went well. Jean remembers the lesson on collaboration and immediately shares the honor with Gina. With a smile of his face he says, "These kinds of examinations are as good as the patient and as bad as the doctor so…"

After she is dressed again, he tells her his findings and makes an appointment by telephone in 2 weeks to discuss the results of the tests.

30.8 Scholarship Aspects of the Gynecological Examination

In this section, two aspects of a careful gynecological examination are discussed. First of all, the right order should be followed, and secondly, the right technique should be used.

30.8.1 Order of a Basic Gynecological Examination

The order of a gynecological examination is indicated in Table 30.1, as are the most common indications for which the different aspects are performed. Depending on the indication, one or more parts of the examination may be omitted. For instance, in women who suffer from provoked vestibulodynia, the examiner focuses on vulvar inspection and examination of the pelvic floor muscle function omitting inspection of the vagina using a speculum. In a case in which there is abnormal menstrual bleeding, all aspects are followed, but examination of the pelvic floor will not need to be carried out. Therefore, it is necessary that the examiner weighs beforehand whether all aspects of the gynecological examination need to be carried out or only some of it.

30.8.2 Technique of the Gynecological Examination

30.8.2.1 Inspection of the Vulva and Perineal Region

With a wet cotton swab, the examiner points out the different structures and tells the patient what he/she is seeing. In this way, the examiner forces himself or herself to carry out the examination as completely as possible and to obtain optimal information. For a good overview, the examiner is spreading the vulva after having announced this procedure and asks to push a little. The woman can also spread her vulva with her hands placed behind her buttocks. This spreading is important as otherwise hyperemic foci, which appear at the basis of the hymen, will never be noticed.

The vulva and perineal region are systematically examined. First the general inspection is described. If indicated (for indications, see Table 30.1) inspection of the pelvic floor can be added.

General Inspection

In general the examiner looks at hair patterns (shaved or not), color of the skin and epithelium, symmetry, scars, lesions, fistula, swellings, and hemorrhoids:

- The vulva is inspected from cranial (mons pubis) to caudal (posterior fourchette) and from the labia majora, via the labia minora, toward the vaginal introitus. The following structures should be inspected: the clitoral prepuce and the clitoral body, labia majora, labia minora, transition region between labia majora and

Table 30.1 Order of a gynecological examination

Type of examination	Additional tests	Indications
1. Inspection of the vulvar and perineal region		Cysts, abscesses, warts, infection, irritation, skin complaints, sexual complaints, vulvar pain, prolapse, incontinence, and female genital mutilation
2. Inspection of the pelvic floor muscles		Sexual complaints, prolapse, vulvar pain, lower urinary tract symptoms, and bowel symptoms
3. Inspection of the vagina and cervix using a speculum		Cysts, polyps, prolapse complaints, abnormal vaginal discharge, signs of pelvic inflammatory disease, pelvic pain, cervical screening, irregular or coital bleeding, abnormal menstrual bleeding, postmenopausal bleeding, and placement of or complaints of an IUD
3a	Swab for culture or PCR	Signs of pelvic inflammatory disease, pelvic pain, irregular bleedings, abnormal vaginal discharge, and risk for STDs
3b	Pap smear	Cervical screening, abnormal menstrual bleeding, irregular or coital bleeding, and postmenopausal bleeding
4. Bimanual vaginal palpation to uterus and adnexa		Abnormal menstrual bleeding, pelvic pain, suspicion of uterine myomata, adnexal mass, or endometriosis externa
5. Bimanual rectovaginal palpation		Suspicion of processes in the rectovaginal septum, such as in (suspected) endometriosis externa, pelvic pain, and (suspected) gynecological malignancy
6. Palpation of the pelvic floor muscles		Sexual complaints, prolapse, vulvar pain, lower urinary tract symptoms, and bowel symptoms
7. Transvaginal ultrasonography (not explicitly addressed in this chapter)		(Ectopic) pregnancy, suspicion of uterine myomata, polyps, endometrium measurement in fertility or postmenopausal bleeding, antral follicle count, follicle measurement, position of the uterus, adnexal mass, abdominal free fluid, etc.

IUD intrauterine device, *PCR* polymerase chain reaction, *STDs* sexually transmitted diseases

minora, urethral orifice, paraurethral glands of Skene, vaginal introitus, hymen (remains), vestibular (Bartholin's) glands, and the vulvar vestibule is examined for inflammatory processes.

- The perineal region is inspected from cranial (posterior fourchette) to caudal (anal region). The following structures should be inspected: perineal skin and anus.

Inspection of the Pelvic Floor Muscles

The terminology used below conforms to the definition recommended by the clinical assessment group of the International Continence Society (ICS) [3].

- Examiners should state the position of the patient (supine, lithotomy, lateral, or standing) and the time of the day.
- Testing for pelvic organ prolapse is an integral part of the physical examination of every patient with pelvic floor muscle complaints. A vaginal and rectal exam is part of this investigation. To quantify pelvic prolapse, the ICS pelvic organ prolapse quantification (POP-Q) examination is advised. This examination is beyond the scope of this chapter, but interested readers are referred to the original publication of Bump et al. [4].
- During inspection the patient is asked to perform a pelvic floor muscle contraction. In the normal situation, a pelvic floor muscle contraction will lead to ventral and cranial movement of the perineum.
- When the patient is asked to cough, the perineum should show downward movement; ventral movement may occur because of the guarding action of the pelvic floor muscles.
- Anal and/or rectal prolapse can be evaluated by asking the patient to strain, as if defecating, while seated.
- Perineal elevation is the inward (cephalad) movement of the vulva, perineum, and anus.
- Perineal descent is the outward (caudal) movement of the vulva, perineum, and anus. The position of the anus and the perineum should be noted at rest and during straining. If perineal descent is seen when the woman has been asked to contract the pelvic floor muscles, this indicates that the patient is straining instead of contracting the pelvic floor muscles.
- Extra-pelvic muscle activity is the contraction of muscles other than those that comprise the pelvic floor, for example, the abdominal, gluteal, and adductor muscles. Extra-pelvic muscle activity is needed for maximal pelvic floor muscle effort.

30.8.2.2 Inspection of the Vagina Using a Speculum

If necessary, the examiner may check the introital and vaginal space by palpating with one finger. When the so-called indications are not present, a standard speculum appears too large and the woman expresses pain, the examiner needs to figure out what the problem is before deciding whether or not to proceed and, if proceeding, how to proceed. A smaller size speculum is not advisable if a woman cannot relax because of anxiety. In such a case the underlying cause needs to be addressed. Preparation aspects of the speculum examination are given in Tables 30.2 and 30.3.

Table 30.2 Preparation of the speculum examination

1. Take care the woman lies well on the gynecological chair (or examination table)
2. Check whether her bladder is empty
3. Remove jewelry, wash hands, and gloves on
4. Focus the light beam

Table 30.3 Preparation for speculum examination including a cervical or vaginal culture, PCR, or Pap smear

Preparation of a cervical or vaginal culture or PCR:	
Gather:	Culture container and/or PCR container
Identification:	Write the woman's name and date of birth on the container
Preparation of a Pap smear:	
Gather:	1. Object glass with fixation material or liquid container for liquid-based monolayer cytology 2. Spatula with Cytobrush or Cervex-Brush®
Identification:	Write the woman's name and date of birth on the object glass or liquid container

PCR polymerase chain reaction

Procedure of the Speculum Examination

- Wet and warm the speculum.
- Check the temperature on the gloved hand and on the inner thigh of the woman.
- Spread with the fingers approximately halfway in the inner side of the labia minora.
- Take care that during spreading, not too much traction occurs at the prepuce (too much pulling down) or at the perineum (too much pulling up).
- Spread with care and horizontally as much as possible.
- Spread the labia until the speculum is inserted completely to prevent pubic hair or labia from being pulled inside.
- Place the speculum at the posterior vulvar vestibule with light, downward pressure.
- Place the speculum in a diagonal position ("5 min to five" or "5 min past seven") to avoid contact with the urethra.
- Ask the woman to push (slightly), which allows the pelvic floor to relax in order to widen the vaginal introitus.
- When the speculum has passed the vaginal introitus, she can quit pushing.
- Rotate the speculum slowly around its longitudinal axis until it is in the transverse position, and turn the speculum sacrally until it reaches the posterior fornix; follow the path of least resistance.
- Open the speculum, and expose the cervix.
- Sometimes it is necessary to move the handle of the speculum more toward the chair, between the buttocks of the woman, in order to scoop the cervix in between the blades.
- If the examiner is inexperienced, it frequently happens in this part of the examination that the speculum is pulled out immediately; mostly only the vaginal walls can be seen.
- This phenomenon can be prevented by fixating the speculum in the posterior position by the thumb of the free hand on the upper edge of the speculum.
- Lock the speculum.
- Only self-supporting specula, such as the Cusco, can be released without unpleasant consequences for the woman; in the open position, the others slip out of the vagina, which is painful.

Solving Problems in Finding the Cervix

Sometimes viewing the cervix is not successful. Some suggestions can be made for such a situation:

- Keep the speculum opened and retract a little, keep watching, sometimes the cervix comes into view.
- Perhaps the speculum is positioned in the anterior fornix; close the speculum partly, retract partially and reposition it (eventually spread the labia again), and direct the speculum a little bit steeper downward.
- When the previous procedures are not successful, it is a possibility to palpate the cervix first to find out what the position of the cervix is (careful if cytological examination still needs to be carried out).

Inspection with Opened Speculum

- Cervix: shape, size, and aspect of epithelium (color, surface, lesions, irregularities).
- Cervical ectropion (cervical eversion): position, shape, and size.
- Cervical orifice: position, shape, size, and discharge.
- Fornices: swellings.
- Lateral vaginal walls: color, lesions, and signs of inflammation.
- Vaginal discharge: amount, color, and consistency. In case of possible mycosis or bacterial vaginosis, a specimen with potassium chloride and sodium chloride can be made to diagnose microscopically mycelia (Candida infection) or clue cells (bacterial vaginosis). In case of normal vaginal discharge, but with (therapy-resistant) complaints, it can be very reassuring for the woman (and her partner) if she can see what normal vaginal discharge looks like with the hand mirror or through a microscope.
- Examine eventual swellings and irregularities on: position, shape, size, surface, color, and limits.

30.8.2.3 Bimanual Vaginal Examination

If indicated, as has been described in Table 30.1, the next step of the gynecological examination is the bimanual vaginal examination. Explain during the bimanual vaginal examination what you are doing, what you are looking for, and what your findings are. Sometimes, for example, in case of fibroids, it can be very informative and valuable to let the women palpate the uterus/fibroids herself.

- Put on gloves and use a lubricant on the palpating fingers (index and middle finger).
- Take the right position: arm of palpating hand rests on upper leg.
- Spread the labia minora midway and lay down the two fingers at the posterior vulvar vestibule.
- Ask the woman to push slightly, insert the two fingers, and ask her to stop pushing after passing the vaginal introitus. Avoid contact with the clitoris.
- When entering the vagina, palpate the dorsal side of the vagina and examine swellings, lesions, tenderness, and prolapse.

Checking for Pelvic Tenderness

- Do not lay the external hand on the abdomen of the woman.
- Put two fingers on the cervical mouth at the place of the external cervical mouth, move the cervix one time slowly toward the head and release the cervix on the fingers (repeat in case of uncertain reaction).
- Place one or two fingers next to the cervix, move the cervix to the side in a quick movement and release it (repeat this in case of uncertain reaction). Repeat the same procedure on the other side. Tell the woman that you are going to move your fingers.
- Another way of testing the same is as follows: put the index finger and middle finger around the cervix, move the cervix horizontally for 1–2 cm to one side and then 1–2 cm to the other side.
- If these maneuvers are painful, then there is peritoneal tenderness and one must be aware of an acute pelvic pain disorder.

Examination of the Uterus

- Place the external hand loosely above the symphysis; do not push into the abdomen.
- Place the internal fingers underneath the cervix and "lift" it to apply counterpressure toward the external hand to palpate the uterus between two hands. Perform this procedure at the moment that the woman, having breathed in, is requested to breathe out, while she keeps her abdominal muscles as relaxed as possible.
- Palpate and examine the uterus regarding position, form, size, consistency, surface, and tenderness to pressure.
- Keep on systematically examining whether there are swellings and irregularities as has been pointed out earlier.

Examination of the Adnexa

- Warn the woman that this examination can be uncomfortable. Ask the patient, as when palpating the uterus, to slowly breathe out and keep the abdominal muscles as relaxed as possible.
- Place the internal fingers in the lateral fornix and place the external hand flat on the abdomen just lateral to the midline, at the same side as the internal hand.
- Push with the external hand, with a smoothening movement, in the direction of the internal hand. Repeat the movement. If necessary to find the ovary, go more laterally or more medially.
- In case of obesity, first smoothen the skin and panniculus above with the external hand and subsequently smoothen the hand deeply back in order to decrease the space between the internal and external hand. Repeat these movements if necessary.
- Palpate and examine with the *internal* fingers the tissues between both hands with regard to shape, size, consistence, surface, and pressure tenderness. Do not fixate the ovaries.
- Same procedure at the other side, warn the woman of your turning internal fingers.
- Pull back the palpating fingers and examine the vaginal walls at the front and at the side.

30.8.2.4 Bimanual Rectovaginal Examination

When indicated (Table 30.1), a bimanual rectovaginal examination needs to be carried out.

- The examiner can continue with the bimanual rectovaginal examination immediately following the bimanual vaginal examination.
- Inspect the glove with blood and discharge. Decide whether or not the gloves need to be changed.
- If a vaginal examination is carried out first, the examiner can let the middle finger slip out and pass the anal sphincter as has been described above. This procedure must be announced and described prior to being performed.
- In case the gloves are changed, use a lubricant on the palpating fingers (index and middle finger).
- Take the right position; arm of palpating hand rests on upper leg.
- Spread the labia minora midway and lay down one finger at the posterior vulvar vestibule.
- Ask the woman to push slightly, insert the index finger, and ask her to stop pushing after passing the vaginal introitus. Avoid contact with the clitoris.
- Lay down the middle finger at the anal sphincter
- Ask the patient to push lightly again and insert the middle finger anally.
- The sphincter tone is observed carefully.
- By gently squeezing both fingers toward each other, the rectovaginal septum can carefully be palpated regarding swellings, lesions, tenderness, and prolapse. Also note the consistency of the feces, which might be palpated in the rectum. This can give additional information about complaints like constipation or diarrhea.

30.8.2.5 Palpation of Pelvic Floor Muscles

When a pelvic floor examination is also indicated, the palpation of the pelvic floor muscles is carried out [3, 5]:

- Digital palpation is used to assess the pelvic floor muscles and surrounding areas at rest and during contraction and relaxation.
- Put on gloves. Palpate the perineum with the gloved finger during instructions for contraction and relaxation. When a flexible resistance can be felt, maximal relaxation is present. When a firm “perineal body” can be felt, there is an increased pelvic muscle contraction.
- Put lubricant on the index finger.
- Put this lubricated finger against the hymen ring and ask the patient to press against the finger. The introitus is widened by this “press paradox.” In this way the woman pushes the introitus around the finger.
- When the finger is 3–4 cm inside the vagina, the woman is asked to stop pushing and to relax.
- The finger is carefully moved dorsolaterally, where at 5 and 7 o’clock, the thickest part of the pubococcygeal muscle, is situated.
- When fully relaxed no or little elastic resistance may be felt. When the muscles are contracted, the examiner can feel a firm or even a hard edge, which can be

painful as well. Digital pressure on the pelvic floor muscles may reproduce or intensify the woman's pain. This pain sign can be unilateral.

- Voluntary contraction of the pelvic floor muscles means that the woman is able to contract the pelvic floor muscles on demand. A contraction is felt as a tightening, lifting, and squeezing action under the examining finger. A voluntary contraction can be absent, weak, normal, or strong.
- Voluntary relaxation of the pelvic floor muscles means that the woman is able to relax the pelvic floor muscles on demand, after a contraction has been performed. Relaxation is felt as a termination of the contraction. The pelvic floor muscles should return at least to their resting state. A voluntary relaxation can be absent, partial, or complete.
- After this, the woman can be asked to contract her pelvic floor muscles and then relax again.
- When the woman does not succeed at this, the woman apparently has no control over her pelvic floor muscles.
- When contracting succeeds, but relaxing of the muscles is difficult for her, then there is evidence of an overactive pelvic floor. An overactive pelvic floor is diagnosed when the woman is not able, despite the instruction of contraction and keeping it up, to continue this for more than a few seconds or "twitching" occurs, an involuntary trembling of the fatigued musculature.
- When the woman is asked to relax the muscles, but contracts her muscles even more, this is called "paradoxical pelvic floor behavior."
- The quantification of a contraction is problematic. There is no validated scale to quantify contractions of the pelvic floor muscles. Therefore quantification beyond absent, weak, normal, or strong is not recommended.

Case History: Continued

After Jean LeBlanc has written down the new appointment, Gina says a bit reluctantly, "It was not easy for you, was it?"

Jean blushes. He realizes that he had done his utmost best, but apparently she has noticed it. Gina was his last patient that morning, so he feels he has time to ask, "What made you say that?"

Gina says, "Well, I am happy that the examination went well, but I noticed that you took a lot of time to let me relax. I appreciated that, but I must have been a difficult patient for you I think."

Jean smiles and says, "Well, I really wanted to be very careful with you, and I was afraid that this examination was harmful for you, so… I did my best indeed. But to say "it wasn't easy," no, I think we collaborated well together. What do you think?"

Gina nods, "Yes, if you can say so, you made me collaborate well with you."

"Well, I consider that a compliment" Jean relies. She smiles at him and they shake hands.

After Gina has left the room, Jean realizes that he feels that he has passed an examination and is relieved.

Conclusion

Every woman needs to undergo gynecological examinations several times in her life. This might be for routine cervical screening, for the insertion of an intrauterine device, or for the examination of a gynecological complaint. For most women, the examination is experienced as an intimate experience, which may be anticipated with embarrassment, possible pain, and fear. It is the responsibility of the physician or HCP to ensure that this examination will be a positive experience and will be carried out with adequate skills and empathy. Perhaps one should describe the effect of the educational gynecological examination as a "nonspecific treatment effect." That is, an effect that takes place on a metalevel, probably summarized in terms of attention, recognition, sense of control, and competence in the patient and involvement in the caregiver; For *how* one does it in medicine is often just as important as *what* one does. And therefore, it is advisable to approach every examination as an educational gynecological examination (EGE) as has been described earlier. In this way the woman is in control, which gives her the best opportunity for a positive experience and gives the examiner the most optimal conditions for making a proper diagnosis. For the HCP, a successful gynecological examination is an important proof of being a medical expert in gynecology.

Acknowledgments The editors gratefully acknowledge the assistance and contribution of Prof. W. C. M. Weijmar Schulz, Mrs. V. Faber, and Dr. R. van Lunsen to this chapter.

Portions of this chapter have been previously published and are reproduced by permission from: Weijmar Schultz WCM, Faber V. Een gynaecologische klacht. In: Heineman MJ, editor. Probleemgeoriënteerd denken in de obstetrie, gynaecologie en voortplantingsgeneeskunde. 2 ed. Utrecht, The Netherlands: De Tijdstroom; 2012: 47–54.

References

1. Frank JR, Snell LS, Sherbino J. The draft CanMEDS 2015; physician competency framework. Ottawa: Royal College of Physicians and Surgeons of Canada; 2014.
2. Hakimi A. The new world of emergent architecture and complex adaptive systems. 10-8-2010. Ref type: internet communication. http://blogs.msdn.com/b/zen/archive/2010/08/10/the-new-world-of-emergent-architecture-and-complex-adaptive-systems.aspx.
3. Messelink B, Benson T, Berghmans B, Bø K, Corcos J, Fowler C, et al. Standardization of terminology of pelvic floor muscle function and dysfunction: report from the pelvic floor clinical assessment group of the International Continence Society. Neurourol Urodyn. 2005;24(4): 374–80.
4. Bump RC, Mattiason A, Bo K, Brubaker LP, DeLancey JO, Klarskov P. The standardization of terminology of female pelvic organ prolapse and pelvic floor dysfunction. Am J Obstet Gynecol. 1996;175:10–7.
5. van Lunsen R. Protocol educatief en seksuologisch onderzoek bij dyspareunie/VVS-PVD/Vaginistische klachten/BBH. Amsterdam: Academical Medical Centre; 2012.