Helping Couples Cope with Women's Cancers

AN EVIDENCE-BASED APPROACH FOR PRACTITIONERS

Karen Kayser ◆ **Jennifer L. Scott**

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In memory of our mothers, Verna
B.E. Kayser, and Audrey B. Scott, who first
taught us the importance of relationships in
coping with illness.

Preface

Our work with cancer patients has been an interweaving of both our professional and personal lives. Each of us began our careers in this area around 20 years ago. In this preface, we individually describe the journeys that led us to our collaboration on this book, beginning with Professor Kayser.

I was working as a post-doctoral fellow on the Childhood Cancer Project at the University of Michigan. This was a clinical research program that offered home-based psychosocial services to families who had a child with cancer. Although I had worked as a couples and family therapist for years before the post-doc, this was my first experience with seeing how cancer diagnosis and treatment can affect an entire family system. Spending time with families in their own homes gave me a more in-depth look into not only the inner workings of the family but also the context of their coping. What intrigued me was how some families who lived in affluent suburban communities with seemingly endless resources were not adjusting to their child's illness as well as some of the families we visited in the poorest parts of the city of Detroit. Numerous questions about what constitutes good coping and what contributes to a good adjustment arose. In addition, I wondered what was the best way for a family, as a whole, to cope. Should family members take on designated roles around managing the demands of the illness? Or should everyone be using the same strategies to cope?

When I left Michigan for a university position in Boston, I continued my work on the psychosocial aspects of cancer. The directors of the social work departments at Brigham & Women's Hospital and Dana-Farber Cancer Institute encouraged my research interests. With practitioners at these institutions, I studied the experiences of mothers with cancer and how close relationships either helped or hindered their adjustment. What became clear from this research was the importance of a mutually supportive relationship for coping with the diagnosis and treatment of cancer. Mothers who had supportive relationships reported higher levels of well-being and lower levels of depression. They also engaged more frequently in positive health care behaviors. Based on these findings, I started to develop a psychosocial intervention that would enhance the coping of the cancer patient and her spouse or partner. Although there were numerous support groups available for patients with cancer, there seldom were any programs for partners of patients. More strikingly, there were no programs available for both patients and partners to work on facing the cancer together, even though the findings were quite definitive that supportive partners are crucial to the well-being of cancer patients. Instead of attempting to create support among a group of strangers, it made sense to me to work with the patient's natural support system—the people with whom she lives.

Collaborating with Dana-Farber Cancer Institute, Brigham & Women's Hospital, and Massachusetts General Hospital, I developed the Partners in Coping Program. It was evaluated through a randomized control trial and, soon after, I began reporting my findings. I then decided to disseminate the Program to practitioners who worked with patients on a daily basis. Around the same time, I met Professor Scott and we began to learn about each other's work—the similarities in our perspectives, our interventions, and our research findings. Based on the similarities of studies conducted in different countries, we decided to collaborate and put our interventions together in a book.

Just as we started our work together, I myself was diagnosed with breast cancer. Fortunately, it was detected early and successfully treated with surgery and radiation treatments. However, it gave me a new lens through which I view the cancer experience. One quickly learns that there is no right or wrong way to cope. The "best" coping method depends on one's personality and life circumstances. Also, cancer is not a simple disease—it appears in various forms, intensities, and is treated by a range of modalities. Similarly, approaches to coping with it will vary from person to person and couple to couple. One of the goals of our book is to help practitioners learn to assist partners in accepting each other's individual way of handling the stress of an illness. It is evident to me that it is not the differences between the partners that create distress but rather the way they handle these differences.

Karen Kayser

After earning my Bachelors Degree some 22 years ago, I took my first job as a welfare officer at a cancer treatment center in the city of Brisbane, in the State of Queensland, Australia. The people diagnosed with cancer, their families, and closest support persons who came to the center often had traveled long distances, many arriving from rural and remote regions of Queensland. Part of my role was to help people complete the necessary paperwork to claim government reimbursement for travel, accommodation, and associated medical costs. As we filled in the paperwork together, I observed that the couple and families who seemed to be adjusting well were very in touch with each others' thoughts and feelings about their cancer experiences. They seemed to be coping as a team. Though their individual coping styles were often different, their ways of coping seemed complementary. This seemed to give family members greater strength than if they stood alone.

The things I learned from these families, and the wonderful medical and allied health colleagues I worked with, have stayed with me for life. These experiences also inspired me to go back to university and seek further training to gain the clinical skills I felt I needed to help families cope with cancer. I completed my Masters Degree in Clinical Psychology, and then pursued my doctoral research. I did not know it at the time, but on opposite sides and in different hemispheres of the world, Karen and I were designing and testing similar programs to harness the power of couples' coping with cancer.

I developed CanCOPE, a couple-based, cognitive-behavioral coping training and support-enhancement intervention. CanCOPE was evaluated empirically through randomized control trials. It was found to be effective for improving adjustment for both the women and their partners, across a range of quality of life outcomes, including mood, coping behaviors, supportive communication, sexual intimacy, and female body image. I have since modified some components of CanCOPE to suit different types of close relationships, where the woman's nominated support person is another family member or close friend.

While I was writing up the results of my trial of CanCOPE for my doctoral dissertation, my dear mother was diagnosed with advanced stage cancer. I moved back to the family home to give support to my parents. I will be forever grateful for this time with them. With dignity, love, and a great sense of fun, they got on with living and getting the most out of each day. They showed me first hand how coping as a couple can sustain people in their darkest hours, even when this means the loss of an intimate bond that, in their case, lasted 50 years.

Jenn Scott

Acknowledgments

My development of the Partners in Coping intervention would not have been possible without the support and generosity of the staff at Dana-Farber Cancer Institute (DFCI), Brigham and Women's Hospital, and Massachusetts General Hospital (MGH). In particular, I want to thank Dr. Lawrence Shulman, Dr. Ursula Matulonis, and Dr. Eric Winer for their commitment and dedication to psychosocial care for patients and families as part of best practices in medicine. I am grateful to Nancy Borstelmann, Ann Daniels, Martha Burke, Barry Feldman, and the clinical social workers from DFCI and MGH who helped with the daily work of recruiting couples and implementing the Partners in Coping interventions. I especially appreciate the time, commitment, and fortitude of the couples who participated in my research during a difficult time in their lives. I am grateful for a grant from the Massachusetts Department of Public Health Breast Cancer Program that facilitated my research.

I also thank Oscar Barbarin who first taught me about family-based interventions with cancer patients and Tracey Revenson and Guy Bodenmann who continue to inspire me in my research on dyadic coping. I deeply appreciate the support of colleague and friend, Jane O'Rourke, who read early drafts of the manuscript and provided an experienced clinical perspective to my research.

I am grateful to my husband, Fred Groskind, whose enduring support helped me in my own journey with cancer and whose tenacious editing helped transform our academic writing into a more readable manuscript. I would like to thank my daughter, Emma, for her patience while I worked on this project. Finally, I thank Jenn Scott for joining me in this book project. Her collaboration and good humor were invaluable.

Karen Kayser

I would like to thank my colleagues and friends working in couples and health who share my passion and have inspired me over the years. In particular, I thank Karen Kayser, Don Baucom, Nina Heinrichs, and Tanja Zimmerman. I very much appreciate the warmth and support shown to me by my workmates and postgraduate students in the School of Psychology at the University of Tasmania. I respect the courage of the families involved in the "CanCOPE" projects, who worked with me

at such challenging times in their lives, and who generously shared their cancer experiences so that others may benefit. I am grateful for research grants from the National Health and Medical Research Council (NHRMC Id 9937170; Australian Clinical Trials Registry No. 12607000061437) and the Cancer Council Queensland.

I am deeply appreciative of the encouragement and understanding that my father, brother, extended family, and friends offer me, for the happiness and sense of purpose these relationships bring to my life. I am grateful to Ben for reminding me that sharing makes things 'Shiny' and to David because he always told me it was so.

Finally, thank you to my cousin Joy, who with grace and love generously shared her artistic vision of the interwoven strength and beauty that flows from "couple living in harrnony"; the theme of her woven tapestry that is the cover art for this book.

Jennifer L. Scott

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Karen Kayser
Jennifer L. Scott

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Introduction

We begin with some of the basic facts about women and cancer, to impress on the reader the seriousness of the problem for women. Breast cancer is the most common cancer among women worldwide. Over one million new cases are diagnosed each year (Seager, 2003). The incidence of breast cancer is highest in industrialized countries, with North America and Australia/New Zealand having the highest and second highest rates of new cases in the world, respectively. In both these regions, the breast is the leading site of female cancers (Parkin, Pisani, & Ferlay, 1999). One in eight women in industrialized countries will develop breast cancer over an 85-year lifespan. Thirty years ago, this number was 1 in 20. Since 1980, breast cancer rates have increased 26% worldwide (Seager, 2003).

Gynecological cancers are also common cancers among women worldwide. Globally, the third, sixth, and seventh most common forms of female cancer are cervical, ovarian, and uterine cancers, respectively (Parkin et al., 1999). An estimated 679,000 women worldwide were diagnosed with cancers of the cervix, ovary, or uterus in 1998. In 2001, an estimated 80,300 American women and 3,885 Australian women will have been diagnosed with gynecological cancers (Australian Institute of Health and Welfare, 2004; Greenlee, Hill-Harmon, Murray, & Thun, 2001). Incidence rates for uterine and ovarian cancers are also highest in industrialized countries. America has the highest incidence rate for uterine cancer and the third highest incidence of ovarian cancer in the world. In contrast, the highest incidence rates for cervical cancer are in developing countries. Cervical cancer incidence and mortality rates in Australia are both well below the averages for the more developed countries of the world, such as the United States, Canada, United Kingdom, and New Zealand. This has been attributed to the success of a National Cervical Screening Program in detecting and following up pre-cancerous abnormalities in Australia.

The good prognosis for recovery from many cancers does not mean that mortality from cancers is infrequent. Cancers are second only to heart disease as the major cause of death in American and Australian women (Commonwealth Department of Human Services and Health, 1994; Murphy, Lawrence, & Lenhard, 1995). Current trends suggest cancers may soon be the leading cause of death because the percentage of deaths related to heart disease (33.5% of all mortality) has been decreasing over the last three decades, while cancer mortality has risen to account for 23.5% of all deaths (Murphy et al., 1995). The major reason for this increase has been the rise

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in the incidence of lung cancer, a disease associated with particularly poor 5-year survival rates (Parkin et al., 1999).

Within countries there can be marked differences in cancer incidence and survivorship across people of different racial and cultural backgrounds. Not all women have benefited from medical advances in early detection and treatment. For example, amongst indigenous Australian females over 35 years of age, the incidence and mortality rates for many cancers are twice that of non-indigenous Australians (Australian Institute of Health and Welfare, 2004), particularly uterine and cervical cancers. In the United States, while there has been a decline in white women to be diagnosed with breast cancers involving large tumors (>3.0 cm), African-American women have not experienced the same trend and are more likely to be diagnosed with larger tumors. Furthermore, African-American women with breast cancer are less likely than white women to survive 5 years after their diagnosis. Their survival rate is 74%, compared to a rate of 88% for white women. Detection occurring at a later stage, disparities in treatment, presence of additional illnesses, lack of health insurance, lower incomes, and unequal access to medical care are several factors that contribute to these differences in incidence and survival. In particular, cancer patients in the United States who do not qualify for government assistance but are working at low-paying jobs with no health care benefits (the "near poor") may be the worst off in accessing the health care system (Bradley, Given, & Roberts, 2001). The high cancer incidence and mortality rates for indigenous Australians have been attributed to factors such as unhealthy diet and lifestyle, economic disadvantage, reduced access to cancer screening programs, and high levels of co-morbid health problems (Australian Institute of Health and Welfare, 2004).

Given the high rate of breast and gynecological cancers, mental health practitioners are likely, at some point, to be counseling women who are affected by these cancers. Our book is intended to assist practitioners in supporting women by using a couple-based treatment protocol. We recognize that some women with cancer may not be in an intimate relationship. In those cases, we provide information on how to involve a support person in the intervention. When the clinician can involve the patient's partner or other caregiver in counseling, he or she is not only helping the patient to cope more effectively but also supporting the partner, who may be experiencing a similar level of stress associated with the cancer. We present the essential elements from the Partners in Coping and CanCOPE interventions and explain the steps involved in teaching couples the skills that are often needed during the course of the illness. We also provide case scenarios that highlight common teaching principles and make suggestions for managing obstacles that may arise during treatment.

Organization and Content of Book

The book is organized into two sections. The first section, "Assessment: Toward an Understanding of how Couples Cope with Cancer," introduces the reader to the psychosocial challenges of cancer and a theoretical framework for understanding the concept of dyadic coping. The second section, “Intervention: Helping Couples Cope with Women’s Cancers,” introduces the reader to the techniques that are used to address particular issues related to the cancer diagnosis and treatment. Each chapter will describe the particular issue and the research findings, describe the techniques, and then illustrate them with a case from one of our programs, Partners in Coping or CanCOPE.

The primary intent of this book is to provide health and mental health practitioners with a guide to a psychosocial intervention to assist breast and gynecological cancer patients and the people close to them. However, to deliver the intervention effectively, the reader must have sufficient knowledge about the disease and its course. Otherwise, they cannot appreciate the serious challenges facing patients and their families. In Chapter 1, the reader is provided with an overview of the main psychosocial and physical tasks related to each phase of the illness course. We examine how factors of race, ethnicity, socioeconomic status, and type of treatment can affect women’s quality of life. We present brief descriptions of the two strongest predictors of long-term adjustment to cancer—adaptive coping and support processes—that the Partners in Coping and CanCOPE programs target.

In Chapter 2, we present compelling evidence that shows the extent to which couples jointly respond to life stressors and how the nature of their dyadic coping and support helps determine both partners’ adjustment to the stressful event. We describe common patterns of relational or couple-coping. These are responses to the cancer experience, expressed at the dyadic level that we have observed in our clinical research. We provide case examples to illustrate the typical coping patterns therapists might encounter in their own clinical work. Finally, we report evidence to suggest that for women with cancer, couple-based interventions may be the optimal treatment of choice and preferable to either individual therapy or peer-support groups.

Chapter 3 provides interview questions and standardized instruments that can be used to assess the impact of breast or gynecological cancers on the couple’s life. The chapter will assist clinicians to clarify each individual’s understanding of diagnosis and recommended treatment(s), assess how well each partner is adjusting, and explore relationship strengths that might facilitate coping and mutual support. We show how couples can be helped to assess the adequacy of their broader social support network for meeting the psychological demands of the cancer. To facilitate this process, we provide step-by-step instructions on how to draw a genogram, which involves a thorough analysis of the family/social network potentially available to support the couple.

Given the tremendous stress of cancer, it is important that couples develop a collaborative approach that spreads some of the demands around in order to conserve and use family energies effectively. Chapter 4 describes an intervention that helps the couple assess how they assign tasks and roles in their family and develop a distribution of tasks that is desirable, feasible, and effective. It illustrates how to help a couple identify the current task/role assignments and develop a more effective distribution of tasks.

In Chapter 5, we illustrate techniques that help partners develop an awareness of their own coping responses and assess the effectiveness of those responses. These are techniques that help deal with the emotional strain and existential issues, and practical demands of living with cancer or a partner with cancer. Often partners differ in their reactions to stress and their ways of coping with stress. The key elements of successful coping among couples are the understanding of, and respect for, each other's different ways of handling problems. Partners need to realize that there is no one right way to manage stress and they need to comprehend and support their partner's way of coping. The techniques described in this chapter further facilitate an open discussion of the impact of the person's coping style on the partner's well-being and also on the deeper existential meanings the couple ascribes to their journey.

Supportive communication skills are crucial for partners' functioning on both an individual and a dyadic level. These skills assist couples in navigating the challenges posed by their cancer experience in several ways. They help each partner assess how the other person is adjusting, augment partner's coping efforts, stay sensitive to each other's support needs, and monitor and increase awareness of the impact of the cancer experience on their relationship quality. Chapter 6 addresses the communication skills that most encourage mutual support and coping. It describes techniques for enhancing couples' supportive communication. Teaching tools include the use of tape-assisted recall to help partners identify helpful and unhelpful conversational exchanges. Couples' proficiency in fundamental communication skills is also assessed. Where appropriate, they are taught to practice the basic yet crucial communication skills. The chapter also introduces the concept of support mobilization, which identifies how a partner communicates his or her needs in order to get the support desired. Because partners need to adapt continually to new circumstances and situations, the support expected and provided by partners will also change over time. Major stressful events require that emotional support is consistent over the course of the relationship.

Chapter 7 provides techniques to help partners individually appraise their coping more broadly and to build and expand their repertoire of coping skills. The aim is to help them have greater flexibility in their ways of managing the diverse and changing challenges they may face across their cancer journey. The reader is introduced to two relaxation techniques that couples can learn—breathing and progressive muscle relaxation—and these are illustrated. Resources for further information on techniques and trainings are provided.

Although issues related to body image and sexual intimacy are common among breast and gynecological cancer patients, discussion of these issues is often avoided by oncology practitioners. Chapter 8 provides information on the potential impact of cancer treatments on couples' sexual functioning and women's body image, and the potential changes in these intimate aspects of their lives that couples may experience. A crucial need of patients and their partners is for accurate information. Myths and misinformation surrounding cancer represent an additional threat to physical closeness. Consequently, they may abstain unnecessarily from all forms of physical contact and sexual expression. The reader is introduced to fascinating evidence for the importance of partner's responses and relationship quality for sexual intimacy and how these also shape a woman's body image and self-concept. How to conduct an assessment of the couple's sexual functioning and women's self, and partner related body image, is a major focus of the chapter. In addition, there are suggestions for dealing with specific sexual and body image problems and for expanding the couple's activities to include alternative ways to be emotionally intimate.

Chapter 9 begins with a review of the current research on the impact of a parent's cancer on children. Using a developmental framework, the social, emotional, and physical needs of children who are coping with a parent's cancer are identified. The chapter provides techniques to help parents in assisting their child(ren) deal with their fears and concerns related to their mother's diagnosis, treatment, and treatment sequelae.

In Chapter 10, we address cancer as a chronic illness. Couples typically move from a pattern of adaptation which is crisis-oriented to one that attempts to normalize their current situation. This involves the acceptance of the fact that life will never be exactly the same for them as it was before the diagnosis. They are encouraged to define what is "normal" life for them as a couple. Although the medical treatment may have ended, there are likely to be emotional aspects of the experience that remain and still need attention. The purpose of this chapter is twofold: (1) to help couples normalize their lives while living with the possibility of a shorter life expectancy or of a relapse requiring further treatment and (2) to help couples for whom treatments have failed and are facing the possibility of death. Techniques that may assist in making a life review, resolving any long-standing family conflicts, and communicating important messages or meaningful good-byes are described. Through guidance from the clinician, it is possible for the couple to learn to transform an otherwise painful and traumatic experience into one in which each person grows through their connection with each other.

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Part I

Assessment: Toward an Understanding of How Couples Cope with Cancer

Chapter 1
The Nature of Cancer and Its Psychosocial Challenges

> *"I didn't know much about endometrial cancer or how it was treated before Carol was diagnosed. I've been on a steep learning curve since we heard she had this cancer."*
>
> *"Everyone's giving you advice, telling you what you should do, or not do. . .or worse still, some people tell you horror stories about the cancer battles of other people they know, as though that is going to make you feel better somehow! I know they mean well, but you have enough to take in from the experts, without every one else adding their two cents worth!"*
>
> *"I was coping ok, but I was very concerned about my son's reactions. He was 10 and another boy in his class at school had lost his mother to breast cancer. I was worried he would think I was also going to die. I didn't want him to be upset and I worried about how he would cope."*
>
> *". . . I, in fact, had a very advanced case of breast cancer by the time I was diagnosed and went through high doses of chemotherapy at the hospital and found that I had to ask for help. I needed a lot of support and needing a lot of help was something that I was not used to asking for or needing. I found that I could do it and that it helped."*

Women and their partners' reactions to a diagnosis of cancer may range widely depending on the meaning of the disease in their roles as intimate partners, parents, and workers. How couples and families cope with the demands of the treatment will also vary. Some women and the people supporting them weave treatment almost seamlessly into their lives. Others find it more difficult to incorporate another demand into their already over-extended lives. The ease with which women and the people supporting them manage the stress that accompanies cancer depends on their own personal fortitude and the supportive relationships that surround them. Cancer survivors in committed relationships who adjust well to the diagnosis and treatments say they do not fight their war against cancer alone and that their partners are their greatest allies (Bloom, 1996; Ell, Nishimoto, Morvay, Mantell, & Hamovitch, 1989; Jamison, Wellisch, & Pasnau, 1978). Many spouses say they look to the patients for inspiration and support. Couples who adapt well to their cancer experiences are suggested to engage in "couple-coping," a process of

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conjoint coping and mutual support that forms a shared approach to managing the stressors they face. To understand how cancer affects couples and how to best work with them on their psychosocial issues, practitioners must have sufficient knowledge about the disease and its course. In this chapter, we provide basic information about cancer and treatments for breast and gynecological cancers before examining the psychosocial challenges of the illness for couples.

The Nature of Cancer

Cancer is a general term given to over 200 diseases characterized by disorders of cell growth involving unrestrained, indiscriminate, and chaotic cell production. These mutated cell masses invade and destroy surrounding tissues and potentially can metastasize (i.e., spread), via the blood or lymphatic system, to seed the growth of new cancers in other parts of the body (Holland, 1998). Common symptoms associated with metastatic disease include anorexia, fever, fatigue, and pain, and the most common frequent sites of metastases involve lymph nodes, brain, skeleton, lung, and liver. Eventually many cancer cells lose their biologic function but are still dependent on the body for nutritional supply (Lenhard & Osteen, 2001). Thus, cancer is essentially “a parasite formed from the patient’s own tissues” (Wingate & Wingate, 1988, p. 91).

Once histology or cytology results confirm cancer diagnosis, the stage of disease is established, a convention that divides cancer cases into classifications that inform treatment selection, facilitate research comparing treatment efficacy, and provide prognostic estimates of survival (Lenhard & Osteen, 2001). The most commonly used nomenclature is the TNM system that classifies cancers according to the size of the primary tumor (T), the extent of disease involvement in the lymph nodes (N), or distant metastases (M) (Fleming et al., 1997; Lenhard & Osteen, 2001; Sobin & Fleming, 1997). On the basis of these TNM markers, most types of malignancies are classified into one of four possible stages. Stage I and Stage II cancers are considered early stage or localized diseases as the tumors are relatively small in size, and there are no apparent signs of lymph node involvement or disease metastases (spread). Stages III and IV cancers are regarded as later stage diseases as they involve tumors of larger size, and there is evidence of lymph node involvement and/or disease metastases. Early-stage cancers are associated with higher survival rates than later stage cancers. In addition to TNM markers, other relevant prognostic indicators include the grade of the cancer cells, based on their degree of differentiation from normal cells, and estimates of their rate of cell growth (Pfeifer & Wick, 2001). Poorly differentiated cancer cells are often associated with worse outcome than well-differentiated cancer cells (Isaacs, Stearns, & Hayes, 2001).

Five-year survivorship figure is the percentage of patients with a particular disease stage who are alive 5 years after cancer diagnosis (Garfinkel, 1995). Prognosis conventionally has been related to 5-year survivorship, though 10- and 15-year survival rates are becoming more widely used as an index of long-term survival for some types of cancers, particularly breast cancers (Henderson, 1995). The chance of recurrence of a cancer declines between 5 and 15 years after initial diagnosis and disease-free survival over this extended period approximates cancer "cure."

The 5-year survival rate for many types of localized cancers is in the order of 92%, but drops markedly to rates below 45% for later stage diseases (Wingo, Parkin, & Eyre, 2001). In breast cancers, a strong prognostic predictor is the number of positive (i.e., cancer involved) lymph nodes. Each positive lymph node is associated with a decrement in survival time. The 10-year survival rate in patients with no positive lymph nodes ranges from 65 to 70%. In contrast, 10-year survival rates in patients found to have four to nine positive nodes drop to 28%, and drop again to 18% in patients with more than 10 positive lymph nodes. Gynecological cancers include cancers of the ovary, uterine corpus, cervix, fallopian tube, vagina, and vulva. The survival rates for gynecological cancers range from almost 100% for carcinoma of the cervix in situ, which is likely to be discovered at an early stage through routine screening procedures, to 39% for ovarian cancer, which frequently is only detected once it has progressed to an advanced stage (Fields, Jones, Thomas, & Runowicz, 2001).

Treatment of Breast and Gynecological Cancers

There are four principal forms of cancer treatments: surgery, radiation therapy, medical oncology, and immunotherapy, and they are used in isolation or in combination. Treatments may be used with the intent to cure, increase survival time, or palliate the symptoms associated with advanced stage disease. There are several treatment options for breast cancer, depending on the medical circumstances and the patient's preferences. Treatment may involve lumpectomy or partial mastectomy (also referred to as breast conservation surgery (BCS)) or mastectomy (surgical removal of the breast) and removal of the lymph nodes under the arm, radiation therapy, chemotherapy, or hormone therapy. Typically, a combination of two or more methods is used, often referred to as "multimodal regimes." Treatments for gynecological cancers involve the same cancer therapies as those used in the treatment of breast cancer, though they target the pelvic region as opposed to the breast. Thus, surgery involves removal of organs in the pelvis that are affected by cancer. Depending on the diagnosis, this may mean removal of the cervix, uterus, ovaries, or all of these organs. In some cases, lymph nodes are also removed from the groin region. The most extensive surgery, usually used to treat recurrent or advanced stage cervical cancer, is a total pelvic exenteration. This involves removal of the bladder, urethera, vagina, colon, and rectum as well as the uterus, ovaries, and cervix. Usually during the operation, a new vagina is surgically crafted and two ostomies (artificial openings) for the bladder and the colon are created.

Does the Type of Cancer Treatments Affect Quality of Life?

How cancer treatments can affect quality of life is important information to share with patients as they are either making decisions about their treatment options or preparing for a treatment that has been recommended. There are many ways of describing health-related quality of life (QOL). In this book, we define it as the physical, social, emotional, functional (work), sexual, and spiritual well-being. Surprisingly, sometimes the more invasive treatments do not necessarily have the more debilitating long-term effect on a woman's quality of life as the less invasive treatments. For example, in one study, women who had breast conservation surgeries (BCS) experienced significantly greater levels of psychological distress, and worse QOL 40 months after surgery, than women who had mastectomies (Cohen, Hack, de Moor, Katz, & Goss, 2000). After controlling for stage of disease, radiation treatment, and age, women who underwent a mastectomy reported marginally worse psychological distress 6 months after surgery but significantly less psychological distress from 40 months after surgery onward than did women who underwent BCS. This finding seems counterintuitive. However, the authors explain that "women who underwent a mastectomy had more advanced disease and worse prognosis. Therefore, they may be expected to have improved mental health over time as they become more confident in remaining disease free. An alternative explanation is that women who had BCS still have an intact breast, and hence they might have increased anxiety about disease recurrence" (p. 432). Women who had the breast conservation surgery had better body image than those who had mastectomy.

Typically, it is not the type of surgery in itself that affects the quality of life, but a combination of time, treatment, and patient characteristics (King, Kenny, Shiell, Hall, & Boyages, 2000). The negative impact of mastectomy on body image was greatest among married women, particularly young married women. Married women who had breast conservation generally had very good body image regardless of age. In a meta-analysis of 40 studies comparing BCS and mastectomy, body/self-image was the only factor that significantly differed between groups: women who had BCS reported better body/self-image (Moyer, 1997).

Adjuvant chemotherapy also affects quality of life (QOL) in various ways that are different from surgery alone. In a cross-national study of approximately 1,200 breast cancer patients, the effects of timing and duration of adjuvant chemotherapy were compared. Overall, chemotherapy had a measurably adverse effect on QOL, but this effect was transient and minor compared with patients' adaptation/coping after diagnosis and surgery. Although the patients were receiving identical treatment during the first 3 months, patients who knew that their treatment would end at 3 months and were not scheduled for later reintroduction therapy reported better QOL at 3 months than those who knew their treatment would continue for 6 months. This suggests that the anticipation of future therapy can have a negative impact on patients' perceived QOL. Recurrence of cancer had a significant, negative impact on QOL, with well-being deteriorating to similar levels as that experienced during arduous treatment.

During the treatment phase of the disease experience, women with gynecological cancers may experience worse functioning in some domains of QOL compared to women with breast cancer. Greimel, Peintinger, Cegnar, Pongratz, & Thiel (2003) assessed 248 women with gynecological and breast cancers before the start of their treatments and followed their recovery for a year. While there was no difference in QOL between the different types of cancers prior to treatment, differences emerged during treatments. Breast cancer patients experienced significantly better physical and role functioning QOL than women with gynecological cancers. The researchers speculated that this difference may have been due to gynecological cancer patients being more likely to receive multimodal and intensive treatments that were associated with more debilitating and pervasive sideeffects. By 6- and 12-month follow-ups, these differences had disappeared, with breast and gynecological cancer patients showing comparable levels of good QOL.

Quality of Life in the Early Phase of the Disease Experience

While most cancer patients will survive with their disease, thousands of women and their loved ones still face the challenges of managing the medical treatments and the uncertainty and unpredictability of this disease. There is an abundance of studies on the QOL of breast cancer patients. In recent years, there has been an increased focus in the QOL literature on gynecological cancer patients. Studies tell us that there is no universal response to the stresses of cancer—a lot depends on factors such as the woman's age, stage of illness, ethnicity, and social context. Furthermore, the diagnosis does not necessarily mean a high level of psychological distress and a low quality of life. In many cases, women can ultimately transform a challenging disease such as breast cancer into a life-affirming experience, one that changes the meaning of their lives in a more positive way.

While rates of psychiatric disorders are not higher among cancer patients than in the general population, many women with cancer nonetheless experience psychological distress, often manifested by depressive symptoms (Dausch et al., 2004). In fact, the most common psychological side effect of cancer diagnosis and treatment is depression (Maunsell, Brisson, & Deschenes, 1992; Sellick & Crooks, 1999; Shapiro, Gottman, & Carrere, 2000). The behavioral manifestations of depression can include insomnia, inability to concentrate, loss of appetite, greater use of alcohol and tranquilizers, thoughts of suicide, sexual dysfunction, and disruption of daily activities (Irvine, Brown, Crooks, Roberts, & Browne, 1991). In general, the more narrowly depression is defined, the lower its prevalence (Badger, Braden, Mishel, & Longman, 2004). For example, when a clinical diagnostic definition is used, about 25% of women with cancer meet the criteria of depression (American Psychiatric Association, 1994). When depression is more broadly defined as a symptom, such as depressed mood, difficulty concentrating, and difficulty sleeping, 56% of cancer patients report depression. The concept of "depression burden" has been used to describe the degree to which depression as a side effect of cancer diagnosis and treatment is perceived as problematic, troublesome, or distressing (Badger et al., 2004). Consistently, researchers have found that how depressed a woman is initially is a strong predictor of how depressed she will be during later stages of the disease.

Posttraumatic Stress Disorder

In recent years, there has been interest in studying cancer as a traumatic event that results in symptoms similar to those women who have posttraumatic stress disorder. According to the DSM-IV criteria, two conditions are required for an event to be classified as a potential PTSD-evoking event: threat to life and strong emotional reaction. Since cancer is a chronic, life-threatening disease and most people who have been diagnosed with cancer will readily report that they reacted with feelings of intense fear, helplessness, or panic, it seems reasonable to classify it as a PTSD-evoking event. Cancer patients are likely to experience the stress-related symptoms such as repeated, disturbing memories and dreams of their cancer treatment, fears of recurrence, fears of death, and physical reactions when something reminds them of cancer treatment or their experience with cancer (Cordova et al., 1995; Hodgkinson et al., 2007). But does that mean that cancer patients are more likely to have the diagnosis of posttraumatic stress disorder? Several studies have examined PTSD symptoms in adult cancer survivors. In these studies, the cancer was identified as the source of trauma and the investigators found rates of PTSD were significantly higher than those found in the general population (1%). Some studies may overdiagnose and inflate rates of PTSD symptoms because they do not use diagnostic screening procedures or the measures used detect treatments and illness-related symptoms (e.g., numbing and arousal) that can mirror PTSD symptomatology (Shelby, Golden-Kreutz, & Andersen, 2005).

The personal and social coping resources that a woman possesses are important indicators of the likelihood of her developing PTSD. Amir & Ramati (2002) compared 39 female survivors of breast cancer with 39 women who had not been exposed to any chronic disease. Survivors had significantly higher rates of full and partial PTSD, scored significantly higher on emotional distress, scored significantly lower on physical and psychological quality of life (QOL), and exhibited coping styles significantly different from those of the control group. Whether they experienced PTSD depended on their coping style and, in particular, their ability to be able to share and express their emotions (Amir & Ramati, 2002).

In summary, most studies of PTSD and “acute stress” disorder in women with cancer find prevalence rates ranging between 3 and 10% (Andrykowski et al, 1998; Dausch et al., 2004). Among persons who are exposed to stressors such as rape, assault, or combat, 20–25% of them meet the criteria of PTSD (Green, 1994). Hence, while rates of PTSD among breast and gynecological cancer patients are higher than the general population, they are still much lower than populations that experience other traumatic events such as rape or combat (Alter et al., 1996; Cordova et al., 1995).

The Course of Recovery of Quality of Life

The first 12–18 months following diagnosis seem to be potentially the most tumultuous time for women with breast and gynecological cancers and may involve a decline in emotional and physical well-being. However, after treatments, there seem to be distinct trajectories in women's recovery of their psychological well-being and QOL. For many women, their mood gradually returns to pre-morbid levels (Glanz & Lerman, 1992; Rowland et al., 2000; Zemore & Shepel, 1989). Other women struggle with cancer-related stress and other emotional issues even years after the diagnosis. In a study that assessed women 2 years after diagnosis, one out of five women reported a high level of intrusive thoughts about breast cancer (Bleiker, Pouwer, van der Ploeg, Leer, & Ader, 2000). The level of intrusive thoughts was rather stable over time, with about 60% of the women who scored high initially also scored high 2 years later. In addition, women who reported a large number of health complaints and problems with sleeping initially appeared to be at risk of experiencing high levels of distress 2 years after diagnosis. Concerns related to quality of life seem to heighten when treatment has been completed, and the uncertainty of recurrence dominates their thinking. Lutgendorf, Andersen, et al. (2000) found a similar pattern of problems with sleep and fatigue in 98 women with gynecological cancers who were assessed 12 months after diagnosis. Age seems to be a strong predictor of long-term functioning. Younger women with breast and gynecological cancers are often found to be more vulnerable to long-term disruption to QOL, particularly their body image and sexual life (Andersen, Anderson, & DeProsse, 1989; Baucom, Porter, Kirby, Gremore, & Keefe, 2005–2006; Fobair et al., 2006).

It is important not to be pessimistic about the long-term impact of cancer on people's lives. A large proportion of women improve in their sense of well-being and QOL (Rowland et al., 2000; Wenzel, 2002). This good QOL outcome is true even for women who have undergone extensive treatments such as pelvic exenteration, a procedure that many people might deem quite mutilating or disfiguring (Roos, de Graeff, van Eijkeren, Boon, Heintz, 2004). There are also heartening findings from at least three methodological rigorous studies that, taken together, have assessed the long-term QOL outcomes in 1,028 women with either breast or gynecological cancers (Capelli et al., 2002; Wenzel et al., 2002). The researchers also compared QOL in the cancer survivors to QOL in age-matched healthy women in the general population. These studies all found that the majority of women with cancer had comparable levels of QOL to women who have never had a major illness. Furthermore, the researchers found that in some QOL areas, women with cancer had more positive psychosocial adaptation than the comparison group. Their life outlook had improved, their interpersonal relationships were enhanced, and they experienced spiritual and religious growth. These results support the notion that cancer is a transforming event that can produce long-lasting changes of both a positive and a negative nature. Hence, now researchers and practitioners are reexamining their earlier assumptions that breast cancer is an entirely negative experience.

Posttrauma Growth

Recently, researchers have investigated the phenomenon of benefit finding or posttraumatic growth among breast cancer patients. Coined by Tedeschi & Calhoun (1995), posttraumatic growth occurs when an individual perceives positive changes in his or her life as a result of their struggle with a life crisis or traumatic event. In order for posttraumatic growth to occur, there needs to be a severe external event like the cancer diagnosis that threatens death or serious harm to oneself or a significant other. As a consequence, individuals may feel intense fear or helplessness and their basic assumptions about themselves and the world may be challenged. The crisis triggers a cognitive process in which the person searches for meaning in the face of great uncertainty and vulnerability (Calhoun & Tedeschi, 1998). This process of constructive thinking leads to positive changes in the perceptions of self, sense of relating to others, and philosophy of life (Weiss, 2002). In a study comparing breast cancer survivors with a healthy comparison group matched by age and education, the breast cancer group showed a pattern of greater growth as shown by their relating to others, appreciation of life, and spiritual change (Cordova, Cunningham, Carlson, & Andrykowski, 2001). This perspective of cancer as a traumatic stressor has lead to the development of new theoretical frameworks and interventions for cancer patients (Baum & Posluszny, 2001; Tedeschi & Calhoun, 1995) and also presents a more complete picture of the experience of coping with breast cancer.

Quality of Life Among Cancer Patients: Considering Race and Ethnicity

Since the rates of cancer incidence and deaths may vary according to race and ethnicity, is there a corresponding variation in quality of life among these different groups of cancer patients? In an investigation that compared breast cancer survivors from four groups—African-Americans, Latinas, Asian-Americans, and Whites—few differences were found (Giedzinska, Meyerowitz, Ganz, & Rowland, 2004). Women across ethnic groups were similar on many quality of life and psychological variables. However, there were several areas of relatively greater distress for some groups of women. Latinas reported worse mental health and emotional well-being than African-Americans and more physical symptoms than women in any of the other ethnic categories (even after controlling for demographic and medical factors). Latinas reported the highest number of body image problems. African-Americans found more meaning in life as a result of having breast cancer than White, Asian-American, or Latina women. There were no differences among these groups on depression. Overall, the quality of life of African-American breast cancer patients is better than that of others in areas of social support, sexual function, and finding meaning (Giedzinska et al., 2004). One limitation of this study was the small sample of Asian-Americans, and hence, caution needs to be taken in generalizing the findings to this group of women.

Given the additional challenges of racism that minority women face, it is puzzling why there are not greater disparities on quality of life between minority and nonminority groups of women. How we measure QOL may partially explain this lack of disparity. According to some researchers, quality of life measures more accurately capture the gap between people's experiences with cancer and their expectations. If a woman from a minority group expects very little regarding how she is treated by the health care system and its providers but experiences an outpouring of support and excellent medical treatment, her quality of life scores may be higher than the woman who expects a lot from her care but experiences little. Also, the QOL measures typically do not measure socioeconomic well-being—an area where there may be a significant disparity among racial groups. Box 1.1 offers some suggestions for standardized instruments that can be used to measure quality of life and to assist practitioners with assessment of an individual patient's adjustment to breast or gynecological cancers.

Quality of life in Australian cancer patients from culturally and linguistically diverse backgrounds is not known. This is of great concern given that almost one-third of women affected by breast or gynecological cancers come from these minority groups. The first national assessment of QOL and unmet needs of this population is currently being undertaken (Psycho-oncology Co-Operative Research Group [PoCOG], 2007). Clearly, an important clinical research focus in the coming years needs to be identifying the needs of these families and exploring the best ways to provide them with psychosocial support for their cancer experiences.

Quality of Life of the Partners of Women with Cancer

Besides impacting on a woman's individual psychological well-being, cancer can subject her partner or spouses to considerable stress (Germino, Fife, & Funk, 1995; Hannum, Giese-Davis, Harding, & Hatfield, 1991; Manne, 1998; Morse & Fife, 1998; Northouse, Templin, Mood, & Oberst, 1998). A woman's cancer diagnosis can often expose her partner to heightened anxiety, depression, feelings of being unprepared to help the woman, fear of losing the partner, and somatic preoccupations (Lethborg, Kissane, & Burns, 2003; Northouse & Peters-Golden, 1993; Sabo, 1990). Husbands commonly suffer from postsurgical distress and mood disturbance after a wife's surgery (Northouse & Swain, 1987) and express problems concerning sexual intimacy (Harwood & O'Connor, 1994; Sabo, 1990). Generally, husbands feel unprepared to cope with their own emotional reaction to their wife's cancer and its treatment and experience similar levels of distress as their ill wives (Omne-Ponten, Holmberg, & Sjoden, 1994; Walker, 1997). For example, Baider & Denour (1999) found that husbands whose wives were 8–34 months postmastectomy reported nearly as many adjustment problems created by the mastectomy as did the women.

Even after treatment ends, fear and worries of recurrence tend to remain for both patients and their partners. The limited literature suggests that patients openly express their fears of recurrence, but spouses may keep these fears to themselves, hoping to spare their wives from additional burden or worry (Germino et al., 1995). As a result, the partners can experience two conflicting responses—the fear of recurrence and the need to be optimistic and cheerful for the patient. When asked, women with breast cancer indicate that they would like to hear about their spouses' fears (Germino et al., 1995). These results point to the importance of open communication between partners when facing complex cancer issues. In general, the research literature reveals that partners of women with cancer have four major concerns: (1) dealing with anxiety over negative outcomes associated with cancer, (2) helping the patient cope with the emotional consequence of cancer, (3) managing the adjustments and disruptions of daily life resulting from the disease, and (4) uncertainty about discussing concerns related to the disease with the patient.

However, the long-term adjustment of partners may also follow similar patterns of recovery as their spouses. Recent studies find that men, who report posttrauma growth following their spouses' breast cancer diagnosis, tend to be in relationships with women who also report posttrauma growth. This suggests that while partners may be affected by the hard times of the cancer journey with their spouses, they may also share the good that comes out of their shared experiences. (Manne et al., 2004; Weiss, 2004b).

The Role of Partner Social Support in the Adjustment to Cancer

Satisfaction with the partner's support predicts good psychological adjustment to cancer. Numerous studies suggest that women report better emotional adjustment after a diagnosis of cancer if their husbands or partners are perceived as highly supportive (Helgeson & Cohen, 1996; Neuling & Winefield, 1988; Wortman, 1984). Furthermore, posttraumatic growth from the cancer experience is positively related to support from the spouse—for both patient and husband (Calhoun & Tedeschi, 1998; Weiss, 2004a, 2004b).

When considering all the sources of support, patients often identify their husbands or partners as their most important confidant from whom to seek support (Figueiredo, Fries, & Ingram, 2004; Maunsell, Brisson, & Deschenes, 1995). Although women may seek support from other sources (friends, neighbors, co-workers), these alternative sources often cannot compensate for the lack of marital support when coping with a life-threatening illness (Cutrona, 1996). A comprehensive study of 1,715 women with breast cancer validates this point. The support provided by friends and family was not perceived by the women as important as the support received from a spouse or significant other (Penman et al., 1986). What appeared to be most important were the women's perceptions that comfort, concern, positive regard, affection, and help with problems would be available from people close to them. Marital status, by itself, was not an important predictor of adjustment. Simply put, being married is not enough to cope successfully with cancer.

There are three types of social support that are commonly recognized (Blanchard et al., 1995). The first is emotional support, which is support that conveys feelings of acceptance, esteem, caring, or concern. Informational support is the communication of opinion or fact used to guide or advise. Practical or instrumental support is the provision of tangible materials or practical assistance, such as transportation or money. Researchers also distinguish between *perceived* and *enacted* support. Perceived support is the recipient's subjective appraisals of the availability or provision of support. Enacted support is the actual support behaviors or actions that occur (Cohen, 1988; Lakey & Lutz, 1996).

Patients rate emotional support as the most helpful form of partner support (Blanchard et al., 1995; Dunkel-Schetter, 1984; Manne, 1994; Martin, Davis, Baron, Suls, & Blanchard, 1994; Neuling & Winefield, 1988; Rose, 1990). Emotional support is often conveyed through communication (Badr, Acitelli, Duck, & Carl, 2001) and involves patients' perceptions of partners' expressions of concern, affection and caring, willingness to listen to worries, and discuss important issues (Lichtman, Taylor, & Wood, 1988; Sormanti & Kayser, 2000; Taylor, Falke, Shoptaw, & Lichtman, 1986). Emotional support facilitates the expression of feelings that may reduce distress and lead to an improvement of interpersonal relationships, thus providing an element of meaning to the disease experience. Partners' responses seem to facilitate women's cognitive processing of their experiences of cancer. Talking about a traumatic experience even for a few minutes, especially with someone who validates the speaker's experience, is associated with reduced intrusive thoughts (Lutgendorf & Antoni, 1999) and enhanced adaptation to stress (Kennedy-Moore, & Watson, 2001; Lepore, Ragan, & Jones, 2000). In cancer patients, talking about the cancer to someone who is perceived to respond in an open and non-critical manner is associated with reduced frequency of intrusive and avoidant thoughts (Cordova, Cunningham, Carlson, & Andrykowski, 2001; Lewis et al., 2001; Manne et al., 1999), less distress generated by intrusive images, and better psychological adjustment (Cordova, Cunningham, Carlson, & Andrykowski, 2001; Lepore & Helgeson, 1998; Manne, Dougherty, Veach, & Kless, 1999).

Satisfaction with emotional support is associated with reduced depression and anxiety, and better quality of life (Helgeson & Cohen, 1996; Peters-Golden, 1982). The woman's report of the frequency of emotional support behaviors is correlated with positive mood (Alferi, Carver, Antoni, Weiss, & Duran, 2001; Mesters et al., 1997; Primomo, Yates, & Woods, 1990; Vinokur, Threatt, Vinokur-Kaplan, & Satariano, 1990), positive self-esteem, and good physical and role functioning (Brady & Helgeson, 1999; Mesters et al., 1997; Roberts, Cox, Shannon, & Wells, 1994; Vess, Moreland, & Schwebel, 1985a, 1985b).

When women with cancer are asked what type of support is unhelpful, they frequently report that "unhelpful behavior" is the failure to provide emotional support. These behaviors include partners' disengagement, emotional withdrawal, trivialization of concerns, minimization of the impact of cancer on the woman's life, forced cheerfulness, and criticism of how the woman is coping (Dakof & Taylor, 1990; Pistrang & Barker, 1995). Avoidance of cancer-related discussion is a common unhelpful behavior (Henderson, Davison, Pennebaker, Gatchel, & Baum, 2002) and predicts worse long-term adjustment in women and their partners (Manne et al., 1999).

Emotional support provided *by* cancer patients can also play a critical role in their partners' adjustment. Marital support was a significant predictor of both emotional and physical adjustments for husbands of breast cancer patients (Hoskins, 1996). Husbands who were dissatisfied with the emotional support they received experienced significantly more negative emotions, such as worry, tension, and uneasiness, which continued throughout the year-long study. In contrast, husbands who felt supported by their ill wives experienced fewer negative emotions and a sense of psychological well-being, such as enjoyment in talking with others, finding work and other things of interest, and feeling needed and useful. In addition, husbands' physical symptoms were related to their unmet needs for support as late as 1 year after the patients' surgery.

Partners' supportive responses also seem to facilitate women's acceptance of their postsurgery appearance. In close relationships, a partner's perceived acceptance plays a significant role in shaping a person's self-image (Drigotas, Rusbult, Wieselequist & Whitton, 1999). In women with cancer, beliefs about their attractiveness to their partners following cancer surgery predict women's long-term psychological well-being, as well as their satisfaction with their appearance and treatment choices (Stanton et al., 1998). However, the role of partners' responses in women's recovery of sexual intimacy and functioning has not been explored.

Relatively few studies have investigated instrumental or informational support. Results from a small number of studies suggest that women also desire instrumental support from partners (Manne, Taylor, Dougherty, & Kemeny, 1997), such as partners' taking on additional household responsibilities while the women undergo and recover from treatments (Rose, 1990), or providing transportation to and from treatment sessions. These types of instrumental support are rated as helpful (Martin et al., 1994; Neuling & Winefield, 1988; Rose, 1990; Smith, Redman, Burns, & Sagert, 1985). In contrast, women are more likely to seek information from health professionals and report higher satisfaction with information about their diagnosis and treatment when it is provided by professionals rather than by partners (Neuling & Winefield, 1988). In summary, women primarily seek emotional and instrumental support from their partners.

Summary of Research

1. A large percentage of women in the early stages of cancer will experience psychological distress. While some will experience stress-related trauma, rarely do they develop PTSD or meet the criteria for a psychiatric diagnosis.
2. Whether this psychological distress continues over time depends on the type of treatment and its duration. Sometimes women with the least invasive treatment experience more distress at a later time.
3. Among four groups of women (African-Americans, Asian-American, Latinas, and Whites), Latinas seem to fare the worse psychologically. Despite the challenges of coping with racism, African-Americans often find meaning in the cancer experience and are not worse off psychologically compared to white women. Research is limited on Asians and their adjustment to cancer.
4. Research on QOL and adjustment to cancer among indigenous Australian women and their families is extremely limited.
5. Partners also experience distress related to the breast cancer—at times as much as the patient, sometimes even more.
6. Partners' emotional support is fundamental to women's psychosocial adjustment to cancer through the entire cancer experience.

A Couple-Based Intervention for Women Coping with Cancer

Our book describes a series of techniques and training strategies to help couples improve their ability to take on the demands of breast and gynecological cancers. This couple-based intervention aims to help couples develop satisfactory reallocation of family tasks/roles, foster effective cognitive coping, learn new coping strategies, facilitate couple communication, promote supportive and intimate behaviors, deal with children's responses to cancer, and build a social support network. The intervention sessions can be implemented over 8–10 sessions during the first year after the cancer diagnosis. Later sessions are also likely to be useful for couples who are well beyond their first anniversary after cancer. The interventions were derived from two programs: Partners in Coping Program (PICP) and CanCOPE. Both programs have been empirically evaluated in randomized clinical trials with samples of 50 couples in the PICP (Kayser, 2005) and 94 couples in CanCOPE (Scott et al., 2004).

Organization of the Intervention Sessions

Work with couples can begin as soon after the diagnosis as feasible depending on the readiness of the couple to engage in emotion-focused and problem-solving discussions. Sessions typically last at least 1 h and can be conducted in a variety of outpatient settings or in the couple's home.

The sessions are typically scheduled biweekly and stretch over a period of 4 months within the first year of the diagnosis. However, this schedule can be adapted to fit the needs of the couple and the clinician's schedule. The first several months after diagnosis can be the most stressful time for patients and their partners, as they learn to accept the diagnosis of cancer, anticipate treatment, make adjustments to the treatment regimen and any side effects, and live with the uncertainty of cancer. The sessions are organized to move from less personal and instrumental issues to more intimate and emotion-focused issues. However, depending on the particular needs of the couple, this order can be altered. For example, if the partners are having difficulty listening to each other's feelings, the clinician may want to move the communication session earlier in the program. The session on caring for children can obviously be skipped if the couple has no children. There is some flexibility in sequencing the sessions, but it is advisable to schedule the more intimate and emotion-focused sessions later in the program, after a working relationship and rapport between the clinician and couple have developed.

Structure of Sessions

Each session has a specific theme. Although the theme is the central focus of each session, the time can be organized using the following sequence:

1. Checking how the couple has been doing since the previous session.
2. Following up on any homework assignments.

3. Addressing the day's theme or training techniques.
4. Assigning homework and planning for next session.

After each session, the clinician is encouraged to write process notes regarding the couple's coping, their interactions during the session, and any issues or concerns that arose during the session.

Instructions Before Implementing Techniques

First, your work with the couple will likely be short term and needs to be focused and structured. Therefore, we would recommend following the components as described in this book as closely as possible. If the clinician does not direct the assessment interview (or any of the other sessions), the couple (and therapist) can easily get sidetracked and discuss topics that are not relevant to the purpose of your meeting. While following a structured format may feel awkward for clinicians who prefer more "free-flowing" interviews, couples who have participated in our programs have expressed that the structured format actually helps to create a feeling of safety or containment to express their innermost feelings.

In the following chapters, we provide a script for each session that includes the topic and discussion questions. At the end of the chapter, there may be boxes and handouts with additional information or illustrations that clinicians can give the couple. While implementing the techniques with couples, the clinician should try to follow as closely as possible the order of the elements of each session as outlined. However, if the couple discusses a topic or question before you bring it up, do not repeat the question. At times, the couple may digress or spend an inordinate amount of time on one topic, so use your judgment in redirecting them to the session's outline. All the elements of each session are intended to be covered in approximately 1 h.

'At the end of each' session, we also provide tips on how to adapt the session content to situations where the woman's support person is someone other than a partner, such as another family member or a close friend. These are based on a recent randomized control trial of an adaptation of CanCOPE, involving 60 women coping with breast cancer and their nominated support persons. Preliminary results show that compared to women in a medical information control condition, women and their support persons who received CanCOPE showed superior functioning across a range of QOL indices (Scott et al., 2000, 2003). The results suggest that many of the couple-based mutual support and coping skills can be successfully modified to meet the needs of different types of support dyads.

Although this book attempts to be complete in providing the clinician with the necessary direction in implementing the interventions, there are several clinical skills that are especially important. These should be used throughout each session:

- *Expressing empathy*—reflecting and validating partner's feelings.
- *Eliciting feedback*—asking for feedback from a partner on what the other partner has said (e.g., "How do you feel when you hear ....").
- *Reframing*—giving a more positive interpretation of a partner's statements about the other partner or about oneself.

- *Clarifying*—restating a partner's communication in order to clarify what was said.

It is also important to ensure that *each* partner is asked the questions and is given equal time to respond to them.

Problem-Solving Paradigm

When problems or decisions are discussed, the following problem-solving process can be useful.

1. Each partner identifies and expresses their individual needs and feelings about the issue.

   Example: **Wife**: "I need help with the physical and manual work around the house." **Husband**: "I need quiet time to do paperwork at home since I'm staying home from my office more."
2. Partners together generate alternative solutions.

   Example: Pick up food "to go" instead of cooking, ask girl next door to help with washing dishes and be a "mother's helper," hire cleaning company, order groceries online, ask neighbor to watch children at neighbor's house, etc.
3. Both partners discuss the advantages and disadvantages of each idea.

   Example: An advantage of hiring outside help is that it would relieve the housework burden. A disadvantage would be the cost. Asking friends and neighbors would be less expensive and would eliminate some of the burden.
4. The partners agree on one idea and make a plan to implement it.

   Example: The couple makes a list of people from whom they can ask help and the type of help. They send an email to people on the list asking if they can help.

Crisis Management

While working with couples around cancer issues, crises in a couple's relationship may occur and additional counseling for the couple may be called for. Examples include a relationship that has had problems prior to the diagnosis of cancer and takes a turn for the worse; or a partner may suddenly threaten to leave the other partner; or a partner is found to have a history of significant psychiatric illness or severely traumatic events that debilitate their current functioning. The couple may also experience life stresses that are unrelated to the cancer but place an inordinate amount of stress on the relationship. Basically, these are situations that cannot be adequately addressed by the protocol in this book and require a referral outside of the program. Referral sources may include National Association of Social Workers, American Association for Marital and Family Therapy, The American Psychological Association, The Australian Psychological Society, Australian Association of Social Workers, and Relationships Australia. The clinician will need to decide if it is still appropriate for the couple to continue with the cancer-related program while attending an outside therapist.

Box 1.1 How Do You Measure Cancer-Related Quality of Life?

Along with checking on the validity and reliability of measures, you need to determine which measurements will be appropriate for your purpose. Will you be using it primarily for research or for clinical assessments? The following instruments are commonly used in the research with cancer patients, and some of them may be useful to practitioners who are interested in assessing quality of life for treatment planning with their patients.

Dimension	Measure and reference	No. of items	Examples of items	What is the item's clinical relevance?
Patient's quality of life (physical, social/family, emotional, functional, additional concerns specific to type of cancer)	Functional Assessment of Cancer Therapy (FACT-G) (Cella, Tulsky, Gray, et al. 1993)	27 (additional 7–10 items specific to type of cancer)	"I am bothered by side effects of treatment" "I get emotional support from my family" "I worry that my condition will get worse" "I am content with the quality of my life right now"	Higher scores = higher overall quality of life for cancer patient
Emotional well-being of partner	Quality of Life Questionnaire for Spouses (QL-SP) (Ebbesen, Guyatt, McCartney, & Oldridge (1990)	14	"Felt concerned or worried?" "Happy, satisfied, or pleased with personal life?"	Higher Score = higher level of emotional well-being
Interference of illness in caregiver's life	Illness Intrusiveness Scale (Binik, Chowanee, & Devins, 1990)	13	"How much does your partner's illness and its treatment interfere with your: Health, Work," etc.	Higher Score = more illness intrusiveness & lower well-being

Both members of couple complete				
Level of distress (symptom distress, interpersonal relations, social role)	Outcome Questionnaire (OQ45) (Lambert, Morton, Hatfield, Harmon, Hamiltion, Reid, et al., 2004)	45	“I get along well with others” “I am a happy person” “I feel hopeless about the future”	Higher score = greater level of disturbance
Depression in general population	Centre for Epidemiology Studies Depression Scale (CES-D) (Radloff, 1977)	20	“I felt depressed”	Higher score = greater level of depression
Symptoms of PTSD	PTSD Checklist (PCL) (Blanchard, Jones-Alexander, Buckley, & Forneirs, 1996)	17	“Repeated, disturbing dreams of a stressful experience?”	Meets criteria for PTSD = clinical cut-off $\geq$ 50, with symptoms persistent at least 1 month or longer
Overall life satisfaction despite cancer	Satisfaction with Life Scale (Diener, Emmons, Larsen, & Griffin, 1985)	5	“If I could have my life over again I would change almost nothing”	Higher score = greater life satisfaction
Threat posed by cancer	Constructed Meaning Scale (Fife, 1995)	5	“I feel my cancer experience has changed my life permanently so it will never be as good again”	Finds the cancer very threatening or negative for life. Higher score = more positive meaning
General optimism	Life Orientation Test-Revised (Scheier, Carver, & Bridges, 1994)	10	“I hardly ever expect things to go my way”	Has a generally optimistic outlook on life
Cancer-coping self-efficacy	Cancer Behavior Inventory (Version 2.0) (Merluzzi, Naim, Hegde, Sanchez, Dunn, 2001)	33	“I am confident in my ability to manage treatment side effects”	Has self-efficacy for coping with common cancer challenges and the areas they find (or fear will be) difficult to manage

NB: For scales that both members of the couple complete, some items should be reworded for the person who is not the patient (e.g., “for my experience of their cancer”).

Box 1.2 Types of Stresses Related to Cancer

Medical stressors
At the time of diagnosis, there are medical stresses associated with negotiating a complex health care organization, reading and processing a wealth of medical information, and making treatment decisions. Treatments, such as surgery, which alter a woman's body image and sexuality, and postsurgical chemotherapy, with its possible side effects of nausea, vomiting, fatigue, and hair loss, challenge a couple's ability to cope. There are concerns about leaving family or work unattended in order to enter the hospital, attend clinic visits, or deal with being ill from the chemotherapy.

Social stressors
This type of stress may be experienced by the couple as they disclose the cancer diagnosis to friends and family (Chesler, & Barbarin, 1987). Decisions about whom to tell and from whom to elicit support need to be made. It is not unusual for some social relationships to change, either becoming closer or more distant. Feeling uncomfortable with the diagnosis, some friends may treat the couple differently and avoid social contact. Social and recreational activities may change for the couple as they need to spend more time at home or desire to be with each other.

Emotional stressors
The *emotional stressors* include depression, sadness, and anxiety. The behavioral manifestations of these emotions can include insomnia, inability to concentrate, loss of appetite, greater use of alcohol and tranquilizers, thoughts of suicide, sexual dysfunction, and disruption of daily activities. Typically, distress increases during the first year after the cancer diagnosis but then patients often return to a pre-morbid level of emotional well-being (Charles, Sellick, Montesanto, & Mohide, 1996; Kayser, & Sormanti, 2002; Polinsky, 1994; Stanton & Snider, 1993).

Similarly, emotional stress of the "healthy" partner may include anxiety, depression, feelings of inadequacy about their ability to help their partners through the crisis, and somatic preoccupations are common (Sabo, 1990). Many husbands feel unprepared to cope with their own emotional reaction to cancer and its treatment and experience similar levels of difficulty in making psychosocial adjustment as do their ill wives (Walker, 1997).

Existential stressors
A final type of stress that is experienced by couples is existential. This stress involves issues around the meaning and purpose of life, the unfairness of the disease, and the possibility of death. However, little is known about how a

couple copes with existential issues associated with a cancer diagnosis. For example, how do they make meaning of the illness in their lives? Couples' efforts to make sense of their experience suggest an attempt to create order out of the chaos they are experiencing and perhaps to gain some sense of control over the uncontrollable as they cope with cancer (Nadeau, 1998).

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Chapter 2
Why Work with Couples?

> *"We share decisions, we share the research. One of us isn't running off saying 'this is what I'm doing. I don't care—it's my disease.' It's shared—it's a we-disease."*
>
> *"I saw it [the cancer] in some way as guaranteed to be relationship building, we were bound to learn a lot, and have to deal with a lot and that's another kind of gift in this—that to deal with crisis and build through it—is good for the relationship we want."*

The stress of a patient's cancer can easily be felt by her partner so that the cancer becomes a shared stress or a "we-disease." In this chapter, we look at how couples experience the cancer diagnosis and treatment and the ways they cope together with the illness. As practitioners, we are particularly interested in understanding the process of dyadic coping and the characteristics associated with a couple's coping that lead to a positive adjustment to cancer.

The Interdependence of Partners' Responses to Cancer

A series of studies have found what most clinicians have already observed among couples coping with cancer: many times the mood of one partner can affect the mood of the other partner, producing a strong correlation between their levels of adjustment. Feelings of hopelessness and emotional distress are easily transferred from one partner to the other. Husbands and wives report similar levels of stress in trying to carry out their usual roles at home and work. This similarity in adjustment to the cancer not only occurs at diagnosis, but also continues over time. For example, when measuring their adjustment at three times (time of diagnosis, 60 days later, and 1 year later) moderately high correlations between patients and husbands were found on each of the adjustment measures (Northouse, Templin, & Mood, 2001). How well husbands adjusted after 1 year had a direct effect on how well their wives adjusted 1 year after the diagnosis. Furthermore, 2–3 years after diagnosis and treatment, wives and their husbands were still showing similar levels of emotional adjustment (Carter & Carter, 1993).

The downside of the strong correlation between partners' adjustment is that when both partners experience similar high levels of distress, they are most at risk for long-term adjustment difficulties. What is the mechanism by which partners' moods

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and adjustment influence each other? A simple explanation may be that the listening and empathizing with a partner's plight and mood may lead to a transfer of mood and emotions to the other partner. Even without empathizing with the person's feelings, just observing a spouse's negative mood can alter the partner's mood. While this spillover of mood may occur, we view the process as more complicated.

The Connection Between Partners' Coping Strategies and Adjustment to Cancer

Just as there is a reciprocal effect of mood between partners, the ways in which each individual manages stress also affect the other. Indeed, studies find that the coping strategies used by one partner affect the other partner's adjustment to the stress of the illness. There is a reciprocal influence between individuals in how they react to stress. They shape each other's coping, and their coping responses, in turn, shape the quality of the support they provide each other. Here are some examples from research. Wives' positive adjustment to breast cancer has been associated with:

- Husbands' use of more problem-focused coping (Ptacek, Ptacek, & Dodge, 1994)
- Husbands' use of external control-resignation coping (Hannum, Giese-Davis, Harding, & Hatfield, 1991)
- Husbands' use of active engagement coping strategies (Kuijer et al., 2000)

Women with cancer are more likely to feel distressed when:

- Husbands use wishful thinking to cope (Ptacek et al., 1994)
- Husbands use denial or optimism (Hannum et al., 1991)
- Husbands are overprotective toward them (Kuijer et al., 2000)

In a similar vein, breast cancer patients' coping strategies also impact their husbands' adjustment. Husbands adjust better when:

- Wives use optimism as a way to cope (Hannum et al., 1991)
- Wives use more problem-focused coping and less avoidance (Ptacek et al., 1994)
- Wives do not use wishful thinking (Ptacek et al., 1994)

These findings illustrate the significant relationship between the coping of one spouse and the adjustment of the other spouse. But we also know from research that how a couple copes together influences an individual partner's well-being. Partners engaged together in coping tend to be communal in their approach to coping; that is, each partner sees that it is in his/her self-interest to approach and manage the stress together. Their communication of support is sophisticated in that they not only acknowledge and validate each others' feelings, but also tend to view a stressful situation as "our" problem, and share the burden and responsibility for managing the problem in a way that balances both individual and relationship needs.

How Is Coping Related to Partner Support?

There is an interaction between individual coping and mutual support processes among couples. For example, healthy partners' appraisals of both their own coping and the coping of the diagnosed partner influences the types of support they report offering to their partner (Kuijer et al., 2000). The type of support partners provide, in turn, affects the coping behaviors employed by patients (Manne & Glassman, 2000). Moreover, patients' coping behaviors may signal the type of support they need and serve to mobilize or discourage support from partners. In fact, individual coping and support processes appear so intertwined that some coping researchers have concluded that the ability to mobilize the desired type and amount of support from significant others is a coping skill in itself (Bodenmann, 2005; Kennedy-Moore & Watson, 2001; Stanton et al., 2000). As an illustration, a partner interprets the other partner's not talking about the cancer as coping well and therefore, offers little support to the other. In contrast, a partner who openly expresses fears about the cancer may be offered a lot of support from the partner, who interprets the concerns as not coping well with the cancer. Thus, couples who are satisfied with the support they give and receive may be skilled in communicating their support needs to each other (Duck, 2002). They mutually shape the nature of their support processes in a way that positively enhances both partners' adjustment to cancer.

Support, then, should be viewed as a mutual activity rather than an individual one. When a partner has cancer, she not only is the recipient of support but provides support to her partner. Typically the value of support is assessed from the perspective of only the recipient and not the provider. Many patients show concern about the effects of their cancer on loved ones and attempt to support those loved ones, while also seeking support from them (D'Errico, Galassi, Schanberg, & Ware, 1999). There is much evidence to suggest that, for a person in a committed relationship who is coping with a severe illness, a major influence on their adjustment is mutual support between partners. It is widely accepted that partner interaction is so crucial in coping with a major crisis that, for the best outcome, the couple should conjointly cope with the stress. Thus, the two partners should interact in ways that positively influence each other's mood and methods of coping.

To illustrate the importance of this couple or dyadic focus, consider the following two studies of couples coping with breast cancer. First, Skerrett (1998) interviewed 20 couples about their coping, focusing on their communication, beliefs regarding illness and health, problem-solving techniques, feelings of loss and disfigurement, and other topics. Based on the interview data, the couples were categorized as either resilient or problematic. Most of the 20 couples were viewed as resilient: They had a philosophy of coping that was mutual and served as a basis for dealing with the ongoing demands of the illness. They strongly believed that they were "in it together" and served as each other's confidante, advisor, and sounding board. Most talked openly about cancer but did not allow the talk of the illness to dominate their daily living.

In contrast, there was a small cluster of "problematic" couples for whom breast cancer had a devastating impact on their lives. The illness seemed to color every aspect of their interaction. The “problematic” couples were unable to formulate a common coping philosophy. Their communication took the form of one of the two patterns: individual retreat into withdrawal and silence or, conversely, reactive, anxiety-driven, tell-all communication. They struggled to find ways to understand and make meaning of the experience.

In the second qualitative study, Zunkel (2002) identified four relational or dyadic processes in which each partner contributed to coping with breast cancer. These were: (1) sharing in the patient’s recovery, (2) helping her, (3) normalizing the household, and (4) moderating or minimizing the intrusion of the cancer. Zunkel (2002) concluded that there were two distinct types of processes: an acknowledging type and a moderating or minimizing type. The acknowledging process attempted to incorporate the illness into family life; couples openly expressed their feelings about its presence and acknowledged their partners’ responses to the cancer and recovery. In contrast, the moderating or minimizing process attempted to limit the cancer’s impact on the family.

A Model for Understanding the Process of Dyadic Coping

Dr. Guy Bodenmann, a Swiss psychologist, has extensively studied and observed how hundreds of couples cope with various types of stresses. He defines dyadic coping as a stress management process where partners either ignore or react to each other’s stress signals in order to maintain or return to a pre-illness level of well-being as individuals, as a couple, and with other people outside the dyad (Bodenmann, 2005). His concept of dyadic coping is an extension of the coping model originally proposed by Lazarus & Folkman (1984) in which coping involves (1) cognitive appraisal, (2) emotional reaction, (3) coping behavior, and (4) adjustment. In Bodenmann’s theory (1995, 1997, 2000), a communication of stress triggers both partners’ coping responses. One partner’s stress signals are sent to the other partner, who perceives, interprets, and decodes them, and then responds with some form of coping (which might involve ignoring these stress signals). Stress can be communicated verbally or non-verbally (e.g., voice tone, sighs, or facial expression). Several cognitive processes are involved in communicating stress: the appraisal of who is troubled by the stress (partner A, partner B, both partners), the appraisal of the causes for the stress event (the partner, others, external causes), and the appraisal of controllability (by partner A, partner B, both). Depending on the stressor under consideration and what is at stake for the individual and the dyad, both partners make efforts to maintain or restore the well-being of the relationship.

Building on Bodenmann’s theory, we have developed a framework by which we can analyze the couple’s process of coping.[1] This process is depicted by a wheel

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[1] This model first appeared in Kayser, Watson, & Andrade (2007).

that illustrates the cycle of coping that occurs repeatedly as a couple is challenged by the series of stresses associated with each phase of the cancer experience (that is, diagnosis, treatment, and end of treatment) (see Fig. 2.1). In the hub of the wheel we have listed three relational qualities that facilitate the movement from one step to another. These included *relationship awareness* (understanding of stress as "our stress"), *authenticity* (honest self-disclosure of feelings and thoughts), and *mutuality* (the ability to empathize with each other). These characteristics of the relationship shape the pattern of coping that couples develop. We identify two distinct patterns among the couples going through this process: mutual responsiveness and disengaged avoidance.

Mutually Responsive Couples

Appraisal. Couples who are mutually responsive in their coping tend to appraise the cancer as a stressor that affects them both. They communicate in terms of a shared stress and experience the intensity of the stress at similar levels. Furthermore, they

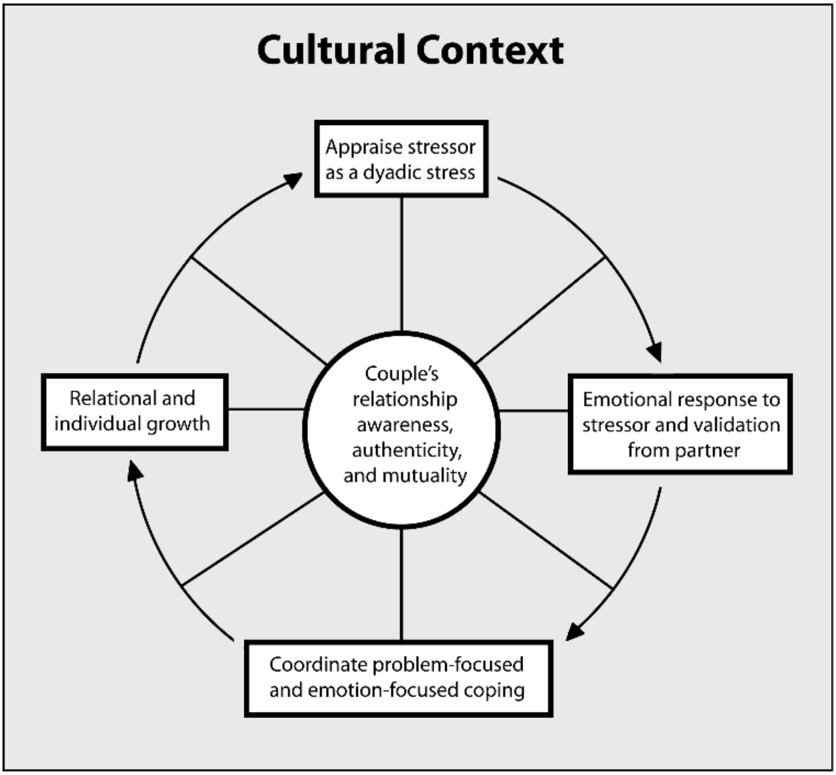

Fig. 2.1 Relational-cultural coping process (Copyright © 2007 by the American Psychological Association. Reprinted with permission from Kayser et al., (2007))

talk about the cancer changing their lives as a couple. The quote at the beginning of this chapter, referring to cancer as a “we-disease,” provides a good illustration of this type of appraisal.

Emotional Response and Validation. As mentioned earlier, when a partner expresses his or her stress to the other partner, it triggers a stress communication process. The partner receiving the stress signals perceives, interprets, and decodes them, and then responds (or does not respond). Certain emotions increase a partner’s potential probability of responding to cues, indicate their level of distress or adjustment, and alert a partner or other members of a support network to a person’s need for support (Keltner & Kring, 1998). In essence, negative affect is a stimulus to a partner to offer support. Positive support occurs when the distress is noticed and responded in a sensitive manner. With mutually responsive couples, each expression of feeling is met with genuine listening and validation from the other partner. The couples with whom we have worked would make comments such as, “He understands my needs and respects my moods,” “we are tuned into each other,” “we pick up on each other’s emotions,” or “we share our sadness.” Successful coping behaviors usually result from this process of emotional response and validation.

Coping Behaviors. After couples appraise their stress and respond emotionally, they use various coping strategies to deal with it. A useful way of categorizing coping behaviors is by distinguishing between problem-focused coping and emotion-focused coping. Problem-focused coping involves strategies intended to change some aspect of the stressor, for example, browsing the Internet to look up information about the effectiveness of various treatment options for breast cancer. Emotion-focused coping may not mean intervening directly to change the stressor, but it does involve thoughts and actions that are intended to manage the distressing emotions (Lazarus & Folkman, 1984). Mutually responsive couples tend to use both problem-focused and emotion-focused coping behaviors. They attend to their own and each other’s emotional and physical needs in a cooperative manner. If they were not using both kinds of coping strategies, they tended to delegate tasks so that one would manage stress by use of problem-focused efforts while the other used emotion-focused strategies. An example of a couple using the same coping strategies simultaneously was the couple who defined their illness as “we-disease.” When trying to make a decision on treatment, they both read about the doctors, they gathered information on the treatment protocols, and they attended religious services together. However, some couples use different types of coping strategies—one uses problem-focused and the other uses emotion-focused—but they coordinate their efforts so that the behaviors complement each other. For one lesbian couple, the partner took on the task of researching medical information about breast cancer by buying books and searching the Internet for resources (problem-focused coping), while the patient made sure they spent time processing their feelings about the cancer (emotion-focused coping). In the patient’s words, “I try to carve out time for us to talk and take time to be sad.”

What is notable about these couples is their relational capacity to accept and support each other’s coping efforts even if they are different. Without the partner’s support for the patient's more emotion-focused coping behavior, for example, validation of her feelings, the patient may stifle her feelings or perhaps seek support for her emotional issues or concerns outside their relationship.

Many couples do not enter the cancer experience knowing how to cope in a mutually responsive way. It takes time to learn what a partner needs in terms of support and how to respond to those needs. It also takes time to move from an individualistic coping style to an interdependent one. Some couples learn during the course of the disease how to transform their individualistic behaviors into cooperative ones. Note how the following couple describes one of their conflicts and how they successfully resolved it:

> *Patient:* I think in the beginning we had a hard time. And what he says is true: I am a strong person but when we first came here to the oncologist, he owns his own business and his cell phone was ringing. I was going to kill him. I was going to throw the phone out the window ... he said he wanted to be here but he's here in body, not mind. I told him, "If your phone calls are that important, don't come. I'll do it myself or I'll bring someone who wants to be here..."
>
> *Partner:* She's right. I wanted to be there, I blocked the day and that's it. Going through it together has helped me. I hope it has helped you.

Through the wife's expression of her needs to her husband and his ability to respond to them, this husband was able to support her efforts to manage the demands of her treatment. Through her authenticity and her husband's responsiveness, the stressful situation was transformed from one of loneliness and isolation to one in which the husband was present *both* physically and emotionally. Again, the point here is that learning to cope together is a process that takes time and may involve errors along the way.

It appears that the particular coping strategies of a couple are less critical than their specific relational abilities, namely, relationship awareness, mutuality, and authenticity. These relational qualities facilitate an acceptance and support of each partner's coping efforts—regardless of whether these efforts were problem-focused or emotion-focused. By relationship awareness, we mean the ability of partners to appraise the cancer as a shared stress in contrast to only perceiving the consequences of the disease on each individual. Mutuality is a concept similar to emotional support. It involves mutual, empathic listening, validation of and response to each other's feelings and communications of stress. Finally, by authenticity, we mean the expression of thoughts and feelings that show a sincere desire to facilitate relational coping, enabling a supportive response from one partner to the other's needs.

Outcome. Through the process of mutual responsive coping there is growth—individually and as a couple. When we ask couples if there is anything positive that comes from the illness, the mutually responsive couples often report a strengthening of the relationship, an increased closeness, or a change in their priorities that allows more focus on the relationship. A result of effective relational coping is an enhancement of the relationship and the individuals involved in the coping.

Often researchers look at individual outcomes such as depression, anxiety, physical symptoms, etc., as indicators of poor or ineffective coping. We take the perspective that dyadic coping can lead to a positive adjustment to cancer.

Case Illustration of Mutual Responsiveness: Alan and Beth

Alan (58) and Beth (56) had been married 26 years when Beth was diagnosed with invasive breast cancer. They had two children—a son and daughter in their early twenties. The couple had many work and family responsibilities—both of them had demanding jobs, they were in the process of remodeling their house, and Beth had an elderly mother to care for. However, they both put the issues of cancer at the front of their list of responsibilities. They had no experience dealing with cancer in their families, nor did anyone else who was close to them.

For Beth, the biggest change since her diagnosis was re-prioritizing her activities and viewing her life from a shorter-term perspective. As she described it, "We're on a different timetable." For the husband, the issues of not having control and the fear of losing his wife were most prominent. For both of them, the hardest part of the cancer diagnosis was dealing with ambiguity and uncertainty. The couple admitted that they could deal better with "black and white," clear-cut decisions. They kept looking for the "right" decision. Hence, for both of them, the unpredictability, uncertainty, and loss of control that accompany cancer were the greatest challenge.

Alan had thoughts about the possibility of Beth dying and was willing to talk about it. He expressed his worries and anxieties. In his own words, "we talk about all of this—we've talked about death, we've talked about all the things in between.… I can't bear to see her suffer. And that is most troublesome." Beth is a planner, but has learned to live with the cancer one day at time, without thinking too far into the future.

When we first met Alan and Beth, they were still in the process of making decisions about treatment. Chemotherapy had been recommended to them but they were undecided about the regimen and where Beth should receive it. They delegated the tasks of researching possible cancer treatments and doctors to Alan but both agreed that Beth would make the final decision about her treatment. Beth arranged her appointments and transportation. In reprioritizing her activities, Beth decided to take a paid leave of absence from her job and focus on taking care of her health needs while still caring for her mother. Alan supported her in this decision. Alan and Beth have an extensive support network—neighbors and friends sent flowers, called and emailed, brought food over, and offered to drive her to her appointments. The couple joked about the number of dishes of lasagna they stored in their freezer.

The coordination of tasks and coping efforts were not always clear-cut and easy for them. Although Alan was able to take time off work to attend Beth's office visits, he was still working long hours at the office. He often would not come home until eight or nine in the evening. Beth told him that she did not need him to take her to her clinic appointments and would prefer that he be home in the evening. Alan considered a leave of absence from work until Beth has completed her chemotherapy.

Alan and Beth anticipated changes in their life due to the cancer. Beth scheduled an appointment for a family photo before she began her chemotherapy, in case she lost her hair. She bought a wig even though she did not think she would wear it. Alan looked on the lighter side of the situation and told his wife that she will save time getting ready to go out because she would not need to shampoo and dry her hair.

Alan and Beth identified multiple benefits that have come from their experience with cancer. They have become more spiritual—even their children are attending church after a long hiatus. They feel that they have become closer to their children. Beth states, “I think I’ve found that there are some really caring people who have reached out and have taught me that perhaps I should have been reaching out to others along the way too.” They were touched by the overwhelming support that they received from their friends and neighbors.

When talking about the illness, this couple often used “we” language. They appraised the stress in similar ways and with a similar level of seriousness. Their empathy and mutuality permeated their conversations. Alan acknowledged that he could not “bear to see her suffer.” Beth stated, “it’s easier to be the patient than the partner.” The couple was always looking at the “silver lining” of their experience such as gaining a new perspective on what is important.

Communication was very important to this couple. Beth was aware that her husband loved her, but his expressing it verbally was especially reassuring to her. Their manner of communicating demonstrated a respect for each other. During their sessions with the social worker, they regularly waited until the other person had finished before voicing their own opinions. They validated each other’s responses by acknowledging the other’s feelings, even when they may have disagreed with their partner’s perceptions.

Disengaged Avoidance

Appraisal. Couples whose coping styles were disengaged and avoidant tended to appraise the cancer as an individual stressor. When asked to talk about their stress as a couple, disengaged partners tended frequently to refer only to their individual experience, excluding any reference to the partner’s experience. “I” was used more frequently than “we.”

When asked what was the most important change that cancer brought into their life *as a couple*, one husband responded that it was the difference in his wife’s physical appearance. He missed the way his wife looked in the past when they first met. He avoided his wife and wished that she could look like the person she was before her treatments. Although he expressed his own feelings about the cancer, he seemed oblivious to the impact on his wife—despite the phrasing of the question to respond “as a couple.”

Some couples who appeared disengaged in their coping with cancer did not appraise the cancer as the most stressful event in their lives. Typically, these couples were dealing with other stressors that overshadow the experience of cancer. This was especially the case for younger couples who cared for young children, were under financial stress, or worked in new careers. These stressors demanded more of their time and resources on a daily basis.

Emotional Response and Validation. The communication of the couples who are disengaged and avoidant in their coping style tend to lack expression of emotion. When feelings are expressed by one partner, the other does not typically validate them. This may occur when a cancer patient who is highly distressed triggers distress in her partner, leading him or her to become increasingly withdrawn or critical during discussions about the cancer. This response is most likely to occur if the partner attributes the patient's distress to unproductive behavior on her part, such as poor coping (Cutrona & Suhr, 1992). A negative cycle can ensue in which the partner's negative behaviors contribute to a worsening of the patient's mood. She reciprocates her partner's negativity by blaming or criticizing him, which then adds to his already bad mood and makes him more reluctant to talk about the cancer. Further, her deteriorating emotional state may impede her ability to interpret accurately the emotions of her partner, as negative mood has been shown to do (Kirchler, 1989). For example, if the patient is depressed, her gloomy, negative perspective on her situation can spill over to her marriage, leading her to view her husband's behavior less favorably.

This disengaged communication was demonstrated in an interview with a young couple in the Partners in Coping Program who were experiencing a number of stressors including caring for a newborn. During the assessment interview, the couple was not talking about the emotional issues around the cancer and seemed to show very little support for each other. The husband, at one point in the interview, described in detail the hard time he had coping with the diagnosis and the uncertainty related to it. At the end of his lengthy and emotional response, his wife turned to the social worker and said, "I forgot the original question." Clearly, she did not acknowledge or validate her husband's distress and his feelings about the cancer.

Coping Behaviors. With disengaged, avoidant couples, at least one of the partners copes by avoiding or denying the stress of the disease. This may be functional to some degree as a way to manage stress, but it does not allow the couple to cope together in an engaged or relational way. In fact, it is a barrier to developing mutuality because neither person is expressing an authentic self or responding empathically to the other. Again, sometimes this pattern of coping is a function of dealing with other stressors in their lives and may be adaptive in their particular situation. They live day-to-day and hope to get through the day using mostly problem-focused coping strategies. By restricting their conversations to practical things, they avoid discussion of existential issues and emotionally charged topics such as death. When one partner wants to talk about his or her feelings and the other partner wants to avoid them, often the unsupported partner will seek emotional support from someone outside their relationship—a family member or friend.

Outcomes. Disengaged, avoidant couples typically do not perceive anything positive resulting from the cancer experience. Unlike the mutually responsive couples, the disengaged couples rarely mentioned how the cancer strengthened their relationship. If they felt close as a couple, they did attribute it to going through the cancer experience.

Case Illustration of Avoidant Disengagement: Charlie and Debra

Charlie and Debra were a couple in their early 30s with a 6-month-old son. Both husband and wife stated that they tried to keep everything normal in the household since the diagnosis. To them, having an infant produced more changes and stress in their lives than the cancer. This was their first experience with a serious illness in their marriage.

During the assessment interview, they described the cancer as something affecting them each individually—there were no references to its effects on them as a couple. Debra focused on the physical effects of cancer—the lethargy, not feeling well, hair loss—and feeling more dependent on her husband and others. She stated, “I don’t know how it is impacting us as couple.” Charlie felt that stress had piled up for him since he had to take care of both an infant and his wife while working at his full-time job. Debra stated that their child had been a blessing because their attention had been diverted from the cancer to their son.

They coped together by trying to avoid the stress of the cancer—they did not talk about it, they tried to keep everything normal, and they focused on other aspects of their lives. Charlie described a friend who talked a lot about his cancer and stated that he thought that this was an ineffective way of dealing with it.

There was very little humor or levity in their conversation. In fact, they sounded more sarcastic and cynical as they talked about the cancer. They defined good coping as the absence of bad interactions—“we’re not disagreeing, we don’t fight,” etc. The social worker perceived a lack of “we-ness” or connection. The closest thing that approached a sense of connection was when Debra described herself as being a strong person and Charlie agreed. Their conversation lacked empathy—Charlie shared some feelings but Debra did not validate or empathize with his feelings. Neither of them could think of any benefits that they had experienced from going through the cancer. The question seemed almost incomprehensible to them. “How can anything positive come from this experience?” questioned Debra.

The Contexts of Dyadic Coping

The Cultural Context

What does culture have to do with the ways that couples cope? Our understanding of stress and coping is predominantly based on the abundance of research with people who live in highly industrialized, Western countries. However, the process of stress and coping cannot be fully understood without taking into account the cultural context. The Western view of how individuals appraise stress, emotionally react to it, attempt to manage it, and then make some meaning of the experience has restricted our understanding of stress and dyadic coping.

Considering the influence of culture, we would like to expand our thinking beyond categories of ethnicity or race and consider some fundamental constructs that underlie cultures and shape the perceptions, beliefs, and behaviors of members who share a common culture. These constructs are organizing principles and the basic structures that influence all other aspects of a culture such as its norms, customs, rituals, and religions (Hardy & Laszloffy, 2003). Examples of these constructs include the independent versus interdependent self, mastery versus fatalism, hierarchal versus egalitarian gender roles, and external versus internal control. There are other cultural constructs having to do with interpersonal relationships, families, and gender expectations within intimate relationships that can also influence the dyadic coping process. Societal norms, customs, rituals, religions, etc., will support the expression of these dimensions of culture.

While discussing each of these constructs as they relate to dyadic coping is beyond the scope of this chapter and the research literature, we encourage clinicians to ask questions that will reveal information about the couple's beliefs, customs, rituals, expectations for families, and gender roles and how these factors will influence how they choose to cope with the cancer experience. Since there can be as many variations within a culture as between subcultures, it is more effective to engage the couple in discussion of their cultural experience rather than relying on stereotypes about a particular ethnic or racial group. This discussion can involve questions such as the following: What is the meaning of the disease to each partner? How are feelings expressed in their culture? How are stresses typically managed? Are they encouraged to seek help outside the family? Is professional help commonly sought for support or do they rely on informal helpers? In each of the following chapters, there is a special section on cultural/social considerations for each of the components of our program. This section is not an attempt to provide suggestions based on stereotypes of particular cultures, but to assist in asking questions and raising awareness of the cultural context of coping.

The Quality of the Relationship as a Context for Coping

Just being married or in a relationship does not guarantee a better psychosocial outcome for cancer patients. A study that compared partnered and non-partnered women with metastatic breast cancer found no significant differences in mood disturbance between these groups (Giese-Davis, Hermanson, Koopman, Weibel, & Speigel, 2000). However, the women's moods were related to their partners' moods and the quality of their relationship. In particular, the cohesion of the relationship and the couple's feeling that they can express themselves were positively associated with a better mood. Higher conflict in the relationship was related to a lower mood disturbance. While this seems counterintuitive, conflict was also positively correlated with marital satisfaction. These findings suggest that relationships in which spouses do not withdraw when there are differences, but confront them directly, can be productive. Another possible explanation is that when a woman has metastatic cancer, she may benefit from open expression of disagreements. Furthermore, alleviation of her distress may be better achieved by focusing on the relationship rather than her individual coping (Giese-Davis et al., 2000). Conflict, then, may be an indicator of engagement, rather than disengagement, between partners.

The quality of the marriage is important to consider, since marital distress can make it more difficult for the couple to cope with illness. Over time, marital satisfaction of the cancer patient is linked to changes in her level of distress (Weihs, Enright, Howe, & Simmens, 1999). When receiving the diagnosis of cancer, a woman needs partner support and intimacy the most. Pre-existing marital distress may exacerbate the woman's stress and lead to greater depressive symptoms (Bloom, 1982; Ptacek et al., 1994). In fact, marital satisfaction at the time of diagnosis is closely related to breast cancer patients' future distress.

The strength of the relationship influences the availability and quality of supportive behaviors (Duck, 2002). When couples are dissatisfied with their relationship the partners often misinterpret the affect and intentions of their partners (Guthrie & Noller, 1988; Noller & Ruzzene, 1991). In contrast, satisfied couples exhibit more positive behaviors, such as approval, caring, and empathy and their perceptions of their partners' affect and intentions are more positive (Birchler, Clopton, & Adams, 1984; Noller, 1982). Overall, distressed couples are less accurate than non-distressed couples in their interpretations of each other's affect, intentions, and behaviors.

Poor communication, inaccurate perceptions of the partner, a low sense of emotional connection, and lack of effective support predict deterioration in relationship satisfaction (Buehlman, Gottman, & Katz, 1992; Carrere, Buehlman, Coan, Gottman, & Ruckstuhl, 2000; Pasch & Bradbury, 1998). However, this does not mean that it is simply a matter of ineffective support eroding relationship satisfaction. It has also been found that deteriorating relationship satisfaction predicts deteriorating couple communication (Noller & Ruzzene, 1991). Thus, there seems to be a reciprocal influence between relationship satisfaction and ineffective communication and mutual support.

Couple-Based Interventions to Enhance Coping

Although both patients and their partners are affected by the stress of breast cancer, there has been little systematic study of the effectiveness of psychosocial interventions targeted at the couple. Neither has there been much study of psychological outcomes for both partners or for the marriage. Given the frequency and intensity of interaction that a patient has with her spouse or partner, psychosocial interventions designed for couples may be more effective than peer groups or cognitive behavioral interventions (Radojevic, Nicassio, & Weisman, 1992). Furthermore, recent changes in medical care have transferred greater responsibility from health care professionals to the spouse and couple, making it all the more important to work with a couple as a unit and include the partner in treatment plans.

In reviewing outcome studies on psychosocial interventions for cancer patients, we could find only seven studies that evaluated interventions that included a spouse or family member (see Kayser, 2005). Most of the studies were of interventions using behavioral training, educational groups, individual counseling, and support groups for patients. While support groups appear to be the most common type of intervention offered to cancer patients, recent studies have questioned their efficacy (Bordeleau et al., 2003; Goodwin et al., 2001). Some researchers have found not just minimal psychosocial benefits of peer support groups for early-stage breast cancer patients, but even adverse effects of peer discussion for some subgroups of women (Helgeson, Cohen, Schulz, and Yasko, 2001). There have been three randomized controlled trials evaluating couple-based interventions. Christensen's (1983) intervention involved four counseling sessions with 20 postmastectomy couples and emphasized communication and problem-solving techniques. Patients who had received the treatment had significantly lower levels of depression than patients in the control group. Also, the husbands who received the treatment had significantly lower levels of discomfort than the husbands who did not receive the treatment. The author noted that with the small sample it was difficult to obtain statistically significant results, but these preliminary results provide some promising findings for couple-based interventions.

The couple-based intervention, CanCOPE, was evaluated in a randomized controlled trial with 94 married women who were recently diagnosed with early-stage breast or gynecological cancers (Scott, Halford, & Ward, 2004). Women in CanCOPE compared to the other two conditions experienced less psychological distress, less avoidance of intrusive negative cognitions, and improved sexual adjustment. There was also a large increase in observed couple-coping, and supportive communication, and a large reduction in couples' coping effort or burden (Scott et al., 2004).

Partners in Coping, a couple-based intervention for breast cancer patients and their partners, was evaluated in a randomized control trial with 50 couples (Kayser, 2005). Patients in the Partners in Coping intervention arm reported higher overall well-being and common dyadic coping than the patients in the standard services arm at Time 2 (6 months post-baseline). Partners in the intervention arm reported higher stress communication coping and lower avoidance and hostile coping than partners in the standard services at Time 2.

A recent meta-analysis of 70 randomized studies on people with chronic illnesses found positive benefits for both patients and family members when including a family member in psychosocial interventions (Martire, Lustig, Schulz, Miller, & Helgeson, 2004). The studies compared interventions using traditional methods to interventions targeting patients' closest family member or both patient and family member. For patients, interventions that involved spouses had positive effects on depression and, in some cases, on mortality. For family members, these interventions had positive effects on caregiving burden, depression, and anxiety. Only 5 of the 70 studies had samples of cancer patients—the illnesses were most frequently cardiac, dementia or Alzheimer's, or chronic pain.

Summary

- Partners' responses to the cancer experience are interdependent: the mood of one partner affects the mood of the other.
- How partners individually manage the stress related to the cancer will affect the adjustment and coping of the other partner.
- Each partner's individual coping efforts can mobilize or discourage support from the other partner.
- Support is a mutual activity with both the patient and the partner giving support to each other.
- The process of dyadic coping can be conceptualized as a cycle involving appraisal of the stressor, emotional response and validation, coordination of coping strategies, and relational and individual growth.
- Three basic relational ingredients facilitate dyadic coping: relational awareness, authenticity, and mutuality.
- There are two general patterns to couples' coping: mutual responsiveness and disengaged avoidance.
- The cultural context that shapes the perceptions, beliefs, and behaviors of a couple will influence how they appraise and respond to the cancer.
- Couples with high levels of pre-existing distress in their relationships will experience more difficulty in coping with the demands of the partner's cancer.
- The influence of emotional support from spouses on their partners' adjustment to cancer, the reportedly high distress levels among husbands of women with cancer, and the positive effects of interventions including family members for both patients and spouses collectively formed the basis for the development of our couple-based interventions.

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Chapter 3

Assessing the Couple's Adjustment to Cancer

> *"When you hear those words 'you have cancer,' all you want to do is run!"*
>
> *"My husband told me that we have dual diagnoses: I have Posttraumatic Breast Disorder and he has Attention Deficit Disorder because no one pays attention to him."*

The initial assessment session is an opportunity to learn firsthand about the couple's experiences with the illness from the time of the diagnosis up to the current time. The assessment also is an opportunity to learn about broader aspects of the couple's functioning, or their individual functioning, that may have an impact on their current coping with cancer. These might be factors such as history of relationship difficulties, psychological or physical health problems, or other concurrent major life stressors. Of course, the assessment session allows the therapist to begin to form a positive connection with the couple.

To facilitate this process, this chapter provides assessment questions and suggestions for standardized instruments that can be used to judge the impact of the breast or gynecological cancers and its treatment on the couple's life. In the second therapy session, often called a feedback session, the therapist reviews with couples their answers to the interview questions and the inventories. In the feedback session, the clinician also describes in lay terms the findings from this assessment session. Areas of strengths, as well as areas suggesting difficulties, are summarized in ordinary terms. The therapist identifies the main coping goals of the couple and then relates them to the coping program outlined in this book. Particular areas needing emphasis are then discussed with the couple. For example, if the couple finds it difficult to communicate in a supportive way, or to discuss sensitive topics, the therapist might describe the communication techniques and exercises (covered in Chapter 6) that are likely to be useful. If one or both partners are found to be experiencing high levels of psychological distress, then the therapist might talk about the stress response and ways to manage stress levels as covered in Chapters 5 and 7.

The chapter provides step-by-step instructions on how to draw a genogram, which involves a thorough analysis of the family/social network potentially available to support the couple. Finally, we describe how to explore individuals' generic beliefs about cancer and cancer treatments, as these attitudes can color their expectations for the spouse's survival, responses to treatment(s), or even the deeper existential meanings they ascribe to their journey.

K. Kayser, J.L. Scott, *Helping Couples Cope with Women's Cancers,*

Not only does the assessment serve as an opportunity for the therapist to begin to build an empathic working relationship with the couple, but it also enables the therapist to observe how the partners communicate with each other, and support each other emotionally, when discussing cancer-related issues. During the interview the therapist should particularly attend to how each partner responds to distress in the other. In some couples the partner will respond with physical or verbal comforting (e.g., a hug or soothing words). In other couples, the partner may seem uncomfortable with the signs of distress and may be reluctant to respond. Though the interaction of the couple in the interview situation may differ somewhat from private interactions, the couple's behavior in the interview should still help the therapist generate hypotheses about the partners' strengths and weaknesses in their support of each other.

There are also some general principles about assessment with couples for a clinician to keep in mind. One of the initial challenges is to analyze two different aspects of the couple's situation: one, the clinician assesses the couple's relationship and their pattern of interaction with each other and, two, he or she assesses the couple's relationships with people outside the couple—their social network. The first meeting, then, focuses on the internal workings of the couple before broadening the focus to look at the couple's relationships with their social environment, through the use of a genogram.

The following are aspects of the couple's interaction that the clinician should attend to:

1. *Affect*. What emotions are being expressed between the members of the couple? Is there a feeling of anger or hostility? Does one partner feel intimidated by the other? Are either inhibited in expressing feelings? Or are they respectful and warm toward each other?
2. *Communication.* Does one partner dominate by interrupting or lecturing? Can each express their feelings, positive and negative? Is there a sense of humor and joking between them? Are there specific cancer or relationship topics they avoid, seem uncomfortable discussing, or react to with strong emotions?
3. *Closeness and intimacy*. Do partners disclose intimate feelings? Do they spend time together and enjoy being with each other? Can they provide each other with emotional support? Are there distancing behaviors?
4. *Mutuality.* Is there a sense of mutual and equal attention to each other's needs? Do one partner's needs predominate? Are the partners empathic toward each other?

Another challenge in working with couples is building a therapeutic alliance with both members of the couple. Unlike individual counseling, the clinician needs to develop an alliance with two people—each possibly having different levels of motivation about being there or different goals for the therapy. Also, there is a tendency for health care practitioners and other people in the couple's environment to attend more to the patient than the partner. Although the couple is there because of the patient's breast cancer, the clinician should be equally attentive to both the patient and the partner. To this end, the questions should be directed to both the patient and the partner, unless indicated otherwise in the instructions.

There are additional aspects of working with couples and cancer to bear in mind. First, your work with the couple will likely be short term and needs to be focused and structured. If the clinician does not direct the assessment interview, the couple (and therapist) can easily get sidetracked and discuss topics that are not relevant to the purpose of your meeting. Finally, the assessment interview focuses primarily on the present, and except for a few of the questions, it does not attend to the couple's history.

Technique 3.1 Assessing the Impact of Illness on the Couple[1]

Introductory Remarks "I am interested in learning about what has happened in your lives since the diagnosis. First, we will talk about the specific ways you have been affected by the diagnosis and illness. Then we will discuss how you are adjusting as a couple. I want to have an accurate understanding of what you both think and feel. It would not be surprising if you have not talked to each other beforehand about some of the things we will discuss today. Most couples use this as an opportunity to share their thoughts with one another. Sometimes they feel hesitant to say what is on their minds because they do not know how the other partner will react. Therefore, if for some reason you are uncomfortable expressing what you really think, just tell me that you would rather not talk about that and we will move on."

"Do you have any concerns about talking together as a couple? (e.g., that something will be said that you are not prepared to discuss)" NO YES [If yes, probe for their concerns]

1. (To patient) "What treatment for your cancer have you received (or about to begin)?" [Probe for any further treatment expected and where she is in the course of treatment.]
2. How would you describe your relationship with your doctor and other key people involved in your (or your loved one's) treatment?
3. (To both partners) "How do you feel about the proposed type of treatments?"
4. (To each partner in turn) "The diagnosis of cancer does not mean the same thing to every person who is told they have cancer, or to every person who supports someone with cancer, so tell me: What does this diagnosis mean to you?"
5. (To each partner in turn) "Each person also has their own feelings about the seriousness of the cancer. How serious do you think the diagnosis is?"

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[1] Some of these questions were adapted from Barbarin, O. A. (1988). *Childhood cancer project treatment manual.* Unpublished manuscript, University of Michigan, Ann Arbor.

6. "What is the most important change in your life as a couple since the diagnosis?" [Allow them to decide who goes first. Unless noted, make sure that with all questions you elicit answers from both of them.]
7. "What things are you handling best as a couple?"
8. "What things are you handling less well?"
9. Next, I would like you to think about how well you, as a couple, are coping with the illness. We will use a scale ranging from "1" indicating poor coping to "10" indicating very good coping. Before selecting a number, tell me how you would define a number "10"? How do you know when you are coping very well? How do you know when you are not; that is, coping at a level of "1"? Using this scale, how well are you as a couple coping with the illness? (Record their answers on the scale below.)

   Patient's
   rating
   1 2 3 4 5 6 7 8 9 10
   poor very well

   Partner's
   rating
   1 2 3 4 5 6 7 8 9 10
   poor very well
10. Is there anything positive for you as a couple that may have resulted from the cancer?
11. Have you as a couple experienced any other cancers or similar major illnesses (involving one of them or someone close to them)? If so, how do you think it has affected the way you think about and cope with your (your partners') cancer? [Probe for whether they feel more or less prepared or more or less fearful.]
12. These next few questions ask about your overall health; How would you describe your general health during the past 12 months?
13. Have you had any other serious illnesses, conditions, or medical problems, and how would you say they impact on your current coping with cancer?
14. Do you suffer from
   (The therapist should check for each of the diagnoses listed and probe for how well these illnesses are managed or controlled)

   diabetes ______________________________
   asthma ______________________________
   heart problems ______________________________
   kidney problems ______________________________
   thyroid problems ______________________________

epilepsy ____________________________
other ____________________________

15. "Sometimes the people who we see are dealing with other challenges in their life, besides cancer. For some people cancer is not the major source of stress. Other matters in life may be more demanding, or cancer is just an added stress. Tell me, what other things you are managing or dealing with in your life?"
(Probe for other major caregiving roles, extreme financial difficulties, child behavior and parenting problems, or major interpersonal problems)
The therapist should now move onto finding out about the couple in the context of the social world.

Technique 3.2 Assessment of Family/Social Network (Genogram)

An assessment is made of the couple's current social network by drawing a genogram.[2] This assessment identifies the important persons with whom the couple comes into close contact and from whom the couple either already receives support or feels comfortable asking for help. These people may include extended family, friends, other breast cancer patients, medical professionals, co-workers, clergy, church/synagogue congregation members, and neighbors. It is important to explain the purpose of the genogram and to continue to be empathic and validating of feelings throughout the interview. For example, if the couple talks about the difficulty in telling the children about the diagnosis, respond with an empathic statement about how difficult it must be and reassure the couple that they may talk more about the children in a later session. In this way, one is using the genogram not only as a tool to obtain information about their support system but also as a context to build rapport and to discuss concerns that they may have.

The discussion should also focus the people they may still want to tell about the cancer, who is able to provide necessary support, and how to seek and accept help from others. Using a problem-solving approach, the couple is asked to think about the types of help that they could use and the specific ways others could be involved.

Introductory Remarks "In order to get an idea of your family support system and others in your social network, I would like to draw a diagram of your family which includes information about each family member. I will use

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[2] For additional information on drawing genograms, see McGoldrick, M., Gerson, R. and Shellenberger (1999). *Genograms: Assessment and intervention* (2nd ed.). New York: Norton.

symbols for people—the circles are females and the squares are males. Again, if there is any information that you would prefer to not share with me, just tell me that you would rather not talk about it and we'll move on."

The clinician draws a genogram on a large piece of paper, attending to the following areas:

1. Nuclear family membership
    a) "How long have you been married (if not married, in this relationship)?
    b) Do you have any children? If so, how many? What are their ages and genders?
    c) Have you had any marriages before this relationship?
    d) Do you have children through any other relationship?
    e) Who lives in the home? (Draw a circle around household members)
    f) What are the relationships like between family members?
    g) Have there been any deaths in the family? If so, what were the causes?"
2. Extended family (Ask each spouse/partner separately)
    a) "How many children are there in the family you grew up in? Are your siblings older or younger than you?
    b) What are their names and ages?
    c) What are your parents' names and ages?
    d) What are your relationships like with each one?
    e) Have any family members had cancer or a serious illness?
    f) Have there been any deaths in the family? If so, what were the causes?"

    For the next sections, write names of people or organizations on the right side of the genogram.
3. Close friends
    a) "Do you have any close friends outside of the family?
    b) Who are they?"
4. Employment settings
    a) "Do you have outside employment? Where? Doing what?
    b) Do you have friends from work?"
5. Religious community/church/temple/mosque
    a) "Do you attend religious services? How often?
    b) Do you have friends from church or temple?"

6. Community agencies
   "Has your involvement with community agencies been more, less, or the same since the illness?"
7. Leisure time involvement
   "What do family members do for fun during their spare time?"
8. Other groups, associations, social contacts
   "Are there groups with whom you have close ties or spend significant amounts of time?"
9. Telling people about the illness
   Place a "T" next to the names of the people with whom the couple has shared information about the illness.
   "Do you share information about your illness with
   a) Your extended family?
      1. NO YES 2. WITH WHOM?
   b) Close friends and acquaintances?
      1. NO YES 2. WITH WHOM?
   c) Members of your community (neighbors, school, church, work, other social contacts, community agencies)
      1. NO YES 2. WITH WHOM?
   d) Do you have difficulty telling anyone?"
      1. NO YES 2. WHOM?
10. For couples with children: "What have you told your child(ren) about being sick?
    a) What terms did you use to describe the illness?
    b) Was there anything you did not tell him/her? Was there a particular reason for this?"
11. "From whom do you get the best help?" (H)
    Place an "H" next to the names of the people who are identified as the best helpers.
    [Probe for persons in their family (nuclear and extended), close friends and acquaintances, and community contacts (neighbors, school, church, work, other social contacts, community agencies)]
12. "With whom have relations changed (that is, who has become closer or more distant)? Who treats you differently?"
    [Probe for persons in their family (nuclear and extended), close friends and acquaintances, and community contacts (neighbors, school, church, work, other social contacts, community agencies)]
13. "Do you have contact with other couples coping with cancer?
    NO YES
    If yes, how? What do you do? How often?
    Is the contact helpful?"

14. If any concerns about the lack of social support surface, discuss these concerns with the couple. Using a problem-solving approach assists the couple in generating ideas regarding types of help that they could use and specific ways others could be involved.

Homework Assignment and Planning for Subsequent Sessions If appropriate, the couple should be asked to select one or two of the ideas for help. Seeking that they generated during the session and to implement them during the next 2 weeks.

At the end of the session it is helpful to provide the couple with an overview of subsequent sessions and to answer any questions regarding their participation. Following the overview, ask the couple the following question:

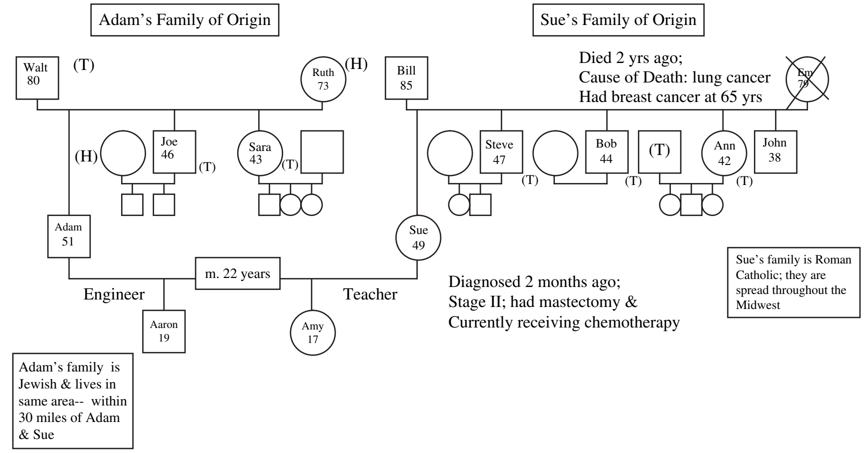
"What do you hope to see happen as a result of our sessions and work together?"

Finally, summarize the content and objectives of the next session (if this has already been decided).

Assessment Summary You should review the information about the couple that was gathered in this initial contact and write a summary of the couple's story. The interview and scales completed by the patient and her partner should help form an initial impression of the major strengths of the couple and any issues that need to be further discussed. This assessment should be used to formulate decisions about problems that might be targeted, sequencing of their sessions, and resources to draw on in work with the couple.

Case Illustration

Susan and her husband, Adam, have been married 22 years. This is the first marriage for both of them. Susan was diagnosed with breast cancer (Stage II) 2 months prior to meeting with the clinician, had a mastectomy, and was receiving chemotherapy. The couple lives in a city in the northeast region of the United States. Both of them work outside the home. Sue had recently started a new job and did not have many close work friends at this point in time. Adam worked in a city about 50 miles away; he often stayed in an apartment on the nights he had to work at his office. When asked about the most important change for them since the diagnosis, they stated that they spent more time together as a couple but there was a decrease in their sexual intimacy. They felt that they were coping well by getting the help that Susan needed around the house and going to her treatment. The area that they felt less able to handle was getting help from their children. They both thought that dealing with their two adolescent children was challenging and added more stress



T = was told about the diagnosis S = Sue; A = Adam
H = provides the best help

Friends	*Neighbors*	*Co-workers*	*Religious Community*	*Organizations*
Robin (S) (H)	Martha (S)	Phoebe (S) (H)	Father Charlie (S)	School Board (A)
Sarah (S)	Martha's Husband (A)	Adam has not told anyone at his workplace	Not involved with church or synagogue	
Mary (S)	Vicki (S) (H)			
Beth (S)	Kathy (S)			
Peg (S)				
Kevin (A) (his wife had Br. Ca)				

Recreation

Coaches soccer (A)
Gardening (S)

Fig. 3.1 Susan and Adam's Genogram

to their adjustment to Susan's cancer. Figure 3.1 is the genogram that the clinician drew based on the information they provided.

While the practitioner was drawing the genogram, the couple became aware of several aspects of their social support system. First, although Susan's family is quite large, they live primarily in the Midwest and other parts of the country. Except for phone calls and email, she infrequently had contact with them and had to rely on friends and Adam's family for the daily help and instrumental support. Although she had just started a new job, she remained in close contact with her previous work friends. While Susan depended on an extensive network of friends for support, Adam had very few friends that he had told about the breast cancer. In fact, he had told none of his colleagues at work. He stated, "I keep things to myself at work. Nobody knows." (Note the "T" next to the people who were told.) Susan felt that she was Adam's sole supporter and expressed the desire for him to tell at least some of his colleagues at work so that they could be understanding and supportive of him, especially if he needed to reduce his work schedule.

Susan is Roman Catholic and Adam is Jewish. Neither of them attends a church or temple on a regular basis. Susan talks to a retired priest, Fr. Frank, about spiritual issues. He helped her when her mother had recently died. However, she has not talked to him about the breast cancer. Adam says that he celebrates the Jewish holidays with his extended family. He feels somewhat connected to Fr. Frank.

The people in their network who were told about the diagnosis were indicated by putting a "T" next to each person's name. Susan stated that there was nobody they shielded information from, but that they did not personally tell everyone. Sometimes they elicited someone else to do the telling. As Susan stated, "It took too much energy to tell everyone."

When asked about who gives the best help, Susan mentioned several friends. Adam, however, has not asked for help from anyone. He stated, "My family is there to help but I haven't asked them." Both Susan and Adam agreed that their two children were not helpful. Susan states, "they are into their own worlds." Adam and Susan then spent some time discussing what the children have been told and their reactions, especially their 17-year-old daughter's worry about getting cancer.

Had any of their relations with people changed? For many patients with a serious illness, there are surprises about who comes forward with unexpected help and who withdraws when help is needed. Susan mentioned one friend in particular whom she thought would be there for her, but that person seemed to withdraw when she heard about the diagnosis. Another friend whom she did not expect would be helpful in any significant way proved to be a nice distraction for her because the friend enjoyed doing simple things with her, such as walking, yoga, and shopping.

The couple stated that they did not have any contact with couples currently coping with a new diagnosis of breast cancer. Adam mentioned that his friend, Kevin, had a wife who was diagnosed with breast cancer several years ago but that they have not gotten together as couples.

As one draws a picture of a couple's support network, one learns how well the couple accesses or elicits support from others. Susan made the comment, "Both Adam and I are oldest children and were not accustomed to asking others in our family for help—they're usually asking us." This illustrates a shortcoming in their approach to help-seeking, especially in Adam's case. He commented several times that people were available for him *if* he asked for help. Adam noticed the lack of his initial, "A," indicating his support network on the genogram. Although he felt that his family was supportive, he realized that he could benefit from talking to some of his friends, especially those at work about it. Except for Adam acknowledging his lack of a broad support network, the couple did not express any other explicit concerns about inadequate support in dealing with the stresses surrounding the diagnosis and treatment. However, the practitioner suggested that in the next session they spend more time discussing how they could mobilize more support, when needed. Before ending the session, the practitioner summarized briefly the main information that came from it. Then, she asked each partner how they felt about the session, and addressed any concerns they had.

What to Do if . . .

The Woman Has Very Recently Received the Diagnosis

Some couples who have just learned of the diagnosis or who are just starting treatments may be in emotional crisis or shock. They may have symptoms of acute stress disorder. This can affect the interview process in two main ways. First, distressed partners may find it difficult to concentrate, or to complete a questionnaire. In this case, the initial session may need to be spread out over two sessions. Second, the therapist's questions can open a floodgate of emotions that the couple has been trying to hold back. Some men have told us that the assessment interview was the first time anyone had asked how they were doing. The therapist needs to respond to strong or sad emotions with appropriate warmth and empathy, and be prepared to pace the session to each partner's emotional needs. Sometimes, conducting a relaxation exercise (see Chapter 7) can help the couple feel more calm. It may also be useful to repeat the relaxation exercise at the end of the session to ensure that that couple leaves the session in a calm state.

If One or Both Partners Seem Reluctant to Talk About the Cancer, Prognosis, and Treatment

It may be that they are trying to protect each other from hurt. They may be trying not to say something they fear will upset the other person or trying not to show their own distress. Frequently, if the therapist acknowledges at the start of the session that many couples feel this way, it helps them to feel more relaxed about talking openly. In addition, it can be useful to interview each partner on their own for some part of the interview session, to give them a chance to voice personal issues.

When the Support Person Is Not a Partner

The therapist should explain to the pair the nature of the questions that will be explored in the interview and then ask each person how they feel about doing the interview together. Most women pick people for support who are emotionally close to them and are willing to be actively involved in the process. In these cases, the interview usually proceeds in much the same format as described earlier. However, some women are being supported by someone they know less well, or by someone who is serving more as a practical support. The therapist should learn the level of intimacy and type of supportive relationship they have and tailor the content of the session accordingly. One of the two may want to have parts of the interview kept private or conducted in an individual session. The genogram can be drawn for each person separately and may be useful to determining the amount of support that the support person has in his or her own life.

Box 3.1 Standardized Instruments for Assessing Close Relationships

Both members of couple complete

Dimension	Measure and reference	No. of items	Examples of items	What is the clinical relevance?
Relationship satisfaction in close relationships	Dyadic Adjustment Scale (Sabourin, Valois, Lussier, 2005: short form) (Spanier, 1976: original form)	4 32	"In general, how often do you think things between you and your partner are going well?"	Indicates level of relationship satisfaction. Higher scores = greater relationship satisfaction
Coping as a couple	Dyadic Coping Inventory (DCI) (English and German) (Bodenmann, 1997)	37	"We help one another to put the problem in perspective and see it in a new light"	Categorizes couple's coping: supportive, delegated, stress communication, and negative
Mutual emotional support in close relationships	Mutual Psychological Development Questionnaire (MPDQ) (Genero, Miller, Surrey, & Baldwin, 1992).	22	"When we talk about things that matter to me, my spouse/partner/ support person is likely to pick up on my feelings"	Partners' level of response with emotional support. Higher scores = greater mutual emotional support
Couple's levels of rapport	Intimate Friendship Scale (Sharabany, 1994)	32	"When something nice happens to me I share the experience with them"	Indicates level of emotional closeness. For use with non-romantic dyads; higher score = higher intimacy

Satisfaction with support	Sarason's Social Support Questionnaire—Short form (Rascle, Bruchon-Schweitzer, & Sarason, 2005)	6	"I know they will not let me down if I need them"	Determines satisfaction with the support they receive from others
Self-neglect and over-involvement with others	Revised Unmitigated Communion Scale (Fritz & Helgeson, 1998)	9	"I often worry about others' problems." "For me to be happy, I need others to be happy"	Distinguishes unmitigated communion from communion
Agency and unmitigated agency	Personal Attributes Questionnaire—extended version (agency and unmitigated agency subscales) (Spence, Helmreich, & Holahan, 1979a, 1979b)	24	List of adjectives: "cynical," "kind," "never give up," "in control"	Distinguishes unmitigated agency from agency
Support person only completes—*These inventories below are useful to assess in support persons helping patients who are receiving treatments, or in palliative stage of illness. The measures are less useful in disease-free cancer survivors who have completed treatments and do not need caregiving*				
Carer Burden	Zarit Burden Inventory—short form (Goldstein et al., 2004)	9	"I feel that (the Patient) does not appreciate what I do for her"	Impact caregiving has on partners'/carers' lives. Higher score = great caregiver burden

Box 3.2 Resources for Cancer Patients and Partners

Books

Gruman, J. (2007). *AfterShock: What to do when the doctor gives you—or someone you love—a devastating diagnosis*. New York: Walker & Company.

Schnipper, H. H. (2003). *After breast cancer: A common-sense guide to life after treatment.* New York: Bantam Books.

Silver, M. (2004). *Breast cancer husband: How to help your wife (and yourself) through diagnosis, treatment, and beyond.* Pennsylvania: Rodale Publishers.

Stern, T. A. & Sekeres, M. A. (2003). *Facing cancer: A complete guide for people with cancer, their families, and caregivers*. New York: McGraw-Hill Professional.

Videos

Spouse to Spouse: What It’s Like when your Partner has Cancer, Cancervive, 6500 Wilshire Blvd., #500, Los Angeles, CA 90048

Pamphlets and booklets

After Diagnosis: A Guide for Patients and Families [American Cancer Society]

Caring for the Patient with Cancer at Home: A Guide for Patients and Families (also available in Spanish) [American Cancer Society]

Caregiving for your Loved One with Cancer [CANCERcare]

When Someone in your Family has Cancer, Bethesda, MD: National Cancer Institute

Scott, J. L., & Halford, W. K. (1996). A Guide for the Partners of Women with Breast Cancer: How to Help, (Booklet) Brisbane: Queensland Cancer Fund

Scott, J. L. (1997). A Guide for the Partners of Women with Gynaecological Cancer: How to Help. (Booklet) Brisbane: Queensland Cancer Fund

Organization websites

American Cancer Society (www.cancer.org)
CANCERcare (www.cancercare.org)
Cancervive (www.cancervive.org)
People Living with Cancer (www.plwc.org)
Partners in Coping (www.bc.edu/sites/breastcancer)

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Bodenmann, G. (1997). Dyadic coping—a systemic-transactional view of stress and coping among couples: Theory and empirical findings. *European Review of Applied Psychology, 47*, 137–140.

Fritz, H. L., & Helgeson, V. S. (1998). Distinctions of unmitigated communion from communion: Self-neglect and overinvolvement with others. *Journal of Personality and Social Psychology, 75*, 121–140.

Genero, N. P., Miller, J. B., Surrey, J., & Baldwin, L. (1992). Measuring perceived mutuality in close relationships: Validation of the mutual psychological development questionnaire. *Journal of Family Psychology, 6*(1), 36–48.

Goldstein, N. E., et al. (2004). Factors associated with caregiver burden among caregivers of terminally Ill patients with cancer. *Journal of Palliative Care*, 20(1), 38–43.

Rascle, N., Bruchon-Schweitzer, M., & Sarason, I. G. (2005). Sarason's social support questionnaire- short form. *Psychological Reports*, 97(1) 195–202.

Sabourin, S., Valois, P., & Lussier, Y. (2005) Development and validation of a brief version of the dyadic adjustment scale with a nonparametric item analysis model. *Psychological Assessment, 17*(1) 15–27.

Sharabany, R. (1994). Intimate friendship scale: Conceptual underpinnings, psychometric properties and construct validity. *Journal of Social and Personal Relationships, 11*, 449–469.

Spanier, G. B. (1976). Measuring dyadic adjustment: New scales for assessing the quality of marriage and similar dyads. *Journal of Marriage and the Family, 38*, 15–28.

Spence, J. T., Helmreich, R. L., & Holahan, C. K. (1979a). Psychological androgyny and sex role flexibility: A test of two hypotheses. *Journal of Personality and Social Psychology, 37*, 1631–1644.

Spence, J. T., Helmreich, R. L., & Holahan, C. K. (1979b). Negative and positive components of psychological masculinity and femininity and their relationships to self-reports of neurotic and acting out behaviors. *Journal of Personality and Social Psychology, 37*, 1673–1682.

Part II

Intervention: Helping Couples Cope with Women's Cancers

Chapter 4

Integrating Tasks of Illness into the Couple's Daily Routine

> *Husband: My wife enjoys working and will work hard even when she's not working. . . . I mean that's just the way she is. But I think that she has slowed down.*
>
> *Wife: Well, it (the cancer) has made me think some about what I was doing, running around all the time, I mean, do you have to do everything you're doing? . . . it's a gradual thing, you just think about what you're doing more, more than just doing it.*
>
> *Husband: We've changed a great deal . . . they're gradual changes because it makes either the work life or the social life better for the two of us, and we learned that we need to do that. So instead of making monumental leaps, we make gradual changes . . .*

The additional demands of cancer treatment on a family's time and resources require couples to develop a collaborative approach to household tasks. This allows them to conserve their energy and use their time more effectively. When couples are initially confronted with the cancer diagnosis, they may attempt to carry on their work outside and inside the home as usual. But when trying to incorporate numerous medical appointments, time to recover from surgery, and weeks of daily clinical visits, the whole experience becomes overwhelming. Some couples and families almost automatically redistribute household work and tasks, while others make very little accommodation to the new situation. Some couples adopt a pattern in which the patient's partner assumes exclusive responsibility for all the household tasks, assists with the patient's medical care, and continues to work fulltime outside the home.

The consequences of the particular strategy a family adopts to deal with these increased demands may not always be evident to the family members themselves. The couple's relationship and the quality of family relations as a whole may suffer when there is an inequitable distribution of family tasks. Couples may require the clinician's assistance in allocating new roles and responsibilities. It may become impossible for individuals to perform roles which are important to them: the patient is unable to work outside the home, she may be unable to do household chores, her partner may not have the time to attend a child's sports events, and so on. Ultimately, the couple will have to restructure how they get their work done.

This chapter focuses on instrumental support, namely, support to carry out the daily tasks of living required of both patient and partner. We present an intervention

K. Kayser, J.L. Scott, *Helping Couples Cope with Women's Cancers,*

later in the chapter that is intended to help couples develop strategies that address the additional demands of cancer treatment. This requires taking the time to discuss their needs and brainstorming ideas to meet them.

Balancing Work, Family, and Self-Care

Given that the majority of married women with children work outside the home, most patients with breast or gynecological cancers will be managing both household work and work outside the home. Even without an illness, a woman's time is likely to be stretched between the obligations of being a parent or spouse on one hand and an employee on the other hand. This tension can create negative stress for the couple (Keene & Reynolds, 2005). When an illness intrudes, the balancing act becomes more precarious and depends to a great extent on the flexibility of the workplace and the adaptability of the spouses. Spouses need to negotiate with each other as well as with their workplaces to free up the time needed to meet the demands of treatment.

Most of this chapter and the technique we describe focus on the adaptability of the spouses or partners. But the flexibility of the workplace also needs to be assessed. For example, what options are available for employees? Can the patient take a paid medical leave? Is it possible to work part-time and still receive insurance benefits? Can a spouse take a family leave—either paid or unpaid—to care for the patient? Can work be done at home? Unfortunately, a paid leave for the caregiver is often not an option, so the caregiving partner is forced to continue with their regular workload. However, spouses are not always aware of the benefits that are available at the workplace and these possibilities need to be explored. Researchers have found that, short of taking a leave, workers' ability to make scheduling adjustments at work is one of the best ways to ease the stress on families (Hewlett & West, 1998). Workers who have control over their work schedules report feeling more successful at balancing work and family life (Tausig & Fenwick, 2001).

Doing Gender and Housework

Especially for heterosexual couples, gender can be the most significant factor in how household tasks are divided. Even the differing demands of employment may be less important. *Doing gender* is a concept that is applied to behavior that is a product of social expectations for men and women. This conceptualization of gender means that gender is not so much a set of traits as it is the product of social expectations (West & Zimmerman, 2002). When we assess how couples do the work of the family, we need to take into consideration that heterosexual couples will behave according to what they believe is appropriate or "natural" for their particular sex. In the work of the family—whether it be housework, yardwork, home maintenance, or child care—there are certain gender-specific activities. When we ask couples to think of alternative ways to do the work of the family, we are also asking them to "do gender" differently. This will be particularly challenging for those couples who adhere to rigid and distinct expectations for their gender.

While some writers in the popular press would want us to believe that things have changed, the research shows repeatedly that wives, even when employed outside the home, continue to do the vast majority of household and child-care tasks. A sample of 13,008 households from the National Survey of Families and Households (NSFH) sheds light on exactly how housework is divided between spouses. The amount of time spent on nine different household activities (meals, dishes, cleaning, laundry, outdoor and maintenance, auto repair, shopping, driving others, and bills) was measured. Among couples in which spouses work full time, average housework time differed substantially by gender, with married men contributing 17 hours and married women 30 hours per week (Stratton, 2003). Although the spouses were employed for approximately the same number of hours, their housework time differed dramatically.

The data also suggest that there is specialization in the type of housework performed by each spouse. Women were found to be primarily responsible for meals, dishes, cleaning, and laundry, and men for outdoor work, home maintenance, and auto repair. Shopping, driving others, and bills appear to be neutral types of housework. Again, keep in mind that when couples allocate their household chores it is rarely a simple question of who has more time, whose time is worth more, or who has more skill. It is more often the gender expectations attached to the work that determine the ultimate distribution of time to work and home (Fenstermaker, 2002).

Researchers have investigated the factors that influence husbands to contribute more time to housework. Economic factors are important. As husbands' incomes increase, they reduce the amount of housework they do (Hersch & Stratton, 1994). However, the same phenomenon does not occur for women. In households where wives contribute more than half of family earnings, the reported housework time tends to be higher for women and lower for men than in households where earnings are more equally divided (Greenstein, 2000).

Inequitable allocation of family work is typically less of a concern with lesbian couples. Several studies show that lesbian couples tend to distribute their household labor more equally than their heterosexual counterparts (Giddings, 2003). It is argued that lesbian couples may be especially attuned to the existing gender expectations and make a concerted effort to divide tasks equally between them (Blumstein & Schwartz, 1983). While women in heterosexual relationships are often overburdened with housework and low status jobs, lesbian couples try to prevent this inequity from developing. Furthermore, contrary to popular belief, lesbian couples do not divide the work of the family according to any stereotypically gendered roles, such as one partner doing outdoor tasks and the other partner doing indoor tasks (Peace, 1993). By eliminating gender as the primary factor in dividing tasks, couples can use other ways to decide on the allocation of housework. For example, performing tasks that they do best or enjoy most can guide how the work is divided (Giddings, 2003). They may also be flexible in their strategies, by rotating household tasks, for example (Weston, 1991).

Since same-sex couples may have had more experience negotiating the division of housework between them, they may be better prepared than heterosexual couples to renegotiate tasks when a partner has cancer. However, there may be social constraints that these couples will face that will make it difficult to manage family work during the cancer journey. Medical insurance, disability insurance, pension benefits, and family leave are just a few of the employment-related benefits that are typically offered to employees' spouses and legal dependents but are not extended to domestic partners of unmarried employees (including gay and lesbian employees) (Giddings, 2003). For unmarried, same-sex couples dealing with a chronic illness, working for employers that do not offer domestic partner health benefits or family leave may put an added strain. The patient will need to have her own health insurance since she will not be able to use her partner's health insurance. Without family leaves applying to a domestic partner, the "healthy" partner will not be able to take time off from work to care for the ill partner.

Helping Couples to Integrate Illness Demands into the Work of the Family

In this section, we describe a technique that helps the couple to develop a coordinated, cooperative approach to the multiple, instrumental demands of the illness[1]. Given the added stresses of cancer on their resources, it is important that the couple discuss how they plan to manage the work of the family in a way that effectively spreads the tasks around to each member. The couple is taught to identify the current task/role assignments and create a distribution they deem desirable and effective. Step-by-step training is provided, as needed, in problem solving and conflict resolution. Accordingly, the objectives for this technique are as follows:

1. Identify how the couple has previously handled the distribution of tasks (housework, child care, work outside the home, medical care, etc.) in the family.
2. Evaluate the effectiveness and efficiency of the distribution of tasks.
3. Discuss the best way to handle the family tasks.
4. Negotiate and resolve any problems around the distribution of tasks.
5. Help partners to ask for support from each other.

The clinician will need a large piece of newsprint or flipchart and a thick marker for this session. If the couple has children who contribute to the household work, the children may be invited to participate in this session.

Technique 4.1 Role Assignments and Negotiation

Introductory Remarks "The illness and treatment will require many changes in the way your family normally operates and spends time together. Many new things related to (patient's name)'s treatment must be done, such as traveling to and from the hospital, spending time at the hospital, arranging

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[1] The instructions are taken with slight modifications from Barbarin, O.A. (1988). *Childhood cancer project treatment manual*. Unpublished manuscript, University of Michigan, Ann Arbor.

child care for young children at home, and finding ways to deal with the added cost of medical care. When the patient is in the hospital, the husband/partner may assume a role to which he she is unaccustomed. In coping with this situation many couples try to figure out a way to keep things manageable for everyone.

The purpose of our discussion today is to identify the strains you experience especially those stemming from the tasks, demands, and expectations currently imposed upon you. We will explore ways in which you can both share the tasks or alter expectations to make things better for everyone."

Procedures

Step 1: "I would like each of you to think about and list for yourself the things you are currently doing to keep the family and household going." (Give them a minute to think about these tasks—you may need to give them a few examples of what you mean.)

"Now would you tell me the important things that you do to keep the family going." The clinician records couple's comments on newsprint. (See Table 4.1 for example) In the first column he/she writes the list of tasks (e.g., cooking, household cleaning, repairs, yard work, laundry, child care, ironing, caring for pets, recreation, etc.). The couple generates this list of tasks together. Make sure that they have included most of the important tasks before moving on. Be sure to ask not only about instrumental tasks but also about interpersonal ones, such as taking care of each other emotionally.

Table 4.1 Format for lists of family tasks

Tasks	Primary person	Helper	Ideal
Meal preparation	Wife	Husband	Neighbors/church
Washing dishes	Wife	Daughter	Daughter
Driving son to soccer	Neighbor	Wife	
Laundry	Wife	Husband	
Lawnwork	Husband	Neighbor	
Driving patient to clinic	Husband		
Communication with extended family	Wife	Daughter	
Housecleaning	Wife		Housecleaning service
Home repairs	Husband		

"Are there any tasks that you may *not* now perform but which would now make life easier if they were performed?"

Step 2: In the next three columns, the current allocation of roles/tasks are recorded. The columns are labeled with the words: "Primary," "Helper," "Ideal."

Step 3: For each task, ask the couple who is primarily responsible for the job and if there is anyone who routinely helps with it.

Step 4: When the listing of tasks is complete, go back and ask whether the current arrangement has resulted in a problem for anyone. What assignment changes would make the situation better? Ask the couple to consider and discuss how they ideally would like to see roles and tasks assigned. Ask whether there are tasks they would do less frequently, would stop from doing, or would seek someone outside of the immediate family to do.

During the discussion note similarities and differences between partners in their perception of important tasks and in their roles in the family. Note individual partner's reactions to any discrepancies, how the partners talk with each other, and how they manage with disagreements.

Step 5: Try to help the couple come to an agreement about what the distribution should ideally be like for the couple or family to function most effectively. The clinician should help the couple negotiate differences, think about alternative solutions, and proceed with a problem-solving approach. This problem-solving paradigm can also be used in subsequent sessions.

Homework Assignment

The couple is encouraged to continue negotiations and problem solving around tasks/roles. The clinician suggests using a problem-solving approach in which partners (1) individually identify their needs, (2) listen to each other feelings and desires, (3) generate alternative solutions, (4) discuss advantages and disadvantages of each of the alternative solutions, and (5) select and implement one of the solutions.

Case Illustration

Ed and Emily are an example of how a couple with three young children distributed the work of the family when Emily was going through chemotherapy for her breast cancer. Ed is an engineer and Emily had worked as an architect until her last child was born 2 years earlier. She had planned to return to work outside the home when he turned three and could be enrolled in pre-school, but decided to put off returning to work until after her treatments were completed. Ed and Emily were in their mid-30s and the ages of their children were 2, 6, and 8 years old. The session took place in the chemotherapy clinic with the social worker. During the first portion of the interview, Emily described how the chemo treatments were making her nauseous and tired and how she needed frequent naps during the week.

After introducing the "Day's Theme," the social worker led Ed and Emily through the first step of identifying all of the tasks that they did to keep the household running. The list that they developed is in column one of Table 4.2.

Table 4.2 Ed and Emily's list of family tasks

Tasks	Primary person	Helper	Ideal
Child care	Wife	Husband	Babysitter or mother during the afternoons
Grocery shopping	Wife (online)	Husband	
Other shopping	Wife (online)	Husband	
Cooking	Wife	Wife's sisters	
Washing dishes	Husband	Wife	
Housecleaning	Wife	Housecleaner Husband	
Driving daughter to piano lessons	Wife	Wife's sister	Sister
Driving son to play group	Wife		
Laundry	Wife	Husband Housecleaner	
Lawnwork	Husband (mowing)	Wife (flower garden)	
Taking children to doctor and dentist appointments	Wife	Husband	
Driving patient to clinic	Husband	Wife's sisters	
Communication with extended family	Wife	Husband	Husband handle all phone calls
House repairs	Husband	Friends	
Car repairs—taking car to dealership	Husband		
Shoveling snow	Husband		Hire someone for the winter
Paying bills	Wife	Sister	
Taking care of cats (feeding, litter box, vet)	Wife	Husband	Ask housekeeper to clean litter box
Arranging social plans	Wife	Husband	
Emotional support	Wife	Husband	
Resupplying the house (e.g., paper towels, water, toilet paper, tissues)	Husband	Sister	
Errands (post office, drycleaners, drugstore)	Husband		
Taking trash to transfer station	Husband		Hire trash pickup service
Buying gifts	Wife (online shopping)	Husband	

As they started to list their tasks, Emily stated that she and her husband had a history of sharing chores and that they usually worked in shifts, depending on how busy they were with their work outside the home. Also, they worked in shifts so that Emily could care for the children during the day and Ed could care for them at night. As the list shows, the tasks were divided along traditional gender lines. Emily did most of the inside work and Ed did most of the outside work.

Since her diagnosis, they had made several changes in the distribution of the family work. First, they hired a nanny/babysitter part-time to help with the child care during the day. A second change that they made was in the area of shopping. Emily used a grocery store that allowed her to order all of her groceries online. This eliminated driving to the store and saved a great deal of time and energy. She stated that simple things like putting her 2-year-old son in the shopping cart were difficult after her mastectomy. Using a computer to shop was much more manageable for her. She not only ordered her groceries in this manner but also began to do almost all of her shopping online, including her children's clothes, toys, and gifts. As they discussed the various tasks of the family, it was apparent that Ed and Emily were able to use their support network to get necessary help. However, most of the time they accepted help only if their friends and family offered to give it. For example, Ed's family raked all the leaves in their yard one weekend which the couple gladly accepted, but they probably would not have asked for such help.

While Ed and Emily appeared to have adapted quite well to the demands of the illness, regarding the distribution of work within the family, the social worker was able to help them identify a few areas that could be improved. During this part of the session, the social worker used a problem-solving process to address the particular concern. The spouses' needs were expressed, and various alternatives were generated. The first concern identified was Emily's lethargy and the side effects of the chemotherapy. Emily expressed the need to take naps during the day, but she needed someone to watch the children. Since the babysitter worked for another family on the days that she was not working for Emily's family, asking her to work additional days was not an alternative. She did not want to impose on her family for more help. However, in looking at the list, Ed noted that his mother was not included in any of the work. He agreed to ask her to fill in for the babysitter on the days that she did not work. As the couple discussed this, they decided another task to add to the list was arranging for help with the family chores, since that in itself took time and effort.

Ed and Emily discussed how important it was for Emily to continue to feel that she was doing her share of the work for the family. Due to her physical limitations, however, she could not do as much as before. Therefore, they decided that she would continue with the tasks that did not require physical effort, such as paying the bills, ordering food online, providing emotional support to family members, and handling phone calls. They also discussed how their 8-year-old daughter could be assigned chores, such as feeding the cats, loading the dishwasher, and tidying up her bedroom.

It was also apparent that Ed was feeling overwhelmed with balancing his current work schedule, which required some evening work, with being available to run errands, take his wife to chemotherapy, and help with child care and housework.

The social worker inquired about his work benefits and the feasibility of taking a paid family leave. Ed had not explored this option and agreed to look into it before their next appointment. If this was not a possibility, he planned to talk to his boss about rearranging his work schedule so that he would not need to work evenings. He admitted that he had not approached his workplace about such modifications, in part because of fear of repercussions. But he was now willing at least to explore the idea.

Overall, Ed and Emily had been negotiating the tasks of the family from the beginning of Emily's illness. They had managed the distribution of the tasks based on each person's availability and competence. They had, in addition, demonstrated remarkable flexibility in shifting roles. As the social worker helped them divide up these concrete tasks, she observed that they communicated care, emotional support, and empathy toward each other. This was an important observation as she planned for her future work with them.

What to Do if . . .

The Couple Cannot Generate an Extensive List of Chores

Help them by giving specific examples of tasks. Also, give examples of emotional tasks, such as listening, empathizing, and accessing support, that are often more intangible but nonetheless are critical during the cancer journey.

The Patient Feels Underutilized and Worthless

This often happens when people around the patient are trying to take care of her by doing everything for her. Make sure there are some tasks assigned to the patient when appropriate. If the patient cannot physically do many of the tasks, assign less strenuous tasks (e.g., paying the bills) and emotional tasks (e.g., listening to children and partner).

A Spouse/Partner Is Not Willing to Make Changes

This occasionally happens when there is too little flexibility or adaptability in the relationship. Explore any beliefs that are obstacles to changing the current distribution. For example, a husband may not want to do housework or cook because it feels emasculating to him. In this case, try to help the husband to see that it is in his best interest and his family's best interest to help in this way. Help him understand that there are new tasks that caregivers may need to take on and that these may feel uncomfortable at first. Reassure the husband that when his wife is feeling better, he may not have to help in this way.

One husband who was participating in the Partners in Coping Program refused to help with the housework but also did not want to pay a housecleaner to clean the house. The social worker had to help the couple generate numerous solutions before the husband was willing to accept one.

The Couple Has "Too Much on Their Plate"

Sometimes the tasks of the family and work demands are overwhelming for a couple. Sometimes couples create their own stress by taking on too many responsibilities. Try to help them reduce the load they have placed on themselves and lower their expectations. For example, does the house *always* need to be clean? Can a spouse take a leave of absence so he can be available when the patient needs the most attention? Can someone else host the holiday party at their house this year?

When the Support Person Is Not a Partner

Friends, family, and other types of support persons often are able to take responsibilities for practical tasks that greatly assist women during their treatments and recovery. The practitioner does need to be attentive that the support person does not over-rely on the practical roles to show support, to the detriment of provision of emotional support. People are often comfortable with providing practical support as it helps them to feel useful. There are also clearer social norms or conventions to guide behavioral exchange between non-partner dyads for the provision of practical support than there are for emotional support provision. The balance between emotional and practical support needs to be maintained.

Sociocultural Considerations

In the case of Ed and Emily, the couple had the financial resources to hire outside help. They owned a computer, subscribed to high-speed internet access, and ordered home delivery of their groceries. The husband's health insurance benefits fully covered all their health-related expenses. In some respects, they preferred to hire outside people rather than ask their own family to help out. In situations where couples do not have the financial resources to obtain so much help, they must rely much more on their informal support network. This is where the genogram that was created during the first session is useful. One patient whose husband was frequently traveling taped her genogram to the refrigerator door so that she could refer to it when she needed help. Also, broadening the network of support works well in situations where the couple adheres to specific cultural expectations for men and women and are not likely to compromise their beliefs. For example, if the husband is unwilling to cook meals, a sister, mother, or friend may be asked to help in this area.

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Chapter 5
Building Cognitive Coping Skills

> *"It was important to understand my reactions to stress. . .it was a turning point. . .I started to feel like I had a future."*
>
> *"You always think the worst sometimes, and it can sort of keep snow-balling."*
>
> *"I could tell she was becoming stressed and that she didn't really think she was going to get through this. I didn't know what I could do to help her get over that."*

The way that individuals think about the challenges of cancer affects how they cope with cancer and, ultimately, how they adjust to it. Blaming oneself and thoughts of helplessness produce high distress in patients and their partners. It affects their social functioning not only at the time of the cancer diagnosis but even long after it (Carver, Meyer, & Antoni, 2000; McCaul et al., 1999; Northouse, Templin, & Mood, 2001; Parle, Jones, & Maguire, 1996). In contrast, viewing stressful events in a more positive way engenders acceptance of the reality of the situation, optimism about the future, and can create a sense of meaning and purpose. The outcome is an improved adjustment in women with cancer (Lepore & Ituarte, 1999; Lepore, Ragan, & Jones, 2000; Scheier & Carver, 2001; Stanton, Danoff-Burg, & Huggins, 2002).

The purpose of this chapter is to foster and reinforce adaptive, cognitive coping strategies in both partners. This is accomplished through a series of techniques that assist the couple in understanding the stress response process, identifying unhelpful cognitions, challenging the validity of these thoughts, and replacing them with more helpful ones. The couple is taught how to support each other as they go through the process of cognitive restructuring.

Cognitive Coping Processes

Cognitions are central throughout the process of coping. How a particular threat is appraised can trigger cognitive and behavioral coping responses that are either adaptive or maladaptive. There are two main categories of cognition: self-related and worldview-related. If either of these types of thinking is rigid and unchanging, they decrease a person's ability to cope with stressful events. Furthermore, individuals with extreme views about themselves, their ability to cope, or the nature of the world

K. Kayser, J.L. Scott, *Helping Couples Cope with Women's Cancers,*

are more likely to develop posttraumatic stress disorder (Ehlers & Clark, 2000; Ehlers et al., 2002; Foa et al., 1999). Examples of unhelpful self-schema include "I am not worthy of love and support and people will eventually abandon me," "I am completely incompetent and a failure," "I deserve this fate," "I am to blame for the sadness and fear I see in my loved ones," and "I am a burden and should not ask for support." Unhelpful worldviews include thoughts such as "things that happen in life are just and fair, so bad things only happen to bad people," "the world is a very dangerous place," "when bad things happen they are totally negative events," and "it is better not to rely on anyone in this world, because eventually everyone lets you down."

Paradoxically, a self-schema that is extremely positive may also predispose a person to adjustment difficulties. For example, persons who view themselves as "very good copers" may encounter situations that undermine their self-view and create a discrepancy between their idealized self and their real self that is hard for them to reconcile (Foa et al., 1999; Heidrich, Forsthoff, & Ward, 1994). These are the women and men who say to us in therapy "but I am normally such as good coper," "nothing ever gets me down," "I don't know what is *wrong* with me to be feeling like this." They may struggle in vain to return to exactly the same person they "used to be before cancer."

When working with couples to improve their cognitive coping skills, the practitioner must be aware that the patient's and partner's cognitive coping are intertwined. The relationship between women and their partners' adjustment may be, in part, accounted for by the manner in which partners influence each other's thinking about their disease experience. For example, partners may hold such distorted schema that that they are unable to encourage helpful thinking in one another. They may reinforce each other's distress by agreeing with, accepting, and even elaborating upon any negative or distorted thoughts that are verbalized.

Partners' cognitive coping processes involve not only thoughts about oneself but also thoughts about the partner and their relationship. Therefore, there is an overlaying of each person's appraisals of one's own coping, with appraisals of their partner's coping, and what this means for themselves and their relationship. Partners think about the value of their relationship for their coping and appraise the impact that the cancer experience may have on the quality of their relationship. Thoughts about a partner's behaviors that can influence a person's coping include views such as "they do not talk to me about the cancer therefore they do not love me and will eventually abandon me" or "they are not coping so I will not burden them with my worries." Examples of relationship appraisals that have implications for a person's coping include "we've never been good at sharing our feelings so we will never get through this" or "if our relationship is strong then we should know exactly what to do or say to support each other".

In summary, interventions that focus on helping individuals understand themselves and their worldview better should enhance their ability to adjust to cancer. A recent meta-analysis of randomized control trials of psycho-oncology interventions found that interventions that promoted active coping, especially helpful cognitive coping and coping self-regulation, had the greatest effect on a range of adjustment outcomes (Graves, 2003). The CanCOPE intervention, which taught couples how to develop a shared cognitive approach to their coping, improved both partners' coping and their supportive communications, as well as women's sexual adjustment (Scott, Halford, & Ward, 2004).

Teaching Cognitive Coping Skills

The steps to building adaptive cognitive coping skills and broadening coping repertoires are taught over several sessions. This is necessary because learning new ways to view the self or the world or to manage challenging situations takes time and practice. Some people report that they feel they are discovering a new self, a new way of "being" that is at once not only enlightening and rewarding, but also daunting. Thus, couples should be encouraged to view couple-coping skills training as an ongoing process of self and relationship development.

The first step is to help each partner better understand their own responses to cancer. Their physical, behavioral, emotional, and cognitive responses to cancer are reviewed and discussed. This affords them a deeper understanding of how their thoughts, feelings, and coping behaviors are linked. Ultimately, it also gives them insight into how their own cognitions and behaviors can enhance or hinder their partner's coping.

Next, couples are taught to monitor their cognitions associated with stressful, cancer-related situations. Once they are familiar with the nature of their own cognitive coping, they practice challenging their negative self-talk. They replace cognitive distortions and negative automatic thoughts with more helpful self-talk. Couples are then taught a shared thought self-monitoring exercise so that they support each other in fostering more helpful thoughts. This process involves the couples (1) helping review each others thought-monitoring forms, (2) identifying and challenging negative thoughts, and (3) practicing self-talk that will enhance coping. It is not important that the partners have the same way of thinking about the cancer. Rather, shared thought self-monitoring helps the couple develop a deeper understanding of each other's fears and concerns and supports them in finding ways of thinking that improve their coping. Using the shared thought self-monitoring approach enables couples to address unhelpful relationship schema, such as unrealistic expectations for support or misinterpretations of partner's support.

Technique 5.1 Teaching Couples About the Stress Response and the Role of Cognitions

Using Handout 5.1, outline the components of the stress response (i.e., the life stressor, thoughts, feeling, behaviors, and physical symptoms). In order to highlight each component, ask the couple to think of examples from their own experience of the stress associated with a diagnosis of cancer. Ask them to identify feelings they have been experiencing since the diagnosis, how they have been behaving, and the physical symptoms they have felt.

Introductory Remarks “When you find out that you, or someone close to you, has cancer, it is common to experience feelings like shock, disbelief, sadness, or even anger. The way you behave around others might be different from usual. You might be a bit quieter or find it hard to concentrate. You may also notice physical signs that you are under increased stress, such as problems sleeping, changes in appetite, or muscle tension. The people who are close to you may also experience some of these stress responses.

The stress response is part of the human body’s normal reaction to things we see as threatening. The stress response prepares us to cope. However, sometimes you can feel over-stressed. The main aim of stress management is to keep stress at levels where you feel in control. To do this, it helps to be aware of your own stress responses. You may be trying to understand medical information, prepare for treatments like surgery, keep other appointments. Some people are busy trying to help others to cope, or keeping people they are close to informed about developments. It can be hard to know exactly what you are thinking or feeling.”

[Give each person a copy of Handout 5.1 ‘The Stress Response,’ and refer to it as you ask the following questions]

“Let’s start with the physical reactions you have noticed since you found out about the cancer. Some people’s reactions to stress are very physical. Others do not have many physical signs of stress at all.

Some common physical reactions to stress are

> muscle tension, headaches, problems with sleep, loss of appetite, racing heart, stomach upsets, and stiff back or shoulders.

What physical responses have you noticed?”

[Ask each person for their response]

“Sometimes the stress responses people notice most after they find out about the cancer are their feelings. Not every person feels the same way. Also, people’s emotions can change quickly at this time. You may feel differently a few days from now.

Common emotions people feel are

> shock, numbness, disbelief, sadness, fear or anxiety, anger, impatience or eagerness to start treatment, sense of things being unreal, guilt or self-blame, irritability, concern for how other people close to them are coping and feeling, uncertainty about how to support loved ones or how to behave around them.

What feelings or emotions have you felt?”

[Allow each individual time to respond]

"Some people notice that they behave a little differently from normal around other people. They may be more quiet than usual. There are many reasons for this. It may be they are lost in their thoughts or are having some difficulty concentrating on things. They may be trying to keep their emotions to themselves. Some people become extra active. They may be trying to keep their mind busy. Other people notice an increased need to share their thoughts and feelings. They may seek out people to talk with.

Common reactions people have when around other people close to them are:

crying, avoiding talking about the cancer, withdrawn and quiet, impatient or irritable, preoccupied, trying to encourage and support others, trying to hide concerns or worries.

How have you been when around others?"
[Elicit responses from each individual]

Thoughts are a very important part of a person's stress response. What you think influences how stressful you find things. People vary in how they think about aspects of their experiences with cancer. Looking at your thoughts can help you to make sense of your feelings and manage your stress.

Sometimes it is hard to sort out feelings from thoughts, especially when under stress. One way to explore your thoughts is to think back to the challenging times when you felt the emotions. When you had these feelings, what things were going through your mind at the time? Thoughts are a bit like things we say to ourselves quietly inside our heads. We call this self-talk. Common self-talk or thoughts people have when they find out they or someone they care about has cancer are:

> "I won't cope," "What if the cancer has spread?", "I'm ok, but I don't think my family will cope," "The cancer treatments scare me," "Why do I have to have my lymph nodes removed?", "I will take forever to recover after surgery and need lots of time off work," "I've made others upset," "I should know exactly the right thing to say to make my loved one feel better"

Technique 5.2 Linking Thoughts and Feelings

Introduce the Cognitive Component of Stress Tell the couple that now we will look at the link between thoughts and emotions or feelings. Some couples may need help in identifying and articulating the thoughts they may have had. Explain that discovering the thoughts can be difficult and that to illustrate the influence that thoughts have on emotions they are now going to do a small experiment for a few minutes. Ask each person to close their eyes and think about something annoying or frustrating happening to them.

Introductory Remarks "I would like to do a small experiment with you for a few minutes. Close your eyes and think about something annoying or frustrating. For example, imagine that you are running late for work and discover you have locked your keys in the car, or that you are waiting for a lift home from the shops and the person forgets to pick you up, or you buy new clothes to wear out that night and discover when you take them home that the items are flawed." [Pause]

[Prompt them to imagine the scene fully, what are they wearing, who else is there, and how are they feeling. After 1 minute, ask them to open their eyes.]

"OK, you can open your eyes now. I would like you to turn to each other and describe how you were feeling during the experiment."

[For the experiment to work, and to highlight the links between thought and emotions and coping, it is not necessary to ascertain what the image was that the person generated. In fact this can lead to discussions that distract from the main teaching goals. It is better for the practitioner to focus on the feelings and physical responses the scene engenders. Write each person's comments and observations down on a white board or sheet of paper.]

Repeat Brief Guided Imagery Process This time, ask each person to close their eyes and imagine something really wonderful and fantastic happening to them, or to someone they care about.

"I would like you to close your eyes again and imagine that something really wonderful and fantastic is happening to you or someone you care about. Imagine that you are going on a long-awaited holiday, or a favorite daydream, or being visited by friends or family you have not seen in a long time, or being given praise from a boss about work performance." [Pause]

[Then prompt them to imagine the scene fully] "Try to remember what you are wearing, who else is there, and how you are feeling." [After 1 minute, ask them to open their eyes].

"Now, open your eyes and turn to each other and describe how you were feeling during the experiment." [Again, write their comments down.]

Now compare the differences in emotions and sensations associated with each experiment. "Across these two brief experiments you had not changed anything, other than what you were thinking about. Yet, look at the differences in how you were feeling and reacting. These experiments highlight how powerfully our thoughts can affect how we feel. The impact of thoughts on emotions can be so quick that sometimes we don't even notice our thoughts, only how we are feeling. This is **NOT** to say that the challenges we face are "all in our head" or a figment of our imagination. Rather, the way we think about a stressful situation, ourselves, our coping, and even the responses of other people close to us, can hinder or help us in our coping efforts."

Technique 5.3 Teaching Cognitive Restructuring

With this technique couples are taught cognitive restructuring or "Coping Self-Talk." During the process of identifying negative self-talk and replacing it with positive thought, the partners support each other. Using the Coping Self-Talk Form, they take turns reviewing and discussing their self-talk with each other. When in the listener role, they should practice providing constructive, validating, feedback in an empathic way. They should also help each other challenge negative self-talk and develop more useful self-talk.

To implement this technique, the clinician should bring to the session two copies of Handout 5.2 'Coping Self-Talk Form,' and the following handouts: 5.3 'Tips for Supportive Talk', 5.4 'Common Unhelpful Thoughts,' 5.5 'Tips for Challenging Unhelpful Thoughts,' and 5.6 'Helpful Thoughts.'

Understanding Their Own and Each Others' Cognitions Explain that now they are about to learn the first steps in "Coping Self-Talk." Explain that Coping Self-Talk involves examining how we think or talk to ourselves when we are under stress, and ensuring that our self-talk assists us to cope effectively rather than causing us increased stress.

Introductory Remarks "The way a person thinks about a situation affects the way they feel and cope. Under stress, thoughts often happen quickly. Some of these thoughts may be unhelpful because they are negative. Some thoughts are inaccurate. Unhelpful thoughts make a person feel worse.

An important part of stress management is to look at your own thoughts when you have felt strong emotions. This lets you see how your thoughts influence your feelings. The best way to learn more about your own thoughts is to write them down on the 'Self-Talk Coping Form' (Give them each a copy of this form—Handout 5.2). Working through the 'Self-Talk Coping Form' with your partner can enrich the emotional support you are able to give one another. It can help you have a better understanding of what each other is thinking and feeling, and why. Learning ways to challenge negative or unhelpful thoughts also enables your support person to feel more useful. This helps them in their coping and adjustment."

Procedure for Completing the "Self-Talk Coping" Forms

1. Think back and recall one upsetting or difficult situation during the last week.
2. What happened, where, and when?
   (write your answer in column 1 headed "Situation")
3. What were you feelings at that time, how strong was that feeling?
   (write your answers in column 2 headed "Mood")

4. What was going through your mind at the time, what thoughts did you have?
   (write your thoughts in column 3 headed "Thoughts")
5. Look at what you have written down. Are there are any unhelpful thoughts? Underline the unhelpful thoughts.
   (Look at the examples of types of 'Unhelpful Thoughts' on Handout 5.4. Compare them to the thoughts you have written down in column 3)
6. Are there other ways you can think about this situation that are more helpful?
   (help each other to challenge unhelpful thoughts and come up with more balanced thoughts. Handout 5.5 'Tips for Challenging Unhelpful Thoughts' will assist you. Look at the examples of Helpful Thoughts on Handout 5.6. Would you find these useful to think about)?
   (write your new Helpful thoughts in column 4 headed "Helpful Thoughts")
7. If you practiced using these new thoughts in situations like this one in the future, how would you feel?
   (Write your new feelings in column 5 headed "New Mood"
   Rate how strong you think this new mood would be)

Highlight Common Errors with Self-Talk Remind couples about the imagination experiments in Technique 5.2 and how it shows that our thoughts, especially when we are stressed, are rapid, almost automatic. We do not often stop to question what we are telling ourselves and instead we take our own thoughts as facts. Give examples of unhelpful self-talk such as black and white thinking. Use the examples provided in Handout 5.4 'Common Unhelpful Thoughts' to help illustrate these types of self-talk.

Ask Each Individual to Examine Own Self-Talk Refer the couple back to their Coping Self-Talk Forms they completed. Ask each person in turn if, after doing the task, they noticed any such forms of negative or irrational self-talk in their own thinking. Some individuals will need help in identifying irrational thoughts as they may hold these thoughts to be truths rather than beliefs.

Teach Steps in Using Coping Self-Talk Remind the couple of the experiment they did in session one and how it highlighted "we are what we think." Now demonstrate the steps involved in learning Coping Self-Talk. Start with the woman and if possible use her examples of a stressful situation from her homework record sheet. Actively include the partner by informing them that their job will be to

a) describe their observations of their partner's reactions to stressor.
b) assist their partner to challenge unhelpful self-talk.

c) assist their partner to reframe thoughts by suggesting new self-talk.
d) assist their spouse in homework task.

During this process, the clinician should model for the partner a manner of responding to the woman that involves empathy, emotional validation, and constructive feedback. The partner should be discouraged from asking "WHY" questions as they lead to justifications and defensive responses.

Repeat Cognitive Restructuring Using Partner's Example Demonstrate the process using the partner's example of a stressful situation from his Coping Self-Talk Form. Actively include the patient by asking her to engage in steps (a)–(d) outlined above. Once again the therapist should use appropriate peer tutoring skills as outlined above.

Assignment and Planning Explain to the couple their homework tasks. These involve using the Coping Self-Talk Record Form and monitoring their self-talk for one or two stressful situations. This time they should also try to challenge their thoughts. When this is done, they are to set aside 20 minutes to review and discuss their homework with each other. The person whose record form is being reviewed has the job of explaining to their partner the contents from each of the columns in the form. Any insights they have had about their own self-talk, or problems they may have experienced in challenging their self-talk, should be shared with the partner. Their partner's job is to practice the skills they learned during the session, such as giving constructive feedback in an empathic and validating way. The partner should also help them challenge any negative self-talk they found particularly hard to stop using and help them to expand their range of Coping Self-Talk. Check for understanding before moving onto the final exercise for the session.

Technique 5.4 Challenging Core Beliefs or Deeper Cognitions

Sometimes women or their partners experience persistent distorted cognitions that undermine their ability to cope and support each other effectively. Some themes evolve from prior relationships with significant others, or from their current relationship, and shape the person's understanding about the nature of support interpersonal relationships. Relationship themes particularly relevant to couples' adjustment to cancer include the durability and dependability of relationships in times of duress, the value of emotional intimacy as a form of support, appraisals of self-worth and entitlement to support, and the behavioral indicators of "good" couple or individual coping (Snyder, 1999).

Distorted relationship themes can lead to unrealistic expectations for support, or misinterpretations of a partner's support and coping behaviors. In turn, this can impede the acquisition of partner support skills. Negative self-evaluation may impair a person's ability to benefit from support. Core beliefs about low self-worth or the inevitability of abandonment are sometimes expressed by individuals who have experienced neglect, abuse, or rejection during their formative years. These beliefs color their interactions with others during their cancer experience. Such people often view close relationships as highly fragile and vulnerable. They may become hyper-vigilant to comments and actions from their partner, or even from health professionals involved in their care, construing them as signs of rejection. They may avoid asking for support for fear of annoying their partner or being abandoned by them.

Core beliefs are addressed with the couple by using the downward arrow approach (Burns, 1980), which helps each individual explore underlying maladaptive core beliefs. This technique involves systematically questioning the meaning behind an unhelpful or distorted thought, until the "bottom line" or essential meaning of a person's unhelpful thoughts is uncovered (Snyder, 1999).

Explore Deeper Meaning and Core Beliefs The practitioner should explain to the couple that sometimes when people learn to identify and challenge unhelpful self-talk they find strongly held beliefs or assumptions. These are called "core beliefs." These beliefs are often formed in childhood and help us to make sense of the world. However, as adults we do not always ask whether these core beliefs are useful for understanding our adult experiences. Instead, as an adult we act, think, and feel as if these beliefs are still absolutely true.

Introductory Remarks "Some unhelpful thoughts can be difficult to challenge because the person holds these thoughts so strongly. The thoughts may stem from experiences in their lives that have taught them to believe certain things about others, or themselves. These deeper thoughts affect their expectations about the emotional or practical support they give or receive. It sometimes influences the way they view relationships with people close to them, or even their relationship with people involved in their medical care. An example of this phenomenon is provided in the case illustration on p. 94. Deep thoughts may also influence the way we evaluate our own, or other peoples' coping. For example, one woman grew up in a family where family members did not often show their emotions. She believed that showing strong emotions indicated that things must be going horribly wrong. This deep belief affected how she coped with some situations during her cancer experience. For example, she became very discouraged when the woman she was supporting was teary and sad for a few days following surgery. She felt she was a failure as a support person, and worried because she believed strong emotions were a bad sign."

Next explain to the partners that one way to identify their core beliefs is to look at their own Coping Self-Talk Forms and see if there are any recurring themes in the records they have kept.

Downward Arrow Technique

***Example One*: Situation or Thought from Coping Self-Talk Form**

I shouldn't cry when I talk to someone about my cancer

↓

What does this say or mean about me?

They will think I am pathetic and helpless

↓

What am I afraid this means?

People will not respect me

↓

What is the worst thing that could happen if it is true?

People will reject me if they see weakness in me

***Example Two*: Situation or Thought from Coping Self-Talk Form**

The only way to support someone in their coping is through actions

↓

What does this say or mean about me?

I guess I feel less of a man if I show my feelings

↓

What does this say or mean about me?

People only like you if they fully respect you

↓

What does this say or mean about me?

I am not a man if I allow myself to feel and show emotions

"Using your Self-Talk Coping Form, look to see if certain types of automatic thoughts or self-talk repeatedly occur. These may be a clue to underlying assumptions or core beliefs about yourself and the world that are hindering your coping."

Another way to uncover core beliefs is to teach the vertical or downward arrow approach to challenging layers of cognitions or self-talk. Using a series of questions, the clinician helps individuals to uncover the *core* beliefs or thoughts that lie behind their negative self-talk.

"In order to help us identify some of your core beliefs that lie beneath your self-talk, I would like to ask you a few questions: [Clinician can select the questions that appear relevant to the person's self-talk]

What does this thought say about you if it is true?
What are you afraid this means?
What is the worst thing that could happen if it is true?
What does this mean about how my partner feels or thinks?
What does this mean about the other people in general?
What images or memories do I have in this situation? If so, what are they?"

Examples of the Downward Arrow Technique are provided above. It basically involves peeling away layers of beliefs to uncover *core beliefs* about the nature of the self, the world, or interpersonal relationships that are strongly held.

Case Illustration

June (55 years) was diagnosed with breast cancer and had undergone a mastectomy. She was about to commence 6 months of chemotherapy. Her husband of 25 years was Raymond (60 years). In previous therapy sessions, June and Raymond had learned about the stress responses and the role of cognitions in responses. They had successfully used their Coping Self-Talk Form to manage some situations they had found stressful. However, when June and Raymond presented for their fifth session of therapy, the therapist noticed there seemed to be some tension between them. After prompting by the therapist, Raymond explained that June had become "unreasonably anxious and upset" about being late for her first chemotherapy appointment. June continued the story, saying that Raymond had arrived home late from work to take her to the appointment. To make matters worse they had become stuck in traffic on the way to the hospital. June stated she had started to become anxious, waiting in the car, and acknowledged that her reactions were "almost hysterical," saying she began "crying and sobbing" and had "shouted angrily" at

Raymond about him not loving her. Raymond added that he felt like he had been blamed unfairly for the events. He said he could not see what the problem was and, that they had eventually arrived at the hospital and the chemotherapy was delivered. June added, “I was still really upset though. It was a terrible way to start treatment.”

The therapist worked with June using the Downward Arrow Technique to explore her thoughts associated with this event. June stated that her reactions were so strong and immediate that all she recalled was “really strong emotions’, rather than particular thoughts.” The therapist asked June to describe what she recalled feeling. June’s recollection was of feeling enormous anxiety that she would get into trouble from her doctor for being late, that he would “disapprove” of her. The therapist asked June, “What would this mean for you if your doctor showed anger towards you and disapproved of you.” June answered that she feared if she annoyed her doctor, he would say that he would not be her doctor anymore. The therapist gently suggested to June that there was strong theme in her comments that related to being disapproved of and being seen as annoying by a figure of significance in her life. June nodded and reflected “I guess I’ve always had some fairly deep feelings about inadequacies and not being worthwhile as a person.” The therapist asked June to think back over her life. Had there been other times in her life she could recall when she had felt the similar emotions that she had felt in the car on the way to the chemotherapy. June began to nod and tears came to her eyes as she recounted that her father had been an extremely critical person whom she felt she could never please. She felt her mother was depressed and had not bonded with her, or protected her from her father’s verbal abuse. June recalled that she would “tip toe around the house” fearful not to raise her father’s ire. Her father had eventually left her family home and she had watched him leave from her bedroom window. She remembered thinking that it was her fault that he was leaving, that she had displeased him.

The therapist commented to June she seemed to have had experienced some deep rejection and criticism during her childhood. This made her believe she was a worthless individual and that eventually all people would abandon her. She felt she had to be careful to never upset other people otherwise they would leave her. This deep belief about her own self-worth affected how she coped with some situations during her cancer experience. June said she could see this in herself—that she was always trying to make other people like her in case “they got sick” of her.

June said that she felt the exploration of the deeper thoughts had been helpful because she felt “less irrational.” She said it also helped her make sense of many of her reactions since the diagnosis because she had been feeling more dependent on others and she could see now why this had made her so uncomfortable and vulnerable. The therapist asked Raymond what he had learned about the deeper thoughts behind June’s reactions to some situations she had found stressful. Raymond said he could “see now where June’s reactions were coming from that day on the way to traffic,” why it was so important for June to avoid upsetting her doctor. The therapist asked Raymond how this insight would help him in his support of June in her cancer journey. Raymond commented that he had always known about how bad her childhood had been but he had never really thought about what this meant for the way she saw herself. He said that in future he felt he would be more patient with June and that he could help her see that she was a wonderful person who deserved love. He felt he would take her comments less personally because "they were from deeper issues in her childhood." He turned to his wife and held her hand saying "Sweetheart, I love you—I will not leave you no matter what, you have to remember that." For their homework assignment, June continued to use her thought monitoring form to focus on managing situations where she found herself feeling the old familiar feelings of anxiety about abandonment. Together Raymond and June worked on challenging these thoughts together, with Raymond using supportive communication skills to discuss June's deepest fears and memories. Over time, and with practice, June came to the realization that these were things from her past that need not overwhelm how she felt about her self in adulthood.

What to Do if . . .

The Person Seems Upset Following the Pleasant Imagination Experiment

Sometimes the picture that people imagine in response to the guided image experimental task can produce "bittersweet" emotions and the person may respond with sadness, rather than positive emotions. Often the image may be of a loved one, long since passed away, or of the carefree days of youth, or some other situation that, though associated with happy memories, is also sad because it is no longer attainable. If this happens the response can still be used as a teaching moment, to highlight the link between thoughts and emotions. However, the practitioner must be aware to debrief the person, and their partner, so that they leave the session in a positive and stable emotional state.

The Person Cannot Imagine Any Scene

This sometimes happens when people are highly emotionally upset or in shock, such as when they are newly diagnosed. The practitioner must be sensitive to people's arousal states and not attempt the experiment when someone is agitated and having difficulty concentrating. The stress and coping model and Coping Self-Talk should be explained in this case without the inclusion of the imagination experiment. The experiment can be conducted with the couple at a later date, if they are having trouble understanding or recognizing the link between thoughts and emotions.

The Person Cannot Find a Negative Core Belief

Many women and their partners will experience few or no problems developing and improving their adaptive Coping Self-Talks skills. These are often people who hold more discerning or flexible views of themselves, the world, and their close personal relationships. Sometimes they have experienced other major stressors in life that have helped them to broaden their view of themselves, of other people close to them, or of coping processes generally. There may not be a negative core belief that the practitioner *needs* to challenge in order for the person to cope effectively with their caner experiences.

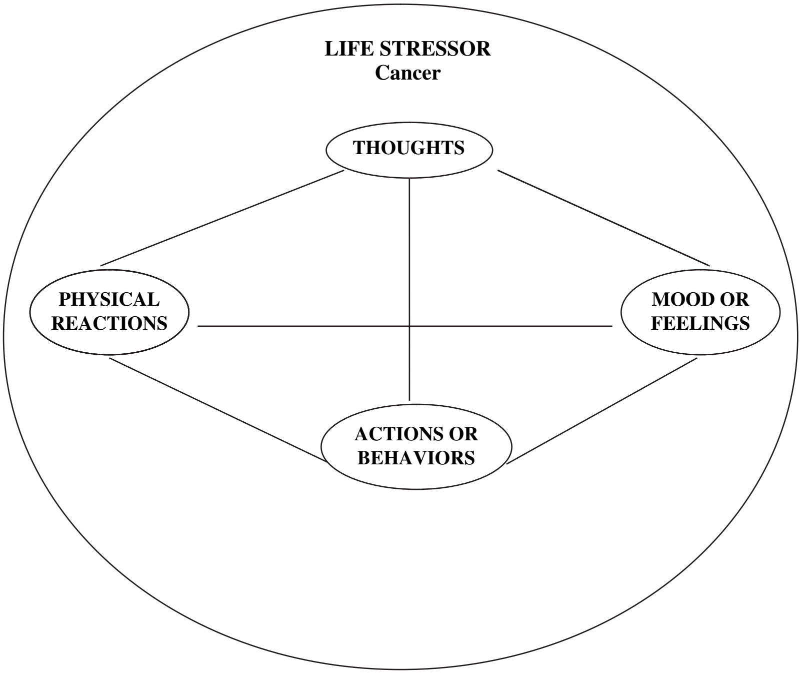
When the Support Person Is Not a Partner

The individual and shared cognitive restructuring tasks presented in this chapter are entirely appropriate for all types of dyadic relationships. However, the therapist needs to exercise caution when exploring deeper beliefs with a person in case they do not wish to share some circumstances of their life with their support person. There may be traumatic events that they have never disclosed with anyone before. If the practitioner is working with a dyad that are not in an intimate relationship, and they suspect that there are deeper thoughts that may need to be explicated, they should alert the person with the comment "some unhelpful thoughts stem from experiences in people's lives that lead a person to believe certain things about others, or themselves." It can be useful to explore a person's life circumstance more fully to understand how this might affect their views of current events that they are experiencing. Before we look at this together, it is important for me to know your preferences for how we continue from this point. How do you feel about discussing your childhood or other life experiences in front of [insert support person's name]. The practitioner should tailor the composition of the session according to the person's wishes and offer them the opportunity to discuss deeper thoughts in individual session(s).

Sociocultural Considerations

The cognitive restructuring components presented in this session have been delivered successfully with people who have minimal formal education (Scott et al., 2003; Scott et al., 2004). However, the relevance of the specific cognitive coping strategies outlined in this chapter for enhancing adjustment in ethnically diverse groups is less clear. There has been relatively little research of these variables in the chronic illness field (Stanton, Revenson, & Tennen, 2007). There is some tentative evidence from recent qualitative research that having a shared cognitive focus is associated with better adjustment in African-American couples coping with breast cancer (Morgan et al., 2005). Generally, results from the few studies that have examined coping in women from minority or ethnically diverse groups suggest that there are minimal differences between white, African-American, Hispanic, and Japanese women in the cognitive antecedents associated with their good adjustment to cancer (Culver, Arena, Antoni, & Carver, 2002; Fukui et al., 2000).

Handout 5.1 The Stress Response



Handout 5.2 Coping Self-Talk Form

NAME: ______________________ *DAY / DATE:* ______________________

1. SITUATION *Who was there?* *What was happening?* *Where was I?* *When did it happen?*	***2. MOOD*** ***a.*** *Feeling?* ***b.*** *Rate strength of feeling (0–100%)*	***3. UNHELPFUL THOUGHTS or IMAGES*** ***a.*** *What was going through your mind?* ***b.*** *Circle any 'hot' thoughts or thoughts that you often have*	***4. New COPING SELF-TALK*** ***a.*** *Write alternative, balanced or more helpful thoughts*	***5. Re-RATE MOODS*** *listed in column 2.* ***b***. *List any new moods (0–100%)*

Adapted from the 'Dysfunctional Thoughts Record' (DTR)[73, p. 62]

Handout 5.3 Tips for Supportive Talk

When you work together with your support person to challenge unhelpful thoughts:

- **Use supportive communication skills**. Share thoughts and feelings, listen to one another. Accept that sometimes you may feel or think differently from one another.
- **Be patient with yourself and each other when trying to identify the thoughts behind feelings**. Monitoring thoughts and challenging unhelpful one takes practice.
- **Avoid asking the other person WHY they have a particular thought**. This may make them feel defensive, unsupported, or misunderstood.
- **Make gentle suggestions about other ways to think about things.** Avoid telling the other person *WHAT* or *HOW* to think, or to *STOP* thinking a certain way. Help them come up with new ways to think about an issue or situation.
- **Encourage the other person to practice their new helpful thoughts in future situations.** Support them in their efforts to use helpful thoughts. Help them review their progress and praise them.

Handout 5.4 Common Unhelpful Thoughts

Sometimes the way we think or talk to ourselves is negative or unhelpful. Some thoughts increase upsetting feelings or make us feel like we are not coping. Below are some examples of common unhelpful or negative thoughts.

The "What ifs?"	*"What if when I start radiotherapy I get bad side effects or reactions? I'll never cope".*
Spiral of negatives	*"I'm going to look really ugly, everybody will reject me everything will be absolutely horrible, I'll probably get very sick".*
Leap to conclusions	*"I feel tired all the time. There must be something terribly wrong with me. Something bad is happening, this isn't right".*

Over-generalize (once therefore always)	*"My neighbor avoided me when she found out I had cancer. Therefore all people will avoid me from now on".*
Guilt and self-blame	*"It is my fault that everybody is upset. I've caused extra drama for everybody".*
Goal irrelevant	*"I must keep all my social and work commitments while having treatment. If I don't, I'm a complete failure".*
Black and white thinking	*"I must get everything done today before I go into hospital tomorrow, otherwise everything will be a complete disaster".*
Strong, uncompromising words	*"I should . . . , I must. . . , definitely will. . .," "absolutely, completely. . . , impossible. . . , worst. . . , most. . . , always. . . , never. . ."*
Unkind or mean to myself	*"I'm ugly, I'm weak, I don't deserve love or" "support, I'm a nuisance , I'm stupid".*

Handout 5.5 Tips for Challenging Unhelpful Thoughts

- If my best friend, or someone I loved, had this thought about themselves or aspects of their cancer experience what would I tell them?
- Five years from now, when I look back will I look at things differently? Will I look at my experience with cancer differently?
- Are there any strengths or positives in me, and how I am coping with my experience with cancer, that I am ignoring?
- Am I jumping to any conclusions about treatment, or what will happen, that are not completely justified by the evidence?
- Am I blaming myself for things over which I do not have complete control?
- Am I thinking about someone I knew who had a bad outcome after getting cancer, and jumping to the conclusion that the same things will happen to me?

Handout 5.6 Helpful Thoughts

Some thoughts are more helpful than others. They help us to manage strong emotions or stress, and help us cope.

One step at a time	*“I’m imagining the worst. I can’t be worrying about things that have not happened and may never happen”.*
Focus on positives	*“I’m making progress each day. I can do more things around the house this week than I could last week”.*
Explore alternative explanations	*“I have read that tiredness is common while on treatment. Maybe I am scaring myself”.*
Assess evidence	*“It is not true that everybody avoids me in all situations. In fact, some friendships have become closer”.*
Reduce self-blame	*“Family and friendship is all about caring for each other through good times, as well as through more difficult times”.*
Focus on reasonable goals	*“My first priority is to help myself stay fit and well during treatment. If I push myself too much, then I’m being unfair to myself”.*
Balance view	*“I will feel frustrated if I can’t get everything done before tomorrow. But I can cope with frustration. Some things will just get done later”.*
Softer or less extreme words	*“Might.., maybe..., perhaps..., possibly..., sometimes..., could...., manageable...”*
Be my own best friend	*“Maybe I being too harsh on myself. I wouldn’t talk to my best friend in such a harsh way. I’ll try to talk to myself in the same I would when encouraging and supporting a friend of mine.”*

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Chapter 6
Communicating Support

> *"When one of the people in a relationship is going through such a frightening, significant experience as you have, there are a lot of times when I wanted to say what I felt but I didn't because you were so upset, or angry, or down or uncomfortable that I thought it was inappropriate or not helpful for me to say how I felt. Because how I felt pales in comparison in terms of its significance and relevance."*
>
> *"I don't know if you realize how much this has affected me. I'm talking about the degree to which I'm frustrated when you don't tell me what's going on... It's tough for me to say I'm worried about it because I have to be the stable one for her. So I'm trying to help her look on the bright side. How can I turn around and say I'm worried about this?"*

A remark that we commonly hear from couples who participate in our programs is that the sessions enable them to talk about things they were thinking about but were too afraid to bring up at home. Yet, in our daily lives, verbal and non-verbal communications are the vehicles by which we demonstrate support, care, and concern. They facilitate other relational qualities such as intimacy, cohesion, and adaptability. Improving communication creates an interpersonal environment in which patients and partners can openly express their thoughts and emotions related to the cancer diagnosis and treatment. In this chapter, we focus on communications that will help couples manage their feelings during stressful situations. The open expression of feelings usually reduces distress and leads to improvement of the couple's relationship. Conversely, patients are less likely to disclose concerns if they feel that their partners will not respond in a supportive way (Figueiro, Fries, & Ingram, 2004).

A recent study sheds light on the types of communication that are supportive and those that are not. Researchers studying women's adjustment to early-stage breast cancer discovered some interesting patterns in the way that patients and their partners talked about cancer-related issues (Manne, Sherman, Ross, Ostroff, Heyman, & Fox, 2004). They observed couples while they discussed a cancer-related issue in a laboratory setting. They coded partners' responses to the patient disclosures as either supportive or non-supportive. The supportive responses were categorized into three types: nurturing and accepting responses, reciprocal self-disclosures, and humorous responses. The non-supportive responses fell into four categories: hostility, withdrawal, negative attributions, and problem solving. Negative attributions involved blaming the person's personality for a particular issue or feeling. Three

K. Kayser, J.L. Scott, *Helping Couples Cope with Women's Cancers,*

findings suggested that patients' self-disclosures and certain partners' responses during cancer-related discussions were associated with patients' level of distress. First, if the partner self-disclosed as a response to the patient's self-disclosure during the cancer discussion, the patient was more likely to experience lower levels of both cancer-specific and general distress. Second, patients who reported more general distress had partners who responded to self-disclosure by trying to provide a solution or by talking about a problem. Third, patients who reported less distress had partners who responded to their self-disclosures with humor. The researchers note that this last finding is especially interesting, given that the patient was sharing her worries and concerns about her cancer. They suggest, "It is possible that humor was interpreted by the patient as assistance in lessening the threat of breast cancer or developing a perspective for difficult feelings and a difficult situation" (p. 668).

The techniques in this chapter teach couples how to improve their communication of emotional support. It is based on the premise that support is an interactive process; that is, it depends on both partners and involves transactions that produce feelings of being supported in both partners.

The Role of Communication in Coping

While it is the desire of most couples to talk openly about things that are bothering them, several obstacles stand in the way of couples who are experiencing cancer. There is the fear of burdening each other, often referred to as the "conspiracy of silence" (Keller, Henrich, Sellschopp, & Beutel, 1996; Zhang & Siminoff, 2003). Couples may avoid the topic of cancer in order to maintain their life as it was or to keep the patient from getting upset (Koocher & Pollin, 2001). In addition, there is the uncertainty of knowing what to do or say that would be helpful to the one facing cancer. Even if the couple has had a relationship with good communication before the cancer, it can still be difficult to broach this fear-provoking subject.

Is there an optimal level of communication for couples dealing with cancer? In a qualitative study of 20 couples coping with breast cancer, Skerrett (1998) found that the communication of "problematic" couples fell into one of two patterns: individual retreat into silence or tell-all communication. The "resilient" couples talked openly about cancer but did not allow the talk of the illness to dominate their daily living. Hence, there seems to be an optimal amount of communication that lies between these two extremes of silence and talking about the cancer constantly.

The communication intervention that we present in this chapter is based on the work of Pistrang & Barker (2005). They have been studying the helping process of couples through a procedure called tape-assisted recall (Pistrang, Baker, & Rutter, 1997; Pistrang, Clare, & Barker, 1999; Pistrang, Picciotto, & Baker, 2001). The process of spouses communicating emotional support to each other is taped and then followed by a discussion of what is helpful or not helpful in dealing with their stress. This process analysis enables partners to explain to each other which communications are especially supportive and which ones are not helpful at all—thus, teaching them how to elicit support and respond with support. According to Pistrang & Barker (2005), "it is important to examine partners' process of communication as it unfolds, from moment to moment, and also to examine partners' moment-by-moment perceptions of, and reactions to, that communication process." In other words, it is important that there is a matching of support provided by one partner with the perception of support received from the other partner.

In our intervention, we place emphasis on sensitive self-disclosures, perspective-taking, and empathic listening. Accordingly, the objectives for the intervention are to

1. Assist a couple in identifying communications that each partner feels are helpful and which ones are less helpful.
2. Facilitate the expression of feelings about difficult topics to one's partner.
3. Assist the patient and partner in demonstrating empathy and developing an understanding of the other's perspective.
4. Assist couples in incorporating time for discussion and communication of support in their daily lives.

To implement this intervention, the clinician needs to have a timer, tape recorder, and blank tape. The clinician uses the method of tape-assisted recall to facilitate the identification of helpful responses to each participant's disclosure of feelings and concerns. Each person is asked to think of a recent, emotionally meaningful experience related to the cancer and to discuss it with their partner. Partners are asked to listen and then give a response that conveys an understanding of the perspective of their partner, without conveying their own personal anxiety about the experiences. The clinician should ask that they start with a relatively non-threatening issue, before moving to more sensitive and intimate issues. Throughout this exercise the couple is encouraged to use "I statements" (e.g., "I feel that ..." or "I have a sense that ..." or "I heard you say that ...") rather than "you statements" (e.g., "You never ..." or You wouldn't ..." or "You should ..."). The interaction is recorded and then played back to both of the participants. The recording can be stopped at salient points in order for the clinician to discover the participants' reaction to the conversation at that particular moment. Both the intention behind a response and its impact on the other can be examined. Here is the procedure to follow[1]:

Technique 6.1 Tape-Assisted Recall: A 10-Minute Conversation

Introductory Remarks "I'm interested in what makes some conversations feel supportive or helpful and others less so. In particular, even within one conversation, some bits of it can feel helpful, while other bits don't. To this end, I'm interested in your views of the conversation—what you felt or thought during the conversation. There are no right or wrong answers. We'll focus

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[1] The instructions are taken, with slight modifications, from unpublished supplementary material supplied by Nancy Pistrang. The procedure was used in a study of couples' transition to parenthood (Pistrang, Picciotto, & Barker, 2001).

very closely on how things were talked about—which might feel a bit odd, as it's something many people are not used to doing."

"I hope that in doing this, you'll be able to talk freely about your reactions to the conversation. I don't want you to feel criticized—either by each other or by me. Conversations rarely go perfectly: for example, we've all had experiences where we've felt misunderstood or where there's been some sort of miscommunication, despite the other person's best intentions. So, the aim is not to put you on the spot, but for us together to try to understand where things go well, and where they don't. Please do tell me if anything is uncomfortable or upsetting—I don't expect that to happen, but if it does we can discuss it, or if necessary, stop."

"I would also like us to focus on something called empathy. Let me explain what I mean by that, since it's a word that people may give different meanings to. Empathy involves listening and accurately identifying the other person's feelings. Being empathic is something that may seem easy, but actually can be quite difficult to do. In fact, mental health professionals, such as clinical psychologists or social workers, often spend years learning how to be empathic. It's not so easy for a helper to set aside his or her own perspective, and to really listen to and understand another person's experience. But I would like you to try this type of listening as your partner is speaking."

"Any questions, before we start? If you do have any questions at any point, please stop me and ask."

***Step 1*:**
Instructions for 10-Minute Conversation "I am asking you to hold a 10-minute conversation, during which the patient (her name) will be the 'Discloser' and her partner (name) will be the 'Helper.' After the conversation I will listen to the tape of the conversation with you and ask you some questions about it. I would just like you to talk with each other in a way that feels natural to you."

***Step 2*:**
Instructions for the Patient "You will act as the Discloser. I would like you to talk about some concern or feelings connected with having cancer. The important thing is to talk about something which has a personal meaning for you. It may be a topic where you think your feelings have not been heard or understood by your partner. Please choose a topic that does not involve a conflict between you and your partner."

***Step 3*:**
Instructions for the Partner "You will act as the Helper. Your task is to try to be helpful to your partner in whatever way feels natural to you."

***Step 4*:**
Conversation Procedure

1. "Take a few minutes to think of the topic you would like to discuss as Discloser. It may be helpful to write down your idea."
2. The clinician will set up and check the tape recording equipment.
3. The clinician will set the timer to 10 minutes or check their watch or clock, turn on the tape recorder, and leave the room.
4. Start the conversation with the Discloser telling the Helper what her chosen topic is. Then proceed with the conversation in as natural a way as you can.
5. Talk until the timer sounds or clinician returns to the room.
6. After 10 minutes, the clinician will come back into the room. "If you need to talk for longer than 10 minutes, you can have more time to complete your conversation."

***Step 5*:**
After Conversation: General Impressions The aim here is to get a sense of the impact of the conversation, before the actual tape-assisted recall.
"Before we listen to the tape, did you have any general reactions to the conversation?"
[Probes: "How typical was this of conversations you normally have?
Was there anything that sticks in your mind that was particularly helpful?
... or that was particularly unhelpful?"]

***Step 6*:**
Response Ratings "I'm going to play back the tape now, so that we can focus in on some specific bits of it. When we listen to the tape, I'd like the Discloser to pay particular attention to how empathic the Helper's responses were. For each response made by the Helper (that is, each time the Helper talks), I'd like you to rate empathy. So, for the Discloser, that means: How much did you feel the Helper really understood what you were feeling? And for the Helper, I'd like to know: How much did you feel you understood the Discloser's feelings?"

"I would like you to use a rating scale, going from 1 to 5, with 1 meaning 'low empathy' and 5 meaning 'high empathy.'"

"I'll stop the tape after each response by the Helper, for you to do your ratings. We'll also note down the counter number of the tape recorder so that we can go back to some of the responses and talk about them together."

"Please tell me, as we go along, if there are any parts of the conversation that were particularly important for you, or struck you as particularly helpful or unhelpful. They may not have anything to do with empathy, but we still want to know about them."

***Step 7*:**
Questions for the Tape-Assisted Recall "We're now going to listen to a few

of the segments of the tape. We'd like each of your views on these parts of the conversation: you'll each have a turn to talk about your reactions. We just want to reiterate that there are no rights or wrongs here, and that the aim is not to criticize. Each of you may have a different perspective on parts of the conversation, and each of these views is important. We want both of your perspectives, so that we can all try to make sense of how conversations work."

After playing a segment of tape with a helper's response, ask the discloser to rate the response using the five-point scale. Then ask the following questions:

Questions for the Discloser

1. "How did you feel at that point?
2. In what way did you feel understood/not understood?
3. What was it about your partner's response that made you feel understood/not understood? (What aspect of what he or she said or how it was said?)
4. How would you have liked him/her to respond to you at that point?"

Questions for the Helper

1. "How did you feel at that point?
2. What were you trying to do in making your response?
3. To what extent did you feel you understood what your partner was feeling or experiencing?
4. Was there anything that got in the way of your being able to understand your partner's feelings at that point?"

Step 8:
Reverse Roles

After reviewing the taped conversation with the patient as the discloser, reverse roles so that the partner becomes the discloser and the patient is the helper. Repeat steps 1–7.

Homework Assignment

The couple is encouraged to find a half-hour period when both of them are generally free of other distractions. They should agree between themselves or flip a coin to decide who will go first.

The half-hour is divided into six 5-minute segments.

1. One person speaks for 5 minutes on a topic or issue regarding the breast cancer about which she or he does not believe her or his feelings have been heard or understood by the other. The partner listens, *without comment*.
2. During the second 5-minute segment, the "helper" tells what she or he heard regarding the "discloser's" thoughts and *feelings.*

3. During the third segment, the "discloser" gives feedback to the "helper" in regard to whether there seemed to be accurate perceptions of what was being communicated.

Then the process is reversed for the last three segments, with the original "discloser" becoming the "helper." As in the earlier exercise, try to use "I statements" (e.g., "I feel that . . ." or "I have a sense that . . ." or "I heard you say that . . .") rather than "you statements" (e.g., "You never . . ." or "You wouldn't . . ." or "You should . . .").

Sometimes a concrete object, such as a bean bag, can be held to remind the partners who is in the speaking role.

There are numerous ways that partners and spouses can give each other support. Give the couple *Handout 6.1 'Ways to Show Support'* for suggested activities that each person can do for the partner before the next session.

Case Illustration

Adam (51) and Sue (49) are the couple that you met in Chapter 3. They have been married 22 years and have a son and daughter—both teenagers. During this session, the therapist instructs them to hold a 10-minute conversation, during which Sue will be the "Discloser" and Adam will be the "Helper." The therapist leaves the room. After the conversation, she returns and they all listen to the tape, with the therapist stopping it periodically to discuss Adam's responses to Sue's disclosures. The therapist explains the exercise to Sue and Adam and asks if they have any questions about the exercise.

Therapist: Do you have any questions?
Adam: No, but I'm a little nervous about doing this.
(Therapist empathizes and reassures him by repeating the purpose of session and that there are no right or wrong answers.)
Adam: So, it's going to help us to communicate?
Therapist: Yes, because sometimes people feel misunderstood and this is a way to help you to listen and respond to their feelings. I'm going to leave the room and then come back in 10 minutes.

After she leaves, Adam turns on the tape recorder. For the next 10 minutes Adam and Sue engage in a conversation. The therapist returns and asks them some general questions about the conversation. She then proceeds to play the tape and then stops it periodically to discuss the Helper responses. The following is the taped conversation with their discussion.

1 Sue: There's one thing that is often not an issue between us but since my diagnosis and treatment, it has bothered me a lot more and that is you

being away so much for your travel and work. It has been really hard for me. There are times when I can keep busy, traveling and take the time to go see friends but I don't have the same amount of energy.
2 Adam: I don't like the travel.
3 Sue: Well, I wasn't saying you liked it—I don't like it either. I miss—I feel more lonely. I just wish . . . I don't know what about it.
4 Adam: You never said anything before about it.

In the tape-assisted recall session, Sue rated Adam's responses as 1 or 2 (not at all to slightly empathic). She felt that Adam was being defensive and it made her think that she had struck a nerve. She said that she was disappointed because it was hard to bring up the subject. The therapist asked her if she felt understood. She responded:

> *I didn't feel that he was empathic the way that you described empathy. But I've been with him a long time and I know how he responds and expresses himself. At least when he said he didn't like it too, he was joining with me. But it also felt somewhat defensive. This made me feel that it was going to be hard to talk about it.*

She would have preferred that he respond with "I know that that's important to you and I wish I could be around more." When the therapist asked Sue about Adam's second response (#4) she stated:

> *I felt like I wanted to bop him over the head. I felt it was getting thrown back at me by saying "well, you never said anything before about this". So I felt that we were getting further away from my feeling with his first comment. I would rate that as a "1" on the empathy scale. I didn't feel understood — I felt it was switching from what I was feeling to his feelings.*
> *Therapist: Was there anything in the way it was said that made you feel not understood?*
> *I guess, the tone could have been more "I'm surprised" or "I didn't realize it" or "It has been on my mind too but I've tried to avoid it—it is uncomfortable." Any of those as opposed to "well, you never brought it up before."*

The therapist asked Adam about his feelings and intentions behind his responses. Adam stated that he got defensive when she brought the topic up and the therapist asked what feeling was behind the defensiveness. Adam responds:

> *Frustration. . . I've been struggling with this for a long time. When I heard her say it, I could no longer deny that it was a problem. I guess, I really didn't want to go further with it and nip it—bring it to an end, . . . Now that I see her reaction, I wish that I could take it back. I didn't really mean it that way. But I guess it was my frustration. It has always been my style to try to solve and fix things and this is something different than that.*
> *Therapist: It is more than just a "fixing of things" here.*

In the next series of responses, Adam moves into his problem-solving mode and tries to come up with a solution.

5 Sue: That's true. I guess I haven't wanted to make you feel bad. It is something I have feelings about.
6 Adam: So you want me around more.
7 Sue: I'm not saying there's an absolute solution—I'm just saying it is harder to tolerate your absences. I used to keep myself busy but I find I'm not as able or interested or have the energy. It has just been more difficult. My family lives out of town so it's not like I can drive down the street to visit my sister, my nieces, or nephews.
8 Adam: I've been thinking of talking to my boss and trying to cut back. I mean, I haven't been telling him what's going on.

The therapist asked Sue again to rate Adam's responses on the empathy scale. The #6 response she rated at least a 2 or 2.5. She stated:

> *Again we have our own way of talking to each other. But he was picking up my point that I miss him. It still felt defensive that he was uncomfortable with me bringing it up. And he seemed to be jumping to a solution—like he needs to be around more.*

The therapist asks Adam how he feels about his responses.

> *Frustration. It's not that I don't want to be around more—but I'm struggling with how to facilitate it.*

For #8, Sue rated Adam's response as a 4–5. She stated:

> *His response indicated to me that he's been thinking about the same issue before I brought it up since he had been thinking of talking to his boss about it. He was already thinking about the problem—although it may have been for him, it was also for me. He was less defensive.*

With the couple, the therapist continued to play the tape.

9 Sue (surprised): You still haven't told him what's going on?
10 Adam: No
11 Sue: Why not?
12 Adam: He's considering some cutbacks and lay-offs. I don't think I want to tell him my problems. . . . No, I haven't told him. So what do you want me to do?
13 Sue: Well, like I said I don't have a solution. I just want you to hear me—to know what I'm feeling because you're so far away it's hard to connect.
14 Adam: I'm glad you're telling me.
15 Sue (again, surprised) You are?
16 Adam: Well, I am and I'm not. I'm frustrated in figuring out how to deal with this—the travel with what's going on with you. I'm going through

this stuff but I haven't figured out a way—we haven't talk about it. Have you told other folks about this?

17 Sue: About missing you?

18 Adam: Yeah.

19 Sue: No, I haven't. Sometimes my friend, Alice, or my sister asks about what it's like to have Adam gone so much. But I haven't said much back. I don't know what I'm looking for. I'm not asking you to change your job. But I felt that it was something that I should share with you—some thing you should know about.

20 Adam: It's been on my mind a lot too as I'm traveling around. But I don't know how to solve it.

21 Sue: I guess I haven't brought it up because you have been really good and supportive for the most part but once in awhile it feels like work has been more important than me. . . . Sometimes you just have to handle one thing at a time. If I learned something from this illness, sometimes you need to look at just one thing.

End of 10-minute conversation
The therapist continued to ask Sue if the responses were helpful. She responded:

> It seems like there was a lot of "dancing around the problem." But the one thing he said that touched me was to know that while he's on the road or flying that he was thinking about me and worried about me. That felt good and was important information to me.
>
> Therapist: Anything else helpful?
>
> I was surprised that he didn't tell anyone at work and was a little concerned that he was holding back. I don't know what to make of it.

The therapist asked them some general questions at the end of the tape-assisted recall:

> Therapist: Is this conversation typical of your talking?
>
> Sue: I think the fact that there is cancer involved—it takes on a different level. I feel more vulnerable when Adam is not around. Whereas if I didn't have cancer, it wouldn't bother me that much.

Summary This brief conversation illustrates several common patterns that we have observed with couples. First, it is very difficult for the "Helper" to just listen and validate feelings without expressing his or her own thoughts, feelings, or opinions. In this case example, Adam immediately responded with his own feelings about traveling so much, instead of validating Sue's feeling. Second, we observe with many couples how a spouse will attempt to protect the other or buffer him or her from stress. Sue admits that she was trying not to express her concerns because Adam had been trying to be supportive and she "didn't want to make him feel bad." Finally, we see an example of how partners have a tendency to want to solve a problem right away instead of just patiently listening to their partners' feelings. As Sue stated, "I don't have a solution. I just want you to hear me—to know what I'm feeling because you're so far away it's hard to connect." Sue wanted the intimate connection and the emotional support—not a concrete solution.

What to Do if . . .

Partners Cannot Think of a Cancer-Related Topic to Talk About

Be prepared to provide some suggestions. Consider developing a cancer issue inventory with topics such as worries about the treatment side effects, uncertainty about the future, concerns about body image, maintaining a satisfactory sex life, how to talk with your children about the cancer, and difficulty in making a treatment decision.

A Partner Uses Hostile Communication like Criticism or Putdowns

Gently confront the person by suggesting an alternative way to say what they are feeling, e.g., using an I-statement rather than a you-statement. Help them to express soft emotions like hurt instead of emotions like anger. Present this information before they begin the exercise but if they still use the negative forms of communication, remind them of the more positive alternatives.

One or Both of the Partners Are Reluctant to Be Audio-taped

Reassure them that the tape is only for the use of the exercise during the session and will not be shared with anyone else. If they do not want to be taped, you can modify the exercise by asking them to converse for 10 minutes with you present and taking notes. Then you can ask the same questions about what was helpful or not helpful, their feelings, and the Helper's intentions.

When the Support Person Is Not a Partner

This supportive communication skills training is vital for non-partner dyads, and their skills will also help them to negotiate and be clear about each other's expectations associated with emotional provision. There are less clear societal norms for the level of disclosure of intimate information between non-partner dyads. Further dyads with less intimate relationship bonds (e.g., friends) may also have shorter shared histories than partner or family member dyads and not know each other as well. They may need to be able to "talk about talking" more, that is the process of how, when, and what to talk about, than more intimate partners where these rules for the patterns of communication may have already been established.

Sociocultural Considerations

What is acceptable and not acceptable communication between intimate partners is a product of socialization and cultural influence. In general, the norms in Western societies encourage the expression of emotions between partners. Intimate relationships and "healthy" marriages are thought to be characterized by open disclosures of feelings. But paradoxically, expressing emotions of hurt, sadness, or distress also challenges the notion of an independent, self-sufficient, and autonomous person. These characteristics are believed by many in the West to be the hallmark of a mentally healthy person. Such feelings are considered signs of weakness and vulnerability. In fact, there are proscriptions against expressing too much emotion in Western societies (Aldwin, 1994). Family members may tell a patient that she is making too much out of a problem and that perhaps she should "keep a stiff upper lip." Expressing too much suffering is considered a weakness in an individualistic society.

In contrast to Western cultures, Asian cultures tend to place a higher priority on interdependence and maintaining close connections with family members. To this end, Asians may be monitoring their emotional expressiveness by taking into account the consequences of the expression for the other person (Markus & Kitayama, 1991). For example, anger is an emotion that causes distance and disconnection between people and can be a threat to the interdependent self. A Chinese wife with breast cancer stated, "It is not that I don't want to blow up in rage, but I can't.... It is not a matter of who is right or who is wrong. Whatever it is I'd just swallow, and not say a word. Nothing has changed for me in this aspect, before and after breast cancer" (Cheung, 2005). Expressing certain emotions may be difficult for couples in both Western and Eastern cultures, albeit for different reasons. In Western cultures, the reason for emotional restraint is to maintain a sense of self-sufficiency and autonomy, while in Eastern cultures, it is to maintain a sense of connection and harmony.

Also, bear in mind that even asking for support may be treated differently in different cultures. Among cultures that promote interdependence over individualism, asking for support may be thought to be placing a burden on or causing distress for the partner or putting strain on the relationship. In Western cultures, people tend to view their relationships as means for promoting individual goals—getting their needs met—and will seek help or aid from their partners in order to achieve more personal goals.

If partners indicate that they have difficulty disclosing their feelings to each other, we suggest that you talk about any cultural beliefs or conditioning that may impact their communication before attempting the exercise. Gender roles may also be included as an aspect of cultural conditioning. For example, what is acceptable for men to disclose may not be the same as for women. Also, men and women may be seeking different outcomes from their conversations. Men may want a problem solved and women may want to be listened to. To resolve such issues, you might discuss what disclosures are appropriate for partners to make and what ones are not. As mentioned, you may modify the exercise by not taping it and suggesting that they talk about an issue that is not threatening to either of them.

Handout 6.1 Ways to Show Support

(1) Discuss with your support person five things they could do for you in the next week that you would find helpful.

(Below are some examples of things other people have found supportive to help you make you list)

Listen to me talk about my feelings
Reassure me that you care for me just the way I am
Go with me to see the doctor
Discuss with me important decisions about my illness
Give me information about my health or treatment
Take charge of my family life
Express understanding of my feelings or mood
Comfort me by showing me physical affection
Arrange to spend extra time with me
Do some pleasant activities with me
Encourage and help me to reintroduce normal routines
Speak about your thoughts and feelings
Speak positively about the future
Help me to think about other things besides cancer
Tell me if there are things I can do to help you
Help me practice my relaxation exercises
Give me words of encouragement and reassurance
Go with me to treatments or clinic appointments

Take care of me if I feel unwell
Provide me with transportation
Do something special for me
Ask me how I am feeling
Do household chores
Joke or kid to cheer me up
Hug me gently
Pray with me or for me
Cuddle me
Help with or do the shopping
Tell me how you are coping
Tell me that you love me
Cook or help prepare meals
Visit me when I am in the hospital
Give me things to read
Take me for outings
Do the gardening
Bring me flowers

Exercise with me, or encourage me in my efforts

Listen to me talk about my feelings and thoughts

Keep other people informed about what is happening

Help me to practice my CanCOPE skills

Tell me how you are coping

Take children to school for me

Babysit my children

Do the laundry

Keep me company

Help me to resume activities

Five things I would find helpful in the coming week.

1)____
2)____
3)____
4)____
5)____

(2) Your support person may like support as well. Together, pick one thing that they would find helpful (pick something you are physically capable of doing at this time).

Something my support person would find helpful in the coming week.

1)____

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Chapter 7
Expanding the Couple's Coping Skills

> *" . . . you're kind of on a see-saw at times. Sometimes you can be very positive about living in the moment and appreciative of today and you can go ahead and enjoy life very much, very much to the fullest and really appreciate things even more than maybe you would have without disease and everything can be very enjoyable to you. But you know, you can be on a run like that for awhile and then all of a sudden one day you get up and you feel like you were kicked in the stomach. None of that applies. It's hard to remember that. Your arms ache, your back aches. You have pains here and there and you think, Oh God, it's taken over. I can't do this. I don't want to face this."*
>
> *"My husband, he broke down finally one time when we thought the cancer was in the lymph nodes and we weren't sure and I think he had just about reached a saturation point and he broke down and cried."*
>
> *"Well, I'm a very family-oriented person. I love to do things and I do get a lot of satisfaction doing things around the home and doing things for my children, for my husband, for other people. Probably I would tell myself in retrospect that I spend too much time doing things for other people and not enough time doing things for myself."*

The strongest predictors of long-term adjustment to cancer are not medical variables, such as the stage of disease or the types of cancer treatments received. The strongest predictor is the person's coping abilities. However, a plethora of coping literature has produced confusing, and at times apparently contradictory, findings about the types of coping associated with improved adjustment in patients (Lazarus, 2000; Somerfield & McCrae, 2000). This makes it difficult for health care practitioners to learn from the literature the types of coping behaviors they should teach to aid clients in their adjustment (Coyne & Racioppo, 2000). One reason for the seemingly inconsistent findings across studies is that the effectiveness of a specific coping strategy varies according to the demands associated with a particular stressor. For example, a study that asks participants about their coping with their overall disease experience may find that emotional ventilation is helpful and is associated with better adjustment than using coping strategies that are more focused on solving a concrete problem. In contrast, another study may find that problem-focused strategies to manage medical issues, such as treatment side effects, may be more helpful for long-term adjustment than emotion-focused strategies (Tennen,

K. Kayser, J.L. Scott, *Helping Couples Cope with Women's Cancers,*

Affleck, Armeli, & Carney, 2000). What works depends more on the fit between the demands placed on the person and the strategies that they are using.

In this chapter, we describe effective coping strategies that clinicians can teach to patients and partners to help them cope with their cancer experiences. We describe step-by-step how a couple identifies their current coping strategies and how they can expand their repertoire to include stress-reduction techniques, such as focused breathing and meditation.

What Is "Good Coping?"

When defining "good coping," the clinician must be mindful of the nature of the particular stressor and at what point in the disease experience coping is being assessed. Generally, good long-term adjustment to cancer is predicted by the use of active coping strategies. Such strategies involve people being able to confront problems, express their concerns, and cognitively process their disease experience, seek information about their cancer and treatment, and explore what they can do to help themselves (Antoni et al., 2001; Glanz & Lerman, 1992; Osowiecki & Compas, 1998; Stanton & Snider, 1993; Stanton et al., 2000). In contrast, use of avoidant coping such as disengagement from finding solutions to problems, giving up, and expressions of helplessness, each predict high distress (Carver, Meyer, & Antoni, 2000; McCaul et al., 1999; Parle, Jones, & Maguire, 1996).

"Good coping" also involves choosing wisely from a broad range of coping strategies. While active coping is, in general, the most useful strategy, there is no ONE right way to cope with cancer, because the journey from diagnosis, through treatment and recovery phases, to life after cancer poses challenges that change over time (Scott, Halford, & Ward, 2004). Further, people typically have to cope with additional stressors, such as caring for an elderly family member, that demand the same or additional coping skills. Though these stressors are not directly related to the cancer experience, they make people's cancer journeys more difficult because of the added burden placed on their coping reserves (Low, Stanton, Thompson, Kwan, & Ganz, 2006).

Good adjustment requires that women and their partners use a range of coping strategies (Epping-Jordon et al., 1999; Glanz & Lerman, 1992; Heim et al., 1993; Parle et al., 1996). For example, when undergoing a painful medical procedure or unpleasant side effects, cognitive avoidance or distraction can reduce anxiety and promote positive affect (Manne et al., 1994). In contrast, when faced with a difficult choice regarding treatment options, or when negative thoughts repeatedly intrude, cognitive avoidance or distraction would be inappropriate.

In order to adapt successfully to the changing difficulties encountered across the course of the illness, women and their partners must pursue solutions to their problems, rather than persistently avoid them. Hence, coping is best conceptualized as a process, as opposed to a trait (Carver & Scheier, 1990). Effective coping is a process of self-regulation, requiring individuals to become skillful in selecting and implementing coping strategies that meet the demands of their illness (Carver & Scheier, 1990; Carver, Scheier, & Pozo, 1992). The process also involves the accurate appraisal of the effectiveness of their coping attempts and the modification of unsuccessful coping efforts. Women diagnosed with breast or gynecological cancers who possess a variety of coping skills and who selectively use these strategies to meet their needs have less mood disturbance than patients with restricted or predominately avoidant coping repertoires (Astin et al., 1999; Carver et al., 1993; Grassi & Molinari, 1988). Failure to attempt to solve problems, low coping self-efficacy, and negative appraisals of coping efforts, all predict poor long-term adjustment in patients (Merluzzi & Martinez Sanchez, 1997; Parle & Maguire, 1995; Parle et al., 1996).

What Happens to Coping Efforts over Time?

Couples seem to use all the coping strategies that are available to them during the acute crisis phase following their diagnosis with cancer. The demand to marshal all available coping resources at this time is understandable, given that many women and their partners describe the time of diagnosis and the commencement of treatments as the most stressful phases of their cancer experience.

The number of coping strategies people use reflects their total coping effort or burden. Coping effort subsequently decreases markedly across the first 12 months following diagnosis (Carver et al., 1993; Heim et al., 1993; McCaul et al., 1999). Several authors suggest that reduction in the reported amount of coping effort occurs because patients begin to adjust to the experience emotionally and learn ways to assimilate the stress into their lives. The person is no longer responding in crisis mode and coping becomes less conscious and effortful (Compas, Connor, Osowiecki, & Welch, 1997). Sustained high coping effort predicts poor long-term adjustment to cancer.

The clinical implication of these findings is that individuals who report high levels of coping burden long after treatments have concluded are probably grappling with an issue that they cannot resolve with their current coping skills (Coyne & Gottlieb, 1996; Parle & Maguire, 1995). They may be facing a cancer-related stressor or multiple stressors that overwhelm their coping resources. Alternatively, some patients and their partners may have recently been informed that the cancer has recurred or metastasized. This news understandably reawakens distress and anxiety in many couples. Coping effort at this time is often markedly higher than the coping strain experienced at the time of initial diagnosis (Cella, Mahon, & Donovan, 1990).

Types of Coping

Generally, when people are asked how they are coping with some situation in their life, they say “I’m coping well” or “I’m not coping.” However, coping is more complex than this and is not simply “bad” or “good.” Rather, there are actually different types of coping. People typically use two types called "emotion-focused" and "problem-focused" coping. Problem-focused coping involves strategies intended to change some aspect of the stressor. Using the Internet to collect data on effective treatment options for breast cancer, physically avoiding the problem that is stressful, or seeking assistance from others to help deal with the problem are all problem-focused strategies.

Emotion-focused coping involves thoughts and actions that are intended to manage the distressing emotions associated with a stressful situation (Folkman et al., 1986; Lazarus & Folkman, 1984) rather than trying to modify the problem in some way. Some examples of emotion-focused coping include crying, joking, distracted thinking, being angry, talking to someone about feelings, daydreaming, or worrying.

These types of coping are not intrinsically "good" or "bad." One type of coping strategy is not necessarily superior to another. Whether a coping strategy is successful or not has to be decided by looking at the specific situation in which it was used. We have to ask ourselves, "Does the strategy meet the demands of the situation, and what might be the short- and long-term consequences of this way of coping if this is my primary or sole way of managing the stressor?" As a general, guiding principle for practitioners, an individual's overuse or heavy reliance on cognitive and behavioral avoidance strategies to manage cancer-related stressors will be detrimental to their long-term adjustment. Better adaptation results from using a broad range of coping skills, both emotion- and problem-focused coping skills, rather than reliance on one single way of coping.

The Influence of Gender and Role on Coping

The research on gender and coping has produced mixed results, mainly because of the variation in the stressors examined. Overall, there appears to be minimal difference between men and women on the use of coping strategies generally (Porter & Stone, 1995). However, recent reviews present substantial evidence to suggest there are significant gender differences in appraisals of stress severity (Taylor et al., 2000; Taylor et al., 2002) and in some types of coping behaviors (Tamres, Janicki, & Helgeson, 2002) according to the nature of the stressor. For example, women tend to appraise stressors as more severe than do men, especially health-related concerns. Descriptive studies of patients coping with cancer concur with this finding and show women frequently report significantly higher levels of distress than men, regardless of whether they are the patient or the caregiver. Further, there are small but consistent sex differences in coping behaviors. Compared to men, women report using more types of coping strategies, more emotional support and emotionally expressive forms of coping, and are more likely to prefer emotional support from their partners during stress (Cunningham & Barbee, 2000; Helgeson & Lepore, 1997; Ptacek et al., 1999; Tamres et al., 2002). Again, these differences were most apparent in the domain of personal health.

There is some fascinating biological evidence for this latter finding. Neuroendocrine findings from animal and human studies suggest that some of the differences we see in men's and women's coping are biological. In particular, neurobiological underpinnings of the attachment-caregiving system provide a foundation for a stress-regulatory system in which females' stress response is often to nature and "befriend," that is, create and maintain social networks to cope with stress. This is in contrast to the "fight" or "flight" reaction that is more common among males. There is a strong tendency among females, across their lifespan, to affiliate under conditions of stress.

The Balance Between Focus on the Self and Focus on Others

Two dimensions of personality, *agency* and *communion,* also hold implications for women's and men's adjustment to breast or gynecological cancers. *Agency* is a construct that reflects positive self-focus, such as autonomy and self-advancement (Bakan, 1966). In lay terms it could be conceptualized as being able to "look after oneself" when one has to, while still recognizing that successful navigation of life's challenges is not a solo journey. Men are characterized by agency more than women. The second construct, *communion,* relates to a positive focus on others, a nurturing and caring orientation. *Communion* is usually found to be higher in women than men.

Agency predicts positive psychosocial health outcomes in chronic illness populations (Helgeson, 1993; Helgeson & Fritz, 1996) while communion is linked with positive interpersonal outcomes, such as higher martial satisfaction (Antill, 1983) and fulfilling social interactions (Wheeler, Reis, & Nezlek, 1983). However, the extreme forms of these two dimensions, termed *unmitigated communion* and *unmitigated agency,* both predict poor adaptation to chronic illness by patients and their support persons (Helgeson, 1993; Helgeson & Fritz, 1996).

Unmitigated communion is characterized by an extreme focus on others, such as helping others to the exclusion of the needs of oneself and to the detriment of oneself (Fritz & Helgesonz, 1998). Like communion, it is typically higher in women than men. Unmitigated communion is associated with the development of depression, relationship problems such as negative social interactions, becoming over-involved in other peoples' problems, and a failure to look after ones' own health needs (Helgeson & Fritz, 1998). In women with breast cancer, unmitigated communion was associated with poor mental and physical well-being at the time of diagnosis, and predicted further declines in functioning across the course of the disease experience (Helgeson, 2003). Unmitigated communion may affect women's adjustment by impeding their cognitive adaptation, since it is at odds with factors that promote cognitive processing (e.g., self-esteem, body image, optimism, and engaged or active coping strategies) (Helgeson, 2003).

Unmitigated agency involves the focus on self to the exclusion of others. Among men with prostate cancer, unmitigated agency was related to problems expressing and sharing emotions and to adjustment problems, whereas agency was related to social support utilization and satisfaction and to good adjustment (Helgeson & Lepore, 1998).

The impact of unmitigated communion and unmitigated agency on couples' adjustment to cancer has not been explored. However, among couples adjusting to the husband's coronary event, the most distressed wives were those who were high in unmitigated communion and whose spouses were high in unmitigated agency (Helgeson, 1993). These two constructs have implications for clinical interventions that aim to help partners mobilize their social supports, extend their coping resources, and share their journey. In our research and clinical experience, we have observed that women who rate highly on unmitigated communion express difficulty learning to ask for, and accept, support from the people close to them. These women will often say "they are not used to being the patient," that they are "usually the one doing all the caring." They also find it difficult to engage in coping strategies that they perceive as "self-indulgent" or self-focused, such as relaxation sessions, hobbies, or other pleasant activities. These women will frequently say that they are uncomfortable focusing on themselves, that they are even anxious when being "pampered or spoiled." In one study of mothers with cancer, women who adhered to these "silencing the self" beliefs, tended to be depressed, reported lower quality of life, and fewer self-care behaviors (Kayser & Sormanti, 2002).

Women who score high on unmitigated communion often report their coping approach is motivated by a desire to protect or buffer loved ones from a perceived burden associated with caring for them. However, the impact of their coping efforts often has the opposite effect on their husbands and support persons. The partners of women high in unmitigated communion often report being distressed or confused by the woman's actions, feeling "shut out," anxious and uncertain about the best ways to show support to their wives. Most importantly these men say they feel emotionally alone and that their offers of support are rejected by their wives.

Although communion and agency are conceptualized as trait-like constructs, in therapy we have observed partners striving to modify their tendencies to cope in overly self-sacrificing or self-reliant ways, and succeeding. In most cases, simply gaining a deeper insight into how their ways of interpersonal coping might be experienced by loved ones motivates people to cut down on extreme self-denying or self-focused coping approaches. Sharing the journey, both the practical and the emotional aspects, and working effectively with loved ones is a skill that partners can learn to improve on. For some people it is the most positive thing to come from their disease experience. Husbands who once took pride in "just getting on with things" and "relying on no one" tell us that they are proud of themselves for learning how to share and discuss emotions. They say they believe these more communal ways of coping have value and are a sign of strength, not weakness. Wives who once said they felt guilty "sitting around having other people wait on me" say they learned the greatest gift they could give loved ones was to show they trusted them and valued their support efforts. These women say they realized that previously they were not being fair to loved ones; that depriving partners and loved ones of a role denied their carers the opportunity to come to terms with their cancer experiences.

The Role of "Carer" Versus "Patient"

Gender is not the only factor that will influence the types of coping that are used during an illness. The role of patient versus caregiver, and the different expectations and capabilities associated with these roles, influence the type of coping strategies. A patient with debilitating lethargy may not have the energy to take direct action to find a solution to her symptoms. Her partner on the other hand may have the time and energy to research possible solutions on the Internet, consult a physician, cook special food for the patient, etc. Hence, the role of caregiver or patient accounts for the difference in coping styles; that is, each spouse or partner may experience and appraise the illness in different ways depending on whether they are the person with the illness receiving care or the well partner who is providing care.

Kershaw, Northouse, Kritpracha, Schafenacker, & Mood (2004) examined the coping strategies employed by 189 women with advanced breast cancer and their family caregivers. Around two-thirds of the caregivers were male, while the remaining third were female family members. The researchers found that the coping profiles for patients and caregivers differed on several types of coping strategies. Patients reported greater use of emotional support, religion, positive reframing, distraction, venting, and humor, while family members reported greater use of alcohol/drug coping. This does not necessarily mean that these strategies were the most commonly used—only that they were the ones on which patients and partners were most significantly different. For example, acceptance, defined as an active attempt to learn to live with the illness and the reality of one's situation, was the most frequently used coping strategy reported by both patients and family caregivers. Use of alcohol or other drugs as a coping strategy was rarely reported by either patients or caregivers.

The gender and role research suggests to practitioners that they are likely to be working with partners who differ in their use of coping strategies. From our clinical experience, many couples are more accepting of each other's ways of coping when they learn that certain ways of coping with the illness are not necessarily *right* or *wrong*. Individuals may be less likely to try to make their partner cope more like themselves when they learn that the differences they observe in the other person's coping may also depend, to a certain extent, on the different roles they have in the illness experience (patient versus caregiver) and their gender. Couples can learn that what is more important than focusing on only the *type* of coping strategy is looking at the *match* between situation and strategy. Equally important is the degree to which they understand and accept the different ways they both cope. Again, pointing out that different situations may require different types of coping efforts may help partners accept their different coping styles.

Helping Couples Identify and Expand Their Coping Strategies

The next steps in building couples' coping skills are to broaden each partner's coping repertoire and to teach them how to support each others' attempts to learn new ways of coping. The techniques incorporate cognitive skills, such as self-talk and challenging dysfunctional beliefs, which were taught in the session on cognitive coping. The objectives for the intervention are to:

1. Assist the partners in identifying their personal coping strategies and assess the benefits and costs of the strategies.
2. Evaluate the adequacy of each person's coping response to the emotional, existential, and practical demands of having cancer, or a partner with cancer.
3. Understand one's own and each other's coping strengths and challenges.
4. Reinforce both partners' coping repertoire.
5. Learn stress-reduction techniques of focused breathing and eliciting the relaxation response for the management of physical symptoms and emotional stress.
6. Assist the patient and partner in developing personal health maintenance plans.
7. Provide a list of resources for managing stress.

To implement these techniques, the practitioner should bring to the session two copies of the handouts: *Types of Coping, Examples of Cost and Benefits with Different Ways of Coping, Monitoring Your Coping*, and *Books and Audiovisual Resources on Stress Reduction.*

The following interventions focus on identifying each partner's personal coping style and assessing the benefits and costs of the strategies that each person is using.

Technique 7.1 Developing Awareness of Personal Coping Strategies

Introductory Remarks "Most people describe how they cope with the stress in their lives as either 'I'm coping well' or 'I'm not coping.' This definition of coping is inaccurate because it is too global. Coping is not *all good* or *all bad*. A person might be coping successfully with one problem, but have difficulty coping in another situation. Frequently we ignore situations where we are coping effectively, only paying attention to situations we feel we are having trouble with.

I am interested in knowing how you, as individuals, cope with a cancer-related stressor and assess whether you are coping well or not."

Examining the Couple's Coping Repertoire "Think about the stressful cancer situations you may be facing at the moment and determine what things you do, think, or say, when trying to cope with these situations. Are there specific things or situations about the cancer which recently have bothered, distressed, or worried you. Think about a time recently when you were feeling anxious, sad, frustrated, scared, uncertain, or overwhelmed. Can you remember an occasion when you felt that way? What was happening? What was the situation?"

[Give them Handout 7.1 ‘Types of Coping’] “Can you identify how you coped from this list? Is this a typical way of coping for you?”
(To the partner) “Were you aware of your spouse’s/partner’s feelings? How would you describe his or her coping strategies?”

Taking turns, each partner shares their coping accounts with the other and the partner responds with their perception of their partner’s coping. This step allows partners to identify any misperceptions and misunderstanding about each other’s coping. For example, a husband’s withdrawal and avoidance may be interpreted by the patient as not feeling any stress or just not caring. The husband may feel that he’s protecting or buffering the patient from stress by not talking about it. So the practitioner should facilitate a discussion about the intentions of the husband’s coping strategies and if they are being accurately interpreted by the wife. The practitioner may help them identify other ways of coping that prevent each other from feeling neglected. For example, the patient could give her husband space and time to be alone; the couple may decide to schedule a time to talk; the patient could ask her partner how he is feeling; or either could raise topics that may be bothering the other. By raising difficult topics, the husband then knows it is OK to talk about them. The couple should work together with the clinician to figure out ways to deal with misunderstandings. Useful approaches to deal with differences include compromising, taking turns listening and disclosing, giving each other time alone, communicating feelings, and reassuring the other of one’s love and concern.

The therapist may need to assist individuals by providing them with examples of helpful coping or by reframing a person’s appraisal of his/her efforts. Persons with negative appraisals of themselves, or their world, may interpret their own coping negatively. For example, a man who holds the worldview that crying is a sign of weakness and a waste of time may interpret his crying when his wife was first diagnosed as a sign of his poor coping or weakness. The therapist needs to help him challenge this thought and inform him of the positive aspects of such a response, such as the value of crying as an emotional release and a signal to his wife that he cares for her deeply.

Assessing the Costs and Benefits of Coping Strategies “Next, I would like you to discuss how effective your coping is by looking at the short- and long-term effects of their strategies. First, look at the situations you are trying to cope with and see whether your strategies match the needs and demands of each situation. Second, weigh the likely short- and long-term outcomes of the strategy. What might be successful in one type of stressful situation may not work as well in another.”

“For example, sometimes people cope with the anxiety associated with getting an injection in the arm by avoiding looking at the needle being injected into the vein. They distract themselves and avoid thinking about what's happening to them by talking about hobbies or other interesting topics with the nurse who is giving the injection. In this case, coping using 'avoidance' and 'distraction' may be highly successful coping strategies for dealing with the anxiety-provoking situation. However, there may be situations when avoiding something, or distracting our thinking, may not be ideal ways to try and cope."

[Give them Handout 7.2 'Examples of Costs and Benefits with Different Ways of Coping.']

"In the example that you described, how successful was your coping strategy given the demands of the situation?"

Generating Examples that Highlight Coping in Specific Situations "Now I would like you to think of stressful cancer situations where you have used avoidance or distraction, or some other strategy, and to assess the likely long-term effect of these strategies. One example might be the situation where someone feels very anxious about seeing the doctor for a follow-up appointment. They fear what he might tell them, so they avoid attending the clinic at all. Whenever they think about the fact that they have failed to keep the appointment they try to block the thought out of their head by distracting their thoughts. Why would avoidance and distraction may not be the most desirable forms of coping in this situation?"

Expanding Coping Repertoire "When facing cancer, having a wide range of coping strategies available for use is the most helpful rather than always relying on only one or two ways. Can you identify one coping strength? Can you identify one weakness that you would like to work on in the future?"

Some coping goals may actually be addressed in the therapy sessions, such as managing difficult emotions or effective communication of feelings. However, there may be some goals that the person may need to work toward outside of therapy. In these cases, ask them also to state one way they might begin to address their goal, for example, by practicing the identified weak skill to manage a challenging situation.

Additional questions for discussion include: "Do you ever wish you could respond to stress differently?" "What effect does your coping style have on others?" "How does your partner cope?" "Do you think you both work well as a couple with the ways you cope?"

The next series of techniques provide the couple with examples of relaxation exercises, including focused breathing and elicitation of the relaxation response. These will be only an introduction to the variety of relaxation techniques that are available to patients and their loved ones. The couple will be given a list of books, tapes, CDs, and websites which they can pursue on their own.

Technique 7.2 Focused Breathing Exercise

Introductory Remarks “There are numerous stress-reduction interventions that involve an integration of mind and body. These techniques help people to relax and manage their physical and emotional distress through meditation, breathing, and therapeutic touch. I will introduce you to a couple of these techniques—focused breathing and the relaxation response. These techniques may feel awkward at first but people report that they get easier and feel better with practice. There are many good books, CDs, and tapes that are available to help learn these skills. I will give you a list of these at the end of today’s session.

First, let’s begin with a breathing exercise:” (practitioner guides couple through the following exercise)

1. Get into a comfortable position (minimize external stimuli by providing a quiet environment).
2. Close your eyes.
3. Now focus on your breathing. Start with what is called a SIGNAL BREATH. (These are actually a series of deep breaths.) EXHALE through your mouth and as you do, begin to let go of any tension. Exhaling the first time is the signal you are incorporating thoughts about breathing into the relaxation exercise.
4. Now BREATHE IN through your nose. Breathe in relaxation and oxygen . . . breathe out tension and discomfort. You should feel your stomach rising about an inch as you breathe in, and falling about an inch as you breathe out. Remember, it is impossible to breathe from the diaphragm if you are holding your stomach in. So . . . relax your stomach muscles. Take a few of these deep breaths. As you do, notice your body beginning to let go and relax (pause but no longer than for 2 minutes).
5. Now slow down your breathing so it is nice and easy . . . gentle . . . breathe with less effort.
6. Notice how you can take a breath and exhale slowly and completely until the breath is all gone. Your breath will flow on its own naturally. Watch . . . observe the next few breaths flow in and out at their own pace (pause).
7. You may begin to notice many things. Perhaps you notice your upper body expanding and rising on the in-breath and settling down on the out-breath. Some people enjoy noticing the COOL FEELING they experience when they breathe in through their noses and the warmth as your breath goes out through your mouth. Try it for a few breaths . . . notice the coolness coming in and the warmth going out (pause).
8. You may notice a slight effort is needed to inhale, while exhaling is just letting go. The breath goes out effortlessly. Letting go is a feeling we are

all familiar with. Imagine what it is like to let go and relax. Explore this feeling of letting go even more on the next out-breath (pause).

The following are "mini-versions" of the above focused breathing exercises. Good times to do a "mini" are: while being stuck in traffic (remind them not to close eyes though) . . . when put on "hold" during an important phone call . . . while waiting in your doctor's waiting room . . . when someone says something which bothers you . . . at all red lights . . . when waiting for a phone call . . . in the dentist's chair . . . when you feel overwhelmed by what you need to accomplish in the near future . . . while standing in line . . . when in pain . . . etc.

Mini Version 1
Count very slowly to yourself from ten down to zero, one number for each breath. Thus, with the first breath, you say "ten" to yourself, with the next breath, you say "nine," etc. If you start feeling light-headed or dizzy, slow down the counting. When you get to "zero," see how you are feeling. If you are feeling better, great! If not, try doing it again.
[You can also substitute words for the numbers. For example, when inhaling, say a word such as "calm," or "peace," or when exhaling, say "calmer." You may choose a word with a particular meaning to you.]

Mini Version 2
As you inhale, count very slowly up to four; as you exhale, count slowly back down to one. Thus, as you exhale, you say to your self "four, three, two, one." Do this several times.
[Again, you can substitute words for the numbers.]

Mini Version 3
After each inhalation, pause for a few seconds; after you exhale, pause again for a few seconds. Do this for several breaths.

Technique 7.3 Eliciting the Relaxation Response[1]

Introductory Remarks "Dr. Herbert Benson is well known for his work on stress and relaxation. In the 1970s he coined the term 'relaxation response' to refer to the opposite of the stress response. When we experience a stressful situation, our nervous system goes into overdrive and increases one's heart rate, blood

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[1] Courtesy of Herbert Benson, MD, /Benson-Henry Institute for Mind Body Medicine at Massachusetts General Hospital.

pressure, breathing rate, and the blood supply to the muscles. The relaxation response has an opposite effect on the nervous system (Silver, 2007). Eliciting the relaxation response is actually quite simple. It involves two essential steps:

1. Repetition of a word, sound, phrase, prayer, or muscular activity.
2. Passive disregard of everyday thoughts that inevitably come to mind and the return to your repetition."

"Let me guide you through a 25-minute technique that is taught to evoke relaxation:"

1. Pick a focus word, short phrase, or prayer that is firmly rooted in your belief system.
2. Sit quietly in a comfortable position.
3. Close your eyes.
4. Relax your muscles, progressing from your feet to your calves, thighs, abdomen, shoulders, neck, and head.
5. Breathe slowly and naturally, and as you do, say your focus word, sound, phrase, or prayer silently to yourself as you exhale.
6. Assume a passive attitude. Do not worry about how well you are doing. When other thoughts come to mind, simply say to yourself, "Oh well," and gently return to your repetition.
7. Continue for 10–20 minutes.
8. Do not stand immediately. Continue sitting quietly for a minute or so, allowing other thoughts to return. Then open your eyes and sit for another minute before rising.
9. Practice the technique once or twice daily. Good times to do so are before breakfast and before dinner.

"Eliciting the relaxation response regularly has been scientifically found to be an effective treatment for a wide range of stress-related disorders. In fact, any disease that is caused or made worse by stress can be helped by the relaxation response. Other techniques for evoking the relaxation response are: imagery, progressive muscle relaxation, repetitive prayer, mindfulness meditation, repetitive physical exercises, and breath focus. You may want to try more than one technique to find the one that suits you best. The relaxation CDs and tapes listed on the handout can assist you in managing stress."

Assignment and Planning

Monitoring Their Coping. During the weeks before the next session, the partners can use Handout 7.3 'Monitoring Your Coping' to monitor individually the types of strategies that they are using in handling stressful situations related to the cancer. The practitioner emphasizes that there are no right or wrong strategies to use, but helps them identify which ones work for them.

Also, partners may need to recognize and accept that their partner may have a way of coping that is different from their own.

Development and Implementation of Health Maintenance Plan. Some individuals have already incorporated in their way of life a concern about health and already utilized available wisdom about balanced, nutritious eating habits, adequate sleep, exercise, avoidance of smoking and other drugs, and preventive medical care. They may already be using relaxation techniques, such as meditation, yoga, and others. The practitioner helps the couple to come up with a realistic rather than idealistic plan for maintaining their health. Help the couple to develop a plan to maintain their physical health and emotional stability—regular exercise, time to get away from it all, walks, meditation, use of recreation and leisure opportunities. The practitioner may ask them to identify two things that they will do over the next 2 weeks to contribute to the maintenance of their health (related to diet, rest, exercise, leisure) and to keep track for the next session. Handout 7.4 provides them with resources to learn additional stress-reduction techniques.

Reading for Next Session. The next chapter will present techniques to manage difficulties with body image and sexuality. To prepare for this session, we recommend that the practitioner give the couple a copy of "Sexuality & Cancer: For the Woman Who Has Cancer, and Her Partner" (American Cancer Society) and suggest that they read the sections that pertain to her particular cancer.

Case Illustration

Carol (64) and Bill (66) had been married for 40 years. They had three grown children—two lived in other states and one lived in the same city. Carol had been diagnosed with Stage 2 breast cancer; she had a mastectomy, recently completed chemotherapy, and was going to begin radiation in the upcoming weeks.

During the session with the practitioner, they each shared a situation that was particularly stressful to them. Bill described how he had been attending church without his wife because she was not feeling well as a result of the chemotherapy. One Sunday he suddenly felt very alone and started thinking that this is what it would be like to be widowed. Although he recognized that there were other people sitting alone in church, it did not alleviate his loneliness. Throughout their married life he was accustomed to his wife sitting next to him. A great sense of sadness came over him as he thought about his life without Carol. In coping with his sadness, he told himself that her prognosis is pretty good and with God's help, he would get through it. Carol stated that his typical way of dealing with a distressful situation is through trying to see the problem in a different light or comparing his situation with others who are worse off. Carol described her husband's way of coping as avoidance or denial. He always appeared stoic to her and she had trouble understanding how he was dealing with her illness. She was glad that he was able to disclose his feelings of sadness and loneliness even though it was difficult to hear them.

Carol described hearing the news of her diagnosis as a stressful event for her. She was at work when the physician called and she immediately "took action" and called her husband, daughters, and son. Looking at the list of types of coping, she identified her typical coping strategies to be direct action and seeking social support. However, she pointed out that it depends on the situation as to which strategy she would use. For example, typically she will take direct action right away and then move into a more cognitive approach such as redefining the situation or acceptance.

Using Handout 7.2 'Examples of Costs and Benefits with Different Types of Coping,' the practitioner discussed the benefits of each of their coping strategies. For example, looking at the situation in a different light helped Bill manage his feelings of sadness and loneliness. Direct action helped Carol feel some sense of control over a situation. The clinician guided them through a discussion on whether their individual coping strategies worked as a couple. Bill stated that Carol was a strong person and seemed "very good" at coping. He stated, "I leave her alone to cope." Carol interpreted her husband's reticence about expressing his feelings as a desire to avoid the illness. Thus, she was seeking support from other people close to her. This, in turn, made Bill feel like he was not needed. Carol stated that she would like more "reaction" from Bill. Bill stated that he would like Carol to ask him for support. Both recognized that their ways of coping helped them as individuals but not as a couple.

The clinician guided them through the focused breathing and relaxation response exercises. The couple became very interested in some of these relaxation techniques and decided to incorporate one of them into their health maintenance plan. Previously they had been very active in tennis and jogging but had gradually quit doing those activities. They expressed an interest in joining a yoga class together.

What to Do if . . .

They Cannot Think of a Stressful Situation

The practitioner can suggest one based on information she/he knows from previous sessions. Sometimes people can recall a situation if they try to remember a particular time during the previous week when they were feeling depressed, sad, or angry. Reminding them of the feelings may help evoke the event which caused them to feel that way. Alternatively, the time when they first heard about the diagnosis is often a time of heightened arousal and stress for most women and their partners. The practitioner can prompt the couple to recall their ways of responding and coping during that tumultuous period of their cancer experience.

Some people cope extremely well and simply do not describe their cancer experiences as "stressful" per se. Often these people have faced other significant challenges in their life that have helped them to hone their cognitive coping and coping self-regulation skills. They tend to approach the challenges they face across their cancer journey with helpful cognitive appraisals, are able to regulate their coping skills, and can draw upon a range of coping skills as required. To reinforce their continued use of adaptive coping it is helpful to highlight for couples their strengths and what they are doing well.

They Cannot Identify with Any of the Coping Categories

The practitioner can remind them that these are general categories and they may use strategies that fall into more than one category. If they are still having difficulty identifying their coping styles, the practitioner may turn to the partner in identifying the category for them and encourage the partner to give an example of how they think their partner's reactions seem to fit the category.

Partners Misinterpret the Other's Coping Behaviors

This can happen and is often associated with deeper core beliefs that the partner holds about the self, or the world, that color the person's interpretation of the partner's behaviors. For example, people with low self-esteem, depression, or anxious attachment report more negative views of their partners' behaviors. In these situations addressing the partner's underlying vulnerability (such as low self-esteem) is necessary. The approach usually involves cognitive restructuring and challenging of core beliefs that contribute to negative self- and worldviews. A discussion probing for the underlying intention of the coping behavior, as opposed to how it was interpreted, may also help in clarifying the behavior.

One Partner Is Critical of Another Partner's Coping

The practitioner helps the critical partner to understand the reason for the coping strategy. If the partner's coping strategy is not adaptive—for example, drinking too much—the practitioner can lead them through the problem-solving procedure to resolve the issue. If it cannot be resolved in working with the couple, the couple may require therapy to address underlying problems, and the therapist should give them referrals for treatment.

A Topic Is Too Difficult for Patient or Partner to Talk About

Ask if there is someone else the patient or partner can talk to, such as clergy, friend, or family member. Offer to see the person individually for a session. If this option is chosen, the clinician needs to give each individual personal time. The practitioner will need to use his/her judgment in deciding whether they have the clinical skills and training to manage difficult issues such as marital infidelity or partner violence. The clinician needs to provide a safe and confidential setting and have professionals to refer them to.

They Cannot Focus Their Concentration During Relaxation Exercises

Reassure them that these exercises require practice. If they do not experience stress reduction through focused breathing or meditation, suggest other techniques that may work for them, such as, yoga, therapeutic touching (massage, Reiki), and repetitive physical exercises.

When the Support Person Is Not a Partner

There are no major caveats to delivering the techniques described here when the dyad are not partners, other than the usual considerations for tailoring the session content and the therapeutic goals to match the level of emotional intimacy between the woman and her support person. The therapist should already be aware from earlier assessment sessions with the dyad about their wishes regarding the extent of discussions about personal information that they are comfortable sharing in front of each other within sessions.

Sociocultural Considerations

There are clearly cross-cultural differences in what is viewed as appropriate and "good coping." Specifically, Western and non-Western cultures differ significantly in the extent to which social support is utilized as a coping resource (Taylor et al., 2004). Often socialization in interdependent or collectivist cultures focuses on maintaining harmony and not bringing the attention of others in their social group to one's personal problems. Asking for help may risk undermining this harmony or be seen as making inappropriate demands on the group (Taylor et al., 2004). Similarly, the coping strategy of protective buffering may be more typical of non-Western cultures, again where the focus is more on the buffering of one's stress so that it does not affect the other.

Further, cultures may differ in terms of the close relationships that are typically viewed as sources of support. For example, Japanese researchers evaluated, in a pilot test, an intervention previously found to be successful for improving adjustment in Western women diagnosed with breast cancer (Fukui et al., 2000). The main aspect of the intervention that needed modification in order to be culturally acceptable was therapists' encouragement of the women to view their partners as a source of emotional support, especially for body image and sexual problems. Around half the women reported that they found same-sex family members, such as daughters, to be far more supportive in these matters than their husbands. However, the sample size was very small (n=10), and there was no information about these women's martial satisfaction, making it difficult to assess the implications of these findings for the viability of couple-based interventions in Asian cultures.

There have been three published randomized clinical trials (RCT) of couples interventions that aim to improve long-term adjustment: one in Australia (Scott et al., 2004), two in North America (Kayser, 2005; Manne et al., 2005), and one pilot evaluation replication study of the Australian CanCOPE intervention (Scott et al., 2004), conducted in Germany (Zimmermann, Heinrichs, & Scott, 2006). To date there has been no RCT evaluation published of a dyadic-focused coping intervention for couples from non-Western cultures. There has been a small pilot RCT (20 couples) of a brief couple-based intervention for Greek couples coping with breast cancer that found short-term benefits in couples' postoperative psychosexual adjustment (Kalaitzi et al., 2007). Unfortunately, the authors do not describe the intervention, so similarities between this program and other published trials are not known. The value and applicability of couple-based interventions with cancer patients in other cultures is simply not known.

On a related note, we know little about how couples from lower socioeconomic groups manage their stress and whether couple-based interventions would be acceptable. Most trials of marital therapy generally, and health coping interventions specifically, involve middle-class, well-educated couples. Working-class couples do not always have the economic resources that couples from middle and upper classes do to cope with a life-threatening illness, such as Internet access, taking extended holidays, and the like. They may feel less mastery over their environment and rely on spiritual coping and internal types of coping to deal with the stresses of the illness. These types of coping strategies may be quite appropriate in circumstances where people have less influence on their environment.

Handout 7.1 Types of Coping

Think about a particular stressful situation regarding the breast cancer during when you were feeling anxious, sad, frustrated, scared, uncertain, or overwhelmed. What was happening? What was the situation?

Use the following types of coping as a guide to identify your coping strategies:[2]

1. *Distraction*—diverting attention away from the problem by thinking about other things or engaging in some activity.
2. *Redefining situation*—trying to see the problem in a different light that makes it seem more bearable, e.g., comparing your situation with others who are worse off or comparing it with a situation from your past; thinking about a hidden benefit of a difficult situation.
3. *Direct action*—behavior intended to change self or problem; thinking about solutions to the problem, gathering information about it, or actually doing something to change oneself or the problem, e.g., exercise, help-seeking, and seeking information.

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[2] Adapted from Porter, L. S., & Stone, A. A. (1995). Are there really gender differences in coping? A reconsideration of previous data and results from a daily study. *Journal of Social and Clinical Psychology, 14*, 191.

4. *Catharsis*—expressing emotions in response to the problem to reduce tension, anxiety, or frustration.
5. *Acceptance*—accepting that the problem has occurred, but nothing can be done about it or things will not get much better; strategies include living one day at a time or changing expectations for problem resolution.
6. *Seeking social support*—seeking emotional support from loved ones, friends, or professionals.
7. *Relaxation*—doing something with the explicit intent of relaxing, e.g. meditation, imagery, tai chi.
8. *Spirituality*—relying on faith or belief in a superior order or deity around which your experiences are organized and rendered meaningful. This strategy may involve, prayer, communal worship, meditation, or seeking comfort in religious explanation.

Handout 7.2 Examples of Costs and Benefits with Different Types of Coping

Different ways of coping	Advantages or benefits (short term or with balanced use)	Disadvantages or costs (long term or if overused)
Use humor or joking all the time	Keep spirits up and feel better Appear positive to others	Others may not know what person is feeling or recognize when they might need support Others may not take them seriously
Drink alcohol whenever felt stressed	Avoid the stressful emotions	Do not learn how to deal with problem so it does not go away. May increase feelings of depression. Bad for health
Avoid thinking about issues or concerns	Avoid the issues that concern or upset them so feel better	Person never learns to cope with issue. Cannot completely stop thinking about problem, so it still keeps upsetting them
Talk all the time about issues or concerns	Feel better afterwards. Others become aware of issues or concerns	Do not learn any ways of coping with the problem so feel helpless Continually upsetting themselves and perhaps others

(continued)

Handout 7.2 (continued)

Different ways of coping	**Advantages or benefits (short term or with balanced use)**	**Disadvantages or costs (long term or if overused)**
Eat whenever feel stressed	Relieve feelings of tension, or stress	Do not learn other ways of dealing with feelings. Gain weight
Cry all the time	Feel better afterwards	Start to feel depressed and helpless all the time Does not focus on finding different ways of coping with problem
Keep all feelings and thoughts to oneself	Avoids acknowledging feelings	No avenue for release or expression of emotions so start to feel worse Others who could perhaps provide assistance are unaware of persons feelings or needs

Handout 7.3 Monitoring Your Coping

Situation	**Your reaction**	**Coping strategy**

Handout 7.4 Books and Audiovisual Resources on Stress Reduction

Books

Benson, H. (1975). *The Relaxation response.* New York: Avon.

Benson, H., & Proctor, W. (2003). *The break-out principle.* New York: Scribner.

Benson, H., & Stark, M. (1996). *Timeless healing.* New York: Scribner.

Benson, H., Stuarat, E., & The Staff of the Mind/Body Medical Institute. (1992). *The wellness book: The comprehensive guide to treating stress-related illness.* New York: Fireside.

Borysenko, J. (1988). *Minding the body, mending the mind.* New York: Bantam Books.

Caudill, M. (2001). *Managing pain before it manages you (Revised Edition*). New York: Guilford.

Hanh, T. N. (1987). *Being peace*. Berkeley: Parallax Books.

Kabat-Zinn, J. (1990). *Full catastrophe living. Using the wisdom of your body and mind to face stress, pain and illness.* New York: Delta Books.

Kabat-Zinn, J. (2005). *Wherever You Go, There You Are*: *Mindfulness Meditation in Everyday Life.* New York: Hyperion Books.

LeShan, L. (1974). *How to meditate.* Boston: Little, Brown.

Rosenbaum, E. (2007). *Here for now: Living well with cancer through mindfulness* (2nd Edn.). Hardwick, MA: Satya House Publications.

Siegel, B. (1989). *Peace and healing.* New York: Harper.

Audiotapes/CDs

The following CDs can be purchased from the Benson-Henry Institute for Mind Body Medicine (http://www.mbmi.org):

- Creating a New “Now” (Ann Webster, PhD).
- Healing Meditations (Leslee Kagan, NP).
- Meditations for Personal Health and Well-Being (Aggie Casey, MS, RN and James Huddleston, MS, PT).
- The Tree of Awareness: Mindfulness Meditation (Patricia Martin Arcari, PhD, RN).
- Therapeutic Meditations for Health the Body and Mind (Ellen Sloawsby, PhD).

Kabat-Zinn, Jon. (1995). *Mindfulness meditation*, NY: Simon & Schuster (2 cassettes). (More Guided Mindfulness Meditation Tapes & CDs by Kabat-Zinn are available through www.mindfulnesstapes.com)

Rosenbaum, Elana. (2002). *A Healing Meditation for Cancer Patients and their Loved Ones, www.mindfuliving.com*

Rosenbaum, Elana (2005). *Here for Now Mindfulness Meditations, www. mindfuliving. com.*

Weil, A. & Kabat-Zinn, J. (2001). *Meditation for optimum health.* CDs on how to use mindfulness and breathing to manage stress.

Websites

http://www.mbmi.org (Benson-Henry Institute for Mind Body Medicine)
http://www.mindfuliving.com (Mindful Living)
http://www.umassmed.edu/cfm/index.aspx (Center for Mindfulness in Medicine, Health Care, & Society)

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Chapter 8
Enhancing Sexuality and Body Image

> *"There were times over those months of treatment when I felt ugly, less feminine. I guess I'd lost a lot of my self-confidence . . .. . .so when John would try to hug me, or get close to me, I would pull away."*
>
> *"I wasn't sure about how to approach things. . . I didn't want to rush her into having sex again, so I just said nothing, and waited for her to make the moves. I realize now she thought I didn't find her attractive anymore."*
>
> *"Resuming our sexual life was an important part of the recovery process for me. I think in a funny sort of way, it was a sign, that things were ok again, that life was getting back to normal for us."*
>
> *"I didn't feel like I wasn't a woman . . . but I felt different."*

Although problems related to body image, physical intimacy, and sexual performance are common among breast and gynecological cancer patients, discussion of these issues is often avoided by oncology practitioners. Furthermore, guidelines to assist allied health professionals to conduct psychosocial assessments, and to formulate treatment plans for people with cancer, frequently provide little or no information about how to improve sexual health outcomes (Luxford & Fletcher, 2006; Nicholas & Veach, 2000). A crucial need of women and their partners is for accurate information. Myths and misinformation surrounding cancer represent an additional threat to physical closeness. Consequently, couples can abstain unnecessarily from all forms of physical contact and sexual expression.

This chapter provides information on the potential impact of cancer treatments on couples' physical intimacy and women's body image. We discuss why women's psychosexual well-being is crucial for their overall adaptation to their cancer experience and why women's body image and sexual adjustment are best understood and treated from a couples' perspective. We provide guidelines on how to assess these problems and present techniques to help couples improve body image concerns and enhance the recovery of physical intimacy in their life.

K. Kayser, J.L. Scott, *Helping Couples Cope with Women's Cancers,*

Women's Cancers and Sexual Intimacy

Importance of Intimacy and Body Image for Adaptation to Cancer

Some couples we have worked with tell us that when they heard about the diagnosis, they felt as if the news had suddenly thrust them into an alien and frightening world. In this world, people spoke a different language, "medical jargon", and the hospital environment seemed cold and uncaring. Across their cancer journey couples said they sometimes felt alone and scared, and acutely aware of their own mortality and the fragility of life (Scott & Brough, 2006).

A wealth of social psychological research shows that people combat feelings of peril and anxiety about death by seeking solace and strength in their connections and bonds with loved ones (Hart, Shaver, & Goldenberg, 2005). Common reactions include a heightened desire for physical and sexual intimacy with their romantic partner and increased emotional commitment to the relationship (Florian & Har-even, 1983; Goldenberg, Pyszczynski, Greenberg, & Solomon, 2000; Victor, Mikulincer, & Gilad, 2002). A seemingly simple act of physical comfort, such as holding the hand of a loved one, has been shown to help women adapt to a stressful situation and promote well-being (Leiber, Plumb, Gerstenzang, & Holland, 1976; Walker, 1997).

In response to life-threatening situations people also report a heightened awareness of their bodies and appearance. This may occur because the body symbolically represents the *self* and the "vehicle through which life passes unto death" (Goldenberg et al., 2000, p. 201). The physical body may take on greater significance for the person, as an indicator of their vitality and their existence in the world.

Increases in body awareness and need for relationship in response to reminders of mortality are very strong human responses. They occur even in situations when the danger is only an imagined scenario (Mikulincer & Florian, 2000). In short, our close relationships, and our sense of self, serve as psychological buffers against anxiety about death (Florian, Mikulincer, & Hirschberger, 2002; Hart et al., 2005).

It is understandable then that in the face of the very real threat that breast and gynecological cancers pose to women's lives, many couples say they feel a heightened need for communication with their spouse, affection and physical comfort, and closeness (Makar et al., 1997; Schover, 2000). For some couples, sexual intimacy is also an important way of coping. It can reaffirm their vitality and bring a reassuring sense of normalcy at a time when many other things seem irrevocably changed (Coan, Schaefer, & Davidson, 2006). However, physical intimacy and women's body image are highly vulnerable to disruption following treatments for breast or gynecological cancers (Andersen, Andersen, & deProsse, 1989a).

Prevalence of Sexual Problems

Around 20–30% of couples in the general community, who are in committed relationships, are estimated to be sexually abstinent or to have a non-sexual relationship, (defined as engaging in sexual activity fewer than 10 times a year)

(Michael, Gagnon, Laumann, & Kolata, 1994). In some couples, particularly older couples, abstinence is a result of health problems in one or both partners. A range of chronic illnesses and their associated treatments can interfere physiologically with sexual responses. For example, erectile dysfunction and impotence are common in men receiving pharmacological or surgical treatments for prostate cancer or heart disease. For some couples coping with breast or gynecological cancers, sexual inactivity is the norm, and they are quite contented with a non-sexual relationship after cancer. Indeed, this is our clinical impression from the CanCOPE intervention study (Scott, Halford, & Ward, 2004). Around 20% of couples reported being sexually inactive for many years prior to the cancer diagnosis, usually as a result of chronic illness in one or both partners. These couples said they were not worried about their sexual inactivity. They did not view it as a sign of marital problems. Most said they had found other ways to show affection and love in their relationship. These couples tended to be happily married at the time of diagnosis, as measured by the Dyadic Adjustment Scale (Spanier, 1976), and to remain so across the 12 months of the study. This tends to support the accuracy of these couples' perceptions that sexual inactivity did not have an impact on their relationship satisfaction.

With couples who have been sexually active prior to the cancer diagnosis, most (60–80%) tend to recommence sexual activity relatively early in the recovery period, usually in the first few months after treatments end (Andersen et al., 1989a; Fobair et al. 2006; Wimberly, Carver, Laurenceau, Harris, & Antoni, 2005). Sexual problems frequently arise in the first 12–18 months of the post-treatment period. An estimated 80% of women diagnosed with gynecological cancers, and 50% of women diagnosed with breast cancer, will experience problems in this aspect of their quality of life (Andersen, 1993; Andersen, Andersen, & deProsse, 1989b; Andersen, Woods, & Copeland, 1997b). Difficulties may persist for many years, despite women experiencing improvements in other aspects of their life, such as their mood.

Around 30% of women perceive that after treatments, their male partners experience sexual difficulties (Andersen et al., 1989b). Some couples report that after cancer the overall quality of their sexual relationship is reduced (Scott et al., 2004). However, the incidence and etiology of diagnosable sexual dysfunction in the partners of women with breast or gynecological cancers is not known (Samms, 1999; Zahlis & Shands, 1991).

Etiology of Sexual Problems in Breast and Gynecological Cancers

The sexual problems experienced by women stem predominately from four sources: (1) the organic effects of treatments, (2) women's perceptions of their sexuality, (3) their partners' reactions to them, and (4) the quality of their relationships. Treatments can cause disruptions in the sexual response cycle, the effects varying according to the type of treatment received. Some treatments, such as surgery, radiation to the pelvic region, and chemotherapy, may anatomically change, or impede, the physiological functioning of reproductive organs involved in sexual responsiveness

(Andersen, 1987; Andersen et al., 1989b; Schover, Fife, & Gershenson, 1989). Treatments may give rise to side effects such as induced early menopause, infertility, vaginal dryness, pain during intercourse, reduced sexual desire, and changed orgasmic capacity. Chemotherapy is consistently found to predict more severe and long-lasting sexual and body image problems in women with breast and gynecological cancers (Rowland et al., 2000). Pelvic radiation for the treatment of gynecological cancers can produce scarring on the vaginal walls, restricting vaginal size and elasticity. Surgery may shorten the vaginal barrel. These side effects can contribute to problems with pain and discomfort during intercourse (Beemer, Hopkins, & Morley, 1988; Schover, 1997).

The number of treatments that women receive can affect the quality of their sexual experiences after cancer. Women who receive prolonged courses of treatment or multiple treatments consistently report worse long-term sexual functioning and reduced satisfaction with their sexual life after cancer. This is especially the experience of women whose course of therapy involves adjunctive chemotherapy (Ganz et al., 2004). Because younger women are more likely than older women to receive chemotherapy, or multimodal treatments, they seem particularly vulnerable to sexual problems (Baucom, Porter, Kirby, Gremore, & Keefe, 2005–2006; Fobair et al., 2006). Prolonged treatments also tend to have a negative effect on women's energy levels. Fatigue is associated with significant sexual problems, especially impairment in desire and arousal responses.

The way women think about certain aspects of themselves, such as their physical appearance, sexual attractiveness, sensuality and femininity, strongly predicts their long term sexual adjustment (Anderson, Wood, & Copeland, 1997a; Yurek, Farrar, Andersen, 2000). Body image also predicts broader aspects of women's adjustment, including their psychological well-being, role and social functioning (Carver et al., 1998; Ganz, Desmond, Belin, Meyerowitz, & Rowland, 1999). Problems with body image are prevalent in women with breast and gynecological cancers. This may be because the tumors and treatments involve sites often associated with femininity and sexuality not only by the woman but also by society more broadly. Thus, for some women, negative body image appraisals might be particularly hard to challenge because these views are ingrained cultural or societal values (Wimberly et al., 2005).

After cancer, a woman's self-concept may be challenged, as she becomes aware of discrepancies between how she currently sees herself (*real self*) and how she ideally sees herself (*ideal self*) (Wilmoth, 2001). For example, before cancer a woman may have seen herself as a vital, confident, vibrant person. After cancer, she may feel that her ideal self has been lost. Menopause may make her feel old before her time, and she may feel less feminine and more vulnerable. She may struggle to reconcile her real self-view with that of her ideal self-view. In people coping with cancer, a high level of discrepancy between their ideal self-view and their real self views predicts worse adjustment (Heidrich, Forsthoff, & Ward, 1994).

Body and sexual self-image also overlap considerably with broader self-appraisals, such as self-esteem and identity. These broader views of the self are vulnerable to negative appraisals after breast or gynecological cancers. Carver and colleagues (1998) examined psychosexual functioning in 66 women with breast cancer, across the first year following their diagnosis. Women who were highly invested in a sense of body integrity or wholeness for their self-esteem experienced a deterioration in their feelings of sexual desirability and a shattering of their sense of identity (Carver et al., 1998).

One reason negative thoughts about body and self-image are so closely linked with poor sexual functioning is that they create emotional reactions that are detrimental to sexual responsiveness. For example, during sex, the woman who feels embarrassed, sad, or self-conscious about her appearance is likely to be anxious and distracted during intimacy with her partner. Cognitive distraction is associated with arousal of the autonomic nervous system, producing negative emotional states that oppose states of sexual arousal and pleasure (Andersen et al., 1997b).

Body/Self-Image and Sexual Functioning from a Relational Perspective

Women's body image, their self-concept, and their sexual responsiveness do not occur in isolation but are shaped within the context of their relationship with their partners. Women worry about their partners' reactions to their appearance after treatments. For example, one study found that women's expectations about how their partners would view their postoperative appearance influenced their choice between mastectomy and breast conservation surgery (Stanton et al., 1998). However, after surgery, if they perceived that their husbands were responding to their appearance differently than they anticipated, women reported regret about their treatment choices and experienced worse long-term psychological distress. Women's perceptions of their partners' reactions to them across their cancer journey are consistently found to influence their own acceptance of their appearance, their sense of femininity, self-esteem, and psychological functioning (Norton et al., 2005; Scott & Brough, 2006; Scott et al., 2004).

In close relationships, general feelings of acceptance by one's partner play a significant role in shaping a person's self-image (Samms, 1999; Zahlis & Shands, 1991). Self-esteem is a critical personal resource for coping with a serious illness (Sedikidies & Skowronski, 1997). Conversely, injuries to self-esteem hinder positive coping. For example, feeling rejected can weaken attempts to cope with demands of the illness (Baumeister, DeWall, Ciarocco, & Twenge, 2005). In a study of 143 women with ovarian cancer, partners' unsupportive behaviors influenced women's adjustment to their illness through the negative impact they had on women's self-esteem (Norton et al., 2005).

In close relationships, partners' responses shape each other's self-views. This has been called the *Michelangelo Phenomenon* whereby partners sculpt one another's ideal self-views through the way that they respond to each other (Drigotas, Rusbult, Wieselequist, & Whitton, 1999). To this end, partners' responses can help us create new sexual identities and reconcile discrepancies between our ideal and our real self-views. Partners' responses can help restore diminished views of ourselves as sexual beings (De La Ronde & Swann, 1998). For example, Feeney (2004) videotaped couples while one partner spoke about their goals related to personal growth. The extent to which the speaker's partner listened, offered encouragement, and shared their own thoughts and emotions had both immediate and delayed effects on the speaker's mood, self-esteem, and their perceptions that they could eventually attain their goals (Feeney, 2004)

Impact of Relationship Quality on Sexuality and Body Image

A strong predictor of the quality of the sexual relationship is the couple's general satisfaction with their relationship. For most women in committed relationships, the quality of their emotional intimacy is particularly crucial for their sexual satisfaction and performance (McCarthy, 2002). Studies of healthy women show that their reports of satisfying sexual experiences are dependent on more than physical pleasuring. Sexual satisfaction for women also depends on whether they feel their intimate psychological needs are met more broadly in the relationship. Feeling that the relationship nurtures psychological growth and self-esteem, and that the partner is emotionally committed, predicts higher sexual satisfaction (Smith, 2007). In particular, a recent study found the frequency with which women engage in, and enjoy, penile–vaginal intercourse and orgasm is strongly associated with their perceptions of the quality of intimacy, trust, passion, and love in the relationship (Costa & Brody, 2007). In women diagnosed with breast cancer, Wimberly and colleagues (2005) found that partner-initiated sexual activity and frequency of sexual intercourse predicted women's psychosexual adjustment, as well as her overall relationship satisfaction. The researchers speculated that partners' sexual behaviors may have served as a relationship barometer for the women, indicating their partner's overall commitment to the relationship. A number of studies of women with cancer find that their reported sexual problems are predicted, in part, by feeling emotionally dissatisfied with their partners and unhappy in their relationship (Fobair et al., 2006; Ghizzani, Pirtoli, Bellezza, & Velicogna, 1995; Wimberly et al., 2005).

Addressing women's body/self-image and sexual functioning from a relational perspective may benefit couples' overall satisfaction with their relationship (Schover, 1997). If left untreated, problems in sexuality and intimacy can have a detrimental effect on marital satisfaction. In couples therapy generally, it is estimated that sexual problems can account for up to 75% of the couple's relationship well-being (McCarthy, 1997). Finally, weakened relationship bonds may hamper couples' mutual support and coping skills more broadly (McCarthy, 2002; Wellisch, Jamison, & Pasnau, 1978).

Enhancing Sexual Intimacy and Body Image After Cancer

Given the importance of relationship quality to sexual intimacy, the clinician should check each partner's scores on the measures of marital satisfaction that were given to the couple at the beginning of treatment, before implementing techniques to enhance sexual intimacy. If it has been some time since the couple completed these measures, and there have been circumstances that have potentially affected their relationship satisfaction, the instruments should be re-administered. Furthermore, sexual problems can also stem from psychological difficulties associated with the cancer experience more broadly. Therefore, the clinician should check each partner's scores on the measures of depression, trauma symptoms, and life and relationship satisfaction, as discussed in Boxes 1.1 and 3.1. Other useful assessment tools are presented in Boxes 8.1 and 8.2. Box 8.1 describes instruments to assess both partners'

1. Satisfaction with the level of acceptance and intimacy that is communicated in their relationship.
2. Current sexual functioning.
3. Current levels of self-esteem, and the degree that cancer has created a discrepancy between their ideal and their real self-views.
4. Satisfaction with the extent to which intimacy needs are being met by the relationship.

Box 8.2 describes four measures, useful for assessing women's adjustment to perceived changes in their body image, including

1. Physical appearance as it relates to the woman's sense of self-esteem.
2. Woman's self-consciousness about her body during physical intimacy with her partner.
3. Negative self- and partner-related appraisal of her appearance.
4. Negative or traumatic reactions as a result of changes to body image.

In this session, we present techniques that can help couples enhance the quality of the intimacy in their relationship. The focus of therapy is guided by the P-LI-SS-IT model (Annon, 1975). This involves the clinician giving the couple *permission* to talk about sexual issues, providing them with *limited information* and *specific suggestions* and referring them, if warranted, for *intensive therapy*. It is not the clinician's responsibility to inform the woman of the biological effects of her particular therapy on her sexual responsiveness. This is a role for her physician. However, many doctors will not bring up the subject of sex during the treatment of their patients (Cox, Jenkins, Catt, Langridge, & Fallowfield, 2006; Hordernand & Street, 2007). Women and their partners may also find it difficult to raise concerns about sexual problems with oncology health professions (Jefford & Tattersall, 2002; Siminoff, Graham, & Gordon, 2006). The goals of this session, then, are to help couples discuss openly their concerns, plan for the resumption of an intimate sexual life, and learn skills to cope with challenges they might encounter in the future.

During the session, the clinician may provide couples with basic reading material about sexuality after cancer. It is therefore advisable that the clinician is knowledgeable about the content of these reading materials, which are listed in Handout 8.1.

We also recommend that practitioners take a preventative approach if possible, by addressing sexual issues before sexual problems develop. If a couple's first sexual experience after cancer treatment is negative, they may become distressed, and are

Box 8.1 Standardized Instruments for Assessing Sexual Intimacy and Self-Esteem

Dimension	Measure and reference	No. of items	Examples of items	This informs the clinician about whether the person (or the relationship)
Both members of couple complete				
Negative and positive behavior exchange in relationship	Frequency and Acceptability of Partner Behavior Inventory (Doss & Christensen, 2006)	20	"My partner was verbally affectionate"	Meets partners' broader psychological needs
Sexual performance	Golombok Rust Inventory of Sexual Satisfaction (GRISS) (Rust & Golombok, 1986)	28	Frequency and satisfaction with range of sexual behaviors	Is experiencing sexual dysfunction
Self-esteem	Rosenberg Self-Esteem Scale*	10	"I certainly feel useless at times"	Have feelings of general self-worth
Value placed on intimacy	Need Fulfilment Inventory, brief form (Kirby, Baucom & Peterman, 2005)	9	"I need to feel complete togetherness with my partner"	Feels the relationship satisfies their intimacy needs

*nb: To measure discrepancies in self-views, administer measure twice, with instructions altered to refer to 'before cancer' (with the first administration), and 'in the last week' (for the second administration) Landa & Bybee (2007)

Box 8.2 Measures of Female Body Image

Dimension	Measure and reference	No. of items	Examples of items	This informs the clinician about the extent the woman's
Women only completes				
Investment in, and concern about, body image	Measure of Body Apperception (Carver et al., 1998)	10	"It's important to me to look my best all the time"	Appearance impacts on her self-esteem
Self-consciousness during physical intimacy	Body Image Self-Consciousness Scale (Wiederman, 2000)	15	"During sexual activity, I am concerned about how my body looks to my partner"	Sexual behaviors are impeded by body image self-consciousness
Self- and partner-related appraisals of body image	The Self-Image Scale (Scott et al., 2004)	11	"I think my partner finds me attractive"	Self- and partner-related appearance appraisals are negative
Body image after cancer	The Body Image scale (short form) (Hopwood, Fletcher, Lee, & Al Ghazal, 2001)	10	Have you been feeling less sexually attractive as a result of your disease or treatment?	Cancer experience has changed aspects of her sexual self-view
Only women treated for breast cancer complete				
Traumatic symptoms following breast cancer surgery	The Breast-Impact of Treatment Scale (Frierson, Thiel, & Andersen, 2006)	13	"I avoid looking at and/or touching my breasts"	Breast cancer surgery gives rise to traumatic stress-like symptoms

more likely to avoid intimacy in the future, or develop chronic problems that are harder to treat (Wimberly et al., 2005). Most couples who were sexually active prior to cancer will attempt to reintroduce sexual activities early in the disease experience, usually not long after they have finished treatments (Wimberly et al., 2005). Thus, clinicians should consider conducting preparatory discussions about sexuality and body image with couples when they are nearing the end of treatments. At this time they can also be provided with information and suggestions regarding specific techniques. In later sessions, the clinician should review couples' progress in their recovery of sexual intimacy and provide specific suggestions of remediation, if required.

A final important consideration is the manner and tone in which this session is conducted. Most people feel somewhat reserved or awkward discussing their sexuality and the level of intimacy in their relationship. Clinicians may also feel awkward about raising certain topics. The best way that clinicians can help couples to overcome their embarrassment is to acknowledge the initial awkwardness of the discussion and to explain how normal it is to feel this way. To facilitate this process, clinicians should model open and relaxed discussion and avoid use of medical jargon. If medical terms are necessary, be sure to provide lay definitions of the terms.

Thus, the goals of this session are to

1. Assess the couple's risk of developing sexual and body imagery problems, or the etiology of problems if they have already occurred.
2. Discuss common sexual and body image problems associated with treatment and provide information about the role of psychological and medical variables in their etiologies.
3. Assist the couple in communicating about any changes in their intimacy and sexual functioning since the diagnosis.
4. Provide couples with an opportunity to discuss their goals for physical intimacy after cancer and to share their concerns on this matter with each other.
5. Provide information on further resources, if needed (books, helping professionals, etc.).
6. Describe specific strategies they might employ as a couple, and as individuals, to prevent the occurrence of sexual difficulties.
7. Make referral to sexual or couples therapists for more intensive therapy if required.

Technique 8.1 Permission to Discuss Sexual and Body Image Issues

The assessment of sexuality and intimacy issues serves as an opportunity for couples to explore their feelings about these matters and to communicate fears and hopes for intimacy in their relationship after cancer. In this session the clinician assesses physical, psychological, and relationship variables that can impact couples' sexual functioning and women's body image. We provide suggestions for how to assess these factors. However, it is important to remember that couples differ in the ways that they normally show affection in their relationship. Their goals for physical intimacy after cancer will also differ. Hence, it is important to first explore what is 'normal' for the couple and their expectations for this part of their relationship. To do this, the clinician should ask questions about the importance of sex within their relationship or the frequency of sexual activity. Then she/he can move to more detailed assessment of current sexual functioning.

Introductory Remarks "Most partners feel somewhat awkward talking about their sexual feelings with each other, not to mention having a third person present. And having cancer might bring up new issues that make it more difficult to talk about sex. The diagnosis and treatments of breast or gynecological cancers often affect couples' physical and sexual intimacy and how women feel about themselves. For example, a woman with breast or gynecological cancers may wonder if she is still physically attractive to her partner after she has lost her hair, has a mastectomy scar, or undergone pelvic treatments. A partner may wonder how to respond to changes in the woman's appearance in ways that are helpful.

In addition to changes in physical appearance, it is not uncommon for a woman undergoing chemotherapy, pelvic surgery, or radiation to experience vaginal dryness and pain during intercourse, or reduced desire for sex. Some couples have experienced problems with sexual intimacy before cancer, which may affect the quality of their intimacy after cancer. Couples are different in how they show their affection and have different goals for maintaining intimacy after cancer. The aim of this session is to develop a good understanding of how **you** as a couple feel about the level of intimacy in your life."

Step 1: Exploring the Impact of Cancer on Sexual Functioning

Ask each partner in turn, their views about. . .

1. "What was your sex life like before the breast cancer?"
2. "Are you currently sexually active?" (This is a relatively non-threatening question, and a "yes" or "no" answer can then be used to probe further.)

If the patient says they are **not sexually active**, ask:

3a. "Is that because of the cancer?"
If the patient says that cancer is **not the reason**, the clinician can then ask in a straightforward manner:

3b. "Do you prefer not to be sexually active?"

The couple may respond that they have not engaged in sexual activity for many years and that they do not view this as a problem. The clinician can then reassure the couples that this choice is fine. The clinician should explore the couple's typical ways of showing affection and intimacy. The remainder of the techniques covered in this session can be adapted to minimize the potential for treatments to affect the couple's usual repertoire of behaviors for showing love and affection in a negative way. It is particularly important that the clinician explore the impact of the cancer experience on the woman's body image and sense of self-worth, as these variables affect her overall adjustment after cancer.

If the couple says their sexual inactivity is **related to the cancer**, the clinician should ask them to describe the nature of the problem and the changes that have occurred.

1. "Did you experience problems with physical or sexual intimacy in your relationship before cancer?"
   (if "yes" explore the nature of these problems and how the couple chose to address them)

2. "Would you personally prefer to have sex more often, less often, or at the current frequency?"

3. "What are your hopes for your sexual life together after cancer?"

If the couple's sexual relationship was not good before the diagnosis, the clinician should assume that it is not likely to improve on its own afterward. However, if the couple did have a good relationship before the cancer, this bodes well for their recovery and maintenance of physical and sexual intimacy in the future.

Step 2: Assessing Physical, Psychological, and Relationship Factors

The next step is for the clinician to assess physical, psychological, and relationship factors which may increase a couple's risk for the development of sexual and body image problems. In the event a couple reports that they are currently experiencing problems, one should explore the etiology of the problems. It can be difficult for the clinician to tease out the relative contributions of organic factors (i.e., caused by the disease or the treatment) and psychological factors (i.e., arising from thoughts or feelings about the sexual self, intimacy with the partner, or the relationship generally). The following questions and suggested assessment materials are designed to help the clinician discover the underlying issues. Partners' answers should be considered in the context of their psychological functioning and relationship quality. To do this, clinicians should refer to individuals' scores on measures presented in Boxes 1.1 , 3.1, 8.1, and 8.2.

In addition, the clinician explores with the couple if there are any additional illnesses that could be affecting their sexual functioning with the following: "Certain chronic illnesses and treatments can impede sexual responses, particularly endocrine, cardiopulmonary, renal, and vascular disorders. Substance abuse (e.g., alcoholism, illicit drug use problems) may cause acute or chronic disruption of sexual activity. Some prescribed drugs for the management of nausea, pain, and mood disorders can also affect sexual responses, especially impeding desire. So, it is important that we explore whether any of these issues might have an effect on your sexual life after cancer."

Ask each partner in turn: "Are there any health-related problems or issues other than the cancer that may be affecting your sex life?"

If either partner reports an existing health problem that may be having an impact on their sexual functioning, then the clinician should try to provide basic information on the subject. The clinician should also ask the person how well they feel the problem is controlled or managed. People with significant health problems, particularly substance abuse problems, should be referred to relevant medical professionals. The practitioner should develop a list of agencies and therapists who specialize in these areas so that he or she can refer the couple to them.

Step 3: Exploring the Impact of Cancer Treatments

Next, the practitioner explores the impact of treatments on the couple's intimacy, each partner's perceptions of the other partner's reactions and the woman's feelings about herself. In asking these questions, the aim is to provide each person with the opportunity to understand their own and their partner's thoughts about these events. For some couples, the opportunity to share their feelings about intimate issues associated with cancer is all the intervention they need to reduce their anxieties.

Because breast and gynecological cancer treatments can affect sexual functioning and intimacy in different ways, the following questions focus on the particular type of treatment (insert woman's name) has received/is receiving and its effects on intimacy and how (insert woman's name) feels about herself and her appearance.

1. "What impact has the surgery (if occurred) had on you?"

If the woman has had **surgery or a lumpectomy**, ask the following:
For patient:

2. "Did you have reconstruction after surgery? What type?"
3. "How has the surgery affected your self-image as a woman?"

4. “How has the frequent examination and treatment of your body by medical providers affected you?” [Probe for partner’s response—how he/she feels]
5. “How has the surgery affected your sexual relationship with your partner?” [Probe for level of interest]

For the partner:

6. “What are your feelings about your wife’s (partner’s) surgery/ surgeries?”
7. “How has it affected your sexual relationship?”

If the woman is receiving radiation, ask the following:
For the patient:

8. “How do you feel, what do you think about your partner touching the part of your body being treated with radiation?”

If the woman is receiving **chemotherapy**, ask the following:
For the patient:

9. “How have the side effects of chemotherapy (e.g., hair loss, fatigue) affected your self-image as a woman?”
10. “Often, women who are receiving chemotherapy can experience vaginal dryness when they desire to engage in sexual activity. Has this happened to you?”
11. (If lubrication deficit) “How long have you had problems with becoming lubricated during sexual activity? Are there particular circumstances during which you have felt more lubricated than others?”

Irrespective of the treatment received, ask the following:
For the patient:

12. “Do you experience any pain with vaginal penetration?”
13. “During sexual activity, either alone or with a partner, can you experience an orgasm?”
14. (If orgasm does not occur) “Are you bothered at all by the absence of orgasm?”
15. “Do you have any feelings of discomfort or pain immediately after sexual activity?”
16. “Are you menopausal? If so, is it due to the chemotherapy or other medications?”

If premature menopause has occurred ask:

17. “Has your physician discussed the possibility of infertility due to premature menopause?”
18. (If patient is unaware of the possibility) “For some women, infertility occurs and you may want to talk to their physician about it.”

19. (If they are aware of the possibility) “How do you feel about the possibility of infertility?”

For the partner:

20. “How has your wife’s, partner’s treatment(s) and side effects affected your sexual relationship?”

Technique 8.2 Providing Information

The most crucial need of patients and partners is for accurate information. The best time to provide information is when the treatment has been determined. The clinician should discuss with the woman and her partner the possibility of continued sexual function and pleasure after surgery, or during chemotherapy and radiation treatments. At this time, people may find written material about sexual functioning helpful since there is so much new information about their disease to process.

Introductory Remarks “Myths and misinformation about cancer and sexuality can interfere with a couple’s physical closeness. People may be misinformed regarding when to resume sexual relations, thinking that they must wait several months. Some people with cancer, or their partners, believe that cancer, or that radiation from treatments, may be contagious, or that sexual activity may cause increased risks for the ill person. Consequently, they abstain unnecessarily from all forms of physical contact and sexual expression.”

The clinician can help the couple reduce their anxiety and foster the return of sexual functioning by giving them feedback on what is healthy and untroubled about their sexual response, and praising them for their courage in talking frankly about a sexual concern. Some couples, especially those reporting a high level of marital satisfaction, are very in tune with each other’s needs and are able to reintegrate intimacy into their lives with relative ease. Often, all they require by way of intervention is provision of useful and accurate information about treatments and side effects and suggestions for how to manage these.

Provide Information to Match Couple’s Needs

The information that the clinician gives to the couple will depend on any concerns that were revealed during the assessment of their sexual functioning. For ways of dealing with specific sexual problems such as vaginal dryness, lack of sexual desire, and genital pain, the clinician may suggest that the couple read pp. 13–19 of *Sexuality and Cancer: For the Woman Who Has Cancer and Her Partner* (American Cancer Society), Chapter 12 in *Living Beyond Breast Cancer* (Weiss & Weiss, 1998), and the chapters in Part 2 of *Sexuality and Fertility After Cancer* (Schover, 1997). Handout 8.1 contains resources for the couple and a copy should be given to them.

For women experiencing anorgasmia, the practitioner can recommend that the couple follow the nine-step self-help program for female anorgasmia in *Becoming Orgasmic* (Heiman & LoPiccolo, 1986).

For vaginal dryness and pain during intercourse, she/he can recommend a vaginal lubricant such as Astroglide, Surgilube, Ortho Gyne-Moistrin, Moist Again, Replens, K-Y Jelly, Women's Health Institute's Lubricating Gel, and Probe.

More severe or long-lasting problems such as vaginismus may require professional help from a sex therapist and a referral should be made. If reproductive issues have been raised, the clinician may refer the couple to a gynecologist who specializes in infertility with cancer patients. Understandably, couples can experience significant grief associated with the loss of fertility, especially young couples who have no children. Coming to terms with the loss and bereavement associated with infertility must be the focus of therapy, before other intimacy issues can be successfully addressed.

Technique 8.3 Promoting Helpful Thoughts About Body Image and Sexuality

Negative and unhelpful thoughts about appearance, and what she thinks her partner thinks about her appearance and sexual attractiveness, altered self-views, can undermine a woman's self-esteem and her interest in intimacy in a relationship. Eventually they can lead to broader problems in coping and adjustment. Partners can also change after cancer, feeling less confident or certain in their intimate relationship with their wife/partner. Some men, especially those who derive a sense of closeness with their spouse from sexual activity in the relationship, may feel rejected if sexual activity has decreased in the relationship. These issues, if not addressed, can also undermine the success of techniques described later in the session, for building positive intimate exchanges in the couple's relationship.

Introductory Remarks "Cancer treatments sometimes affect the way women feel about themselves. A number of things may alter a woman's appearance, such as surgical scars, weight changes, and hair loss. Some women feel less attractive after treatment and they find it difficult to come to terms with changes to their body. They may not like the way they look undressed or in their clothes. Other women fear that their partner will find them unattractive and reject them. Sometimes partners feel uncertain about how to react to changes in their spouse's appearance, such as scars. They may worry about the right way to reassure their partner that they find her attractive. For some partners, changes in intimacy in the relationship lead them to feel rejected. One way to manage these concerns is to share thoughts and feelings in an open, supportive way."

[Show them the list of 'Common Unhelpful Self-Talk About Appearance and Intimacy' from Handout 8.2].

"This list provides examples of unhelpful self-talk about intimate issues that women and their partners sometimes have about their sexual intimacy and their physical appearance. Some of these thoughts may be experienced by only one person or may be common for both partners. Often these thoughts are difficult to share.

Sometimes partners try to read each other's minds or guess each other's thoughts. The result of this mind reading is incorrect assumptions or misinterpretations of the intent behind their partner's behaviors. Left unchallenged, these thoughts can do harm to a couple's intimacy and self-esteem. Do you have any similar types of thoughts?" Help couples to discuss their feelings and to challenge unhelpful self-talk through the same process that is presented in Chapter 5.

Technique 8.4 Teaching Sexual Coping Skills

The clinician can suggest several sexual and non-sexual exercises to help the couple restore their normal sexual activity. The *Sensate Focus* approach (Masters & Johnson, 1966) is a widely used method in couples and sexual therapy. The aim is to help couples become familiar with, and relaxed about, sensations and in pleasuring each other sensually, without focusing on actual sexual or coital performance. This may seem a paradoxical approach, but taking couples, attention away from sexual performance reduces anxiety that impedes sexual responsiveness. It also encourages mutual pleasure and realistic intimacy goals, so that the couples develop a sense of mastery and confidence in their sexual life, as opposed to a fear of failure in intimacy.

These exercises may be especially helpful in cases where there are discrepant levels of sexual interest. Non-demand pleasuring exercises are exercises that involve gentle stroking and caressing in an effort to become familiar with one another's bodies again in an atmosphere free of the demand to perform sexually. The exercise can be presented in three steps: non-genital caressing, gentle genital caressing, and more intense genital caressing (Bach, Wincze, & Barlow, 2001).

Introductory Remarks "The first time a couple makes love after treatment can be an anxious time. Each person worries about the other's reactions. Set aside time to be alone together without interruptions. Spend time getting used to being naked together. The focus should not be on intercourse, but on feeling relaxed and comfortable with each other. Take things slowly. Enjoy exploring and becoming familiar with each other's body again. Each partner takes a turn at being the giver and receiver, and for approximately 20 minutes they give or receive the caress. Focus on sensations and touch. Show each other how you want to be touched by physically placing your hand over the caresser's hand, and indicate the pressure, speed, and motion you enjoy"

Step 1: Introduce the Sensate Focus Skill

Provide the couple with detailed instructions on how to do this exercise (see Box 8.3 at the end of the chapter). Besides touching, holding, and caressing, there are other activities the clinician can suggest. For example, taking a bath or shower together, taking a mini-vacation, "petting," and dancing. Chapter 5 in *Sexuality and Fertility After Cancer* offers numerous suggestions. It is better if the clinician can help the couple develop their own list of intimate activities. Some of these activities may have been enjoyed prior to the cancer, but have been avoided or overlooked since the diagnosis.

Step 2: Summarize Discussion

At the end of the discussion, summarize the partners' feelings, desires, and requests. Verify what each partner heard the other partner say and clarify any misunderstandings. Compliment them on discussing the topic with you. Emphasize that their communication should be ongoing in order for their needs to be met and their feelings understood.

Step 3: Involves Assignment and Planning

Ask the couple to have a private conversation about their sexuality and goals for return to sexual activities, taking turns at being speaker and listener. They are to practice the skills of supportive communication during these discussions. Some couples will wish to practice the steps in the *Sensate Focus* approach. To assist with the management of negative self-view or cognitions about appearance and intimacy, some people may also benefit from using the Coping Self-Talk Form, found in Chapter 5.

Case Illustration

Ruth (42) and John (45) have been married for almost 15 years and have two children: a 6-year-old son and a 4-year-old daughter. Ruth has had a hysterectomy and pelvic radiation treatments for cervical cancer. During the assessment and discussion about the impact of the treatments on self-views, Ruth revealed several negative thoughts about herself and about intimacy after cancer. Her primary fear was that John did not find her attractive anymore. She stated, “John is not coming near me anymore.” She took as a sign that he had “lost interest in me as a woman.” Ruth stated that she had been left with an ovary and therefore her “hormones were ok.” Her doctor had mentioned something about the “shape of her vagina might change after treatments.” She said she could not recall all the information he had discussed with her when she was diagnosed. But she did remember him saying “something about, there might be some pain during sex.” The clinician prompted her to elaborate on this information and what it meant for her. Ruth admitted that she had been worrying about his comments and how much pain she might feel during sex.

The clinician asked John to talk about how he felt about Ruth’s self-disclosures. John replied that he was “astounded that Ruth felt that way” and that he felt sad that she would see him “as so shallow!” He stated that he was not “turned off by” Ruth, but rather was “giving her space” because he did not want to rush her into sex. He was leaving it to her to “make the first moves.”

During the discussion, the clinician gently suggested to the couple that they were both thinking about how to show affection to each other and how to feel close in their relationship. But each one was worried about the other’s reactions. The clinician helped the couple to challenge the negative thoughts they held about each other’s behaviors. The couple was asked to review Handout 8.2 and to discuss together how these thoughts were similar, or different, from their own. During this sharing task, John commented that he hadn’t realized how insecure Ruth felt after cancer, how much less confident she felt as a person. He said he was “just happy to have her alive” and that he had not really focused beyond that, to how treatments might have affected her. He said he realized he “shouldn’t have taken offence” at her comments about him not finding her attractive. He stated he could see how, with her confidence down, she would have interpreted his behavior as “aloof or not caring.”

Next, the clinician provided the couple with information about the impact of pelvic surgery and radiation on vaginal lubrication, shape and elasticity, and ways to prevent pain during intercourse. Specific suggestions included the use of vaginal lubricant and sexual positions that allow the woman to control the rate and depth of penile penetration. The role of unhelpful thoughts and anxieties in impeding arousal during intercourse, particularly anticipatory concerns about pain, was also explained. For homework, the couple was asked to read pp. 13–19 of *Sexuality and Cancer: For the Woman Who Has Cancer and Her Partner* (American Cancer Society, 1999).

In the next session, the clinician followed up on their suggestions for managing potential problems during intercourse and answered questions that they had. Next the therapist suggested the *Sensate Focus* approach to help John and Ruth develop other ways to show reassurance and affection and to take the emphasis off the "all or nothing" view they had held previously. John was also encouraged to explore ways he might reassure Ruth that she was attractive and feminine to him. John joked that he was not a "great romantic" but he thought that if he could arrange for them to have a "date together, without the kids" this would be a nice treat for both of them. The couple decided they would ask Ruth's mother to mind the children for the weekend. Ruth said this would help her to feel more relaxed and reduce her anxiety that the children might "burst in on them at any time."

In the next session, Ruth and John seemed somewhat coy as they entered the therapy room. They sat down, and grinned, and stated that they had "a confession to make." Ruth said that "even though we were not supposed to do *it* just yet" they had both felt so relaxed during their weekend away without their children that they had progressed to intercourse. The clinician explored how this experience had been for them. Ruth stated that she had felt no pain but joked that they had used "an awful lot of lubricant just to make sure." The clinician praised the couple for having the courage to discuss difficult topics with each other and to work as a team to ensure they kept important, positive, caring behaviors in their relationship. John joked that he was glad they did not get in to trouble for being "over ambitious" and that he would also like some praise for the fact that he had "bought Ruthie flowers this week too!"

What to Do if . . .

Either Partner Reports a History of Sexual Abuse, or an Eating Disorder

These types of problems, if they are still affecting a person's current psychological functioning, often require intensive therapy. Unless the clinician is significantly experienced in the treatment of these disorders, she/he should refer the person to a therapist who specializes in the treatment of these problems. This does not necessarily preclude the clinician from continuing to work with the couple to help them to cope more broadly with their cancer experiences. This should be decided in consultation with the clients.

The Couple Has a Negative Sexual Experience While Practicing Sexual Intimacy Skills

It is important to help couples place setbacks into perspective so that they do not catastrophize about what one event means for their long-term sexual adjustment. All couples, at some point in their relationship, are likely to have sexual experiences that are not pleasing in some way. Help the couple to explore if there were environmental factors that may have contributed to the situation. One person may have felt too tired but did not want to disappoint or turn down their partner; quiet time may have been interrupted; or there may have been expectations that good sex would "just happen."

The Woman Does Not Have a Partner

A woman who does not have a partner may have questions and concerns about the impact of treatments on future intimate relationships. Common questions include "at what point in a new relationship should I tell my partner about my cancer and treatments?" and "how much should I tell them?" Again, the clinician should help the woman to challenge negative thoughts she might have about the likely response of a potential partner to her disclosures. The clinician should suggest that if she decides the person is someone she would like to build an intimate relationship with, then open, honest discussion is the best approach. Secrets can create barriers to developing emotional intimacy and trust, and these ingredients are needed for the success of a long-term relationship. Role playing an open, honest discussion with the woman can help her to build confidence in her communication skills.

Partners' Goals for Resumption of Sexual Activities Differ Radically

Ideally, these goals should be mutually acceptable to both partners. When a couple's goals for resumption of sexual activities differ markedly, the therapist needs to acknowledge it and find out if it relates to a pre-existing sexual problem or is symptomatic of an underlying relationship problem. When partners hold these goals rigidly and will not compromise, it is likely that they need referral to an expert who can provide more intensive couples and/or sexual therapy.

There is Significant Relationship Distress, or Psychological Disturbance in One or Both Partners

Couples should be referred to an experienced couples therapist for the management of relationship distress. Individuals with psychological problems may require referral to a mental health professional for prescription medication to manage symptoms and/or more intensive therapy to improve their psychological well-being.

Sociocultural Considerations

Research on women coping with cancer indicates that there are more similarities across a range of cultural and ethnic groups in terms of women's body image and sexual adjustment after cancer than there are differences (Pikler & Winterowd, 2003; Spencer et al., 1999; Takahashi & Kai, 2005). Community samples of healthy women suggest that African-American women may have wider and more flexible standards of attractiveness and body image acceptance than white women (Celio, Zabinski, & Wilfley, 2002). However, the differences between African-American and white women are greater in women under the age of 30. Recent research suggests that some aspects of these cultural differences between African-American and white women have diminished over time, though this seems primarily limited to attitudes chat weight (Roberts, Cash, Feingold, & Johnson, 2006). We could find no studies related to body image or sexual functioning in indigenous Australian women coping with cancer.

When addressing the needs of women from minority groups, it is important to note that research studies are based on group data. They do not necessarily inform us about the needs of individual couples we might see clinically. Thus, body image and sexuality should be addressed in the context of their subjective importance to each women and her partner, or support person.

Couples from non-Western cultures may experience difficulty in talking to a clinician about their sexual intimacy. In these situations, private discussions alone with each partner may be more productive. The gender of the clinician may be an issue and it may be preferable to have a female practitioner talk with the woman and a male practitioner talk with the man. Depending on the degree of each person's comfort after the individual discussions, the clinician may consider a joint session with the couple.

When the Support Person Is Not a Partner

In dyads where the support person is not the partner, the therapist should ask the woman about her preferences for how she would like to address these matters in the session. The therapist should explain that it is possible to cover some, or all, of the counseling in individual, confidential sessions with the clinician. Physical aspects of body image, feelings about sexuality, and goals for sexual behaviors are likely to be inappropriate topics to discuss in the context of some types of dyad relationships. Some women do feel completely comfortable discussing these issues with a close female friend or a family member but are less comfortable discussing these issues with a male family member, such as a son. Women's choices regarding how these issues are managed in session depend on the level of emotional intimacy in the dyadic relationship.

Handout 8.1 Resources on Sexuality for Cancer Patients and Their Partners

Books

American Cancer Society, (1999*). Sexuality & cancer: For the woman who has cancer, and her partner*. Atlanta, GA: ACS. (is available from the local office of your ACS or from the website www.cancer.org or calling 1-800-ACS-2345)

Cash, T. F., (1997). *The Body Image workbook: An 8 Step Program for learning to like your looks*. New York: Harbinger publications

Heiman, J. R., LoPiccolo, L., & LoPiccolo, J. (1988). *Becoming orgasmic: A sexual & personal growth program for women.* New York: Fireside.

Schover, L. R. (1997). *Sexuality and fertility after cancer*. New York: John Wiley & Sons.

Foley, S., Sugrue, D., & Kope, S. (2002). *Sex Matters for Women: A Complete Guide to Taking Care of Your Sexual Self.* New York: Guilford Press.

Weiss, M. C. & Wiess, E. (1998). *Living beyond breast cancer: A survivor's guide for when treatment ends and the rest of your life begins.* New York: Random House.

For referrals to a certified sex therapist

www.aasect.org/directory.asp

(This is a directory for the American Association of Sexuality Educators, Counselors, and Therapists. AASECT certified professionals are listed for North America, China, Israel, and the United Kingdom)

www.psychology.org.au

(This is the website for the Australian Psychological Society. Look under marital therapists for clinicians who are trained in sex therapy)

Handout 8.2 Common Unhelpful Self-Talk About Appearance and Intimacy

Thoughts of the woman with cancer	Thoughts of the intimate partner
"He/she does not find me attractive anymore"	"She is never going to regain her interest in sex"
"Losing my breast/reproductive organs means I am less of a woman"	"She does not love me because she does not respond to my attempts at initiating intimacy"
"She/he does not care about me, they just want sex"	"I'm a bad/insensitive person because I am thinking about when we can have sex again"

"Sexual intercourse is going to be painful"	"I should not show I am interested in sex as this will make her feel pressured into starting before she is ready"
"I will never regain my interest in sex"	"I will hurt her and make her recovery slower/her cancer worse"
"There is something major wrong with me because I am not feeling like sex" "I'm an old person now, cancer has changed me for the worse"	"We should not have to use lubricants or gels, sex should happen naturally" "She is just doing this for me, she is not interested"
"I have to have sex with my partner or they will stop loving me/find someone else"	"I won't be able to perform sexually/achieve an erection/orgasm"
"If we really loved each other this problem would not happen"	"I can't tell what she is thinking anymore, she is like a different woman"
"They don't feel like sex because they don't find me attractive anymore"	"Sex used to be fun and spontaneous, now it is no good because it is clinical and planned"

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Box 8.3 The Body Caress: An Exercise to Enhance Sexual Intimacy[1]

To ensure that the exercise will go as smoothly as possible, make certain that you set aside sufficient time for a relaxed, unpressured body caress. Plan at least 30–45 minutes for the caress and discussion period afterward. You may want to arrange the setting with soft music, low lights, candles, etc. You may also like to use lotion or oil for the caress.

People who are not accustomed to being stroked for an extended period of time may initially find the passive *receiving role* uncomfortable. In this case, it may be preferable to begin with a much shorter body caress—5–10 minutes—and then gradually extend the time with each practice session. It is far better to end a short massage feeling good than to spend a longer period of time and feel anxious or negative about the experience.

The woman will be the first to give the caress and the man will be the receiver. After approximately 15–20 minutes, you will switch roles.

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The Role of the Giver

The job of the person giving the massage is simply to stroke, caress, and in other ways attend to the area to be massaged. Since this first body caress is not designed to be sexual in nature, please do not include the genitals. Otherwise, include the whole body—front and back—in the caress.

Don't worry about massage technique. Massage technique is not the emphasis of the exercise. So do not let concern about your proficiency as a masseuse hold you back from completing this exercise.

The body caress should be conducted from the vantage point of the giver's own interest and not just as an effort to please the receiver. This is a very important point. Most often, when we give a massage, we try to do it in the way that our partner will most appreciate and respond to. Our focus is more on our partner's reaction than on our own feelings about the experience of touching. However, this caress is to be carried out from a different perspective. The object is to enjoy touching. You are not to rub your partner in an attempt to relieve his or her shoulder tension. However, for your own interest you may want to experiment with a firm pressure or pressing with your thumbs or fingertips while massaging certain areas. You may also want to experiment with a light touch or with circular motions. Make the endeavor an interesting one. Learn new things about your lover's body, about its curves, muscles, skin, and bones.

Also, do not try to continue caressing once your interest has waned. If you are losing interest, see if you can figure out why. Are you getting bored because you are not used to stroking another person for a long period of time? Are you unable to think of any new ways of touching your partner that might make the experience more interesting to you? Have you used different types of touches or other things for variety. If you have tried to experiment and still have lost interest, it is best to let your partner know this and to terminate the exercise. Since one of the main objects of the caress is to convince the receiver that the giver is enjoying the experience, the giving must be genuine. If the giving is being done with resentment or disinterest, the receiver will only have more reason not to believe they are being given to joyously.

The Role of the Receiver

It is important that the giver be able to experiment with new touches without having to worry about making the receiver uncomfortable in any way. Therefore, when you are in the role of the receiver, be sure to let the giver know when any touch is not enjoyable for you. Holding your breath and hoping that the way you are being touched will soon stop will only cut off your feelings of arousal. It is better not to grin and bear it—the object is pleasure, not discomfort. Some people have had very little practice at letting their lover know when they do not like something. They often feel they are protecting their partner from hurt by remaining silent, but in reality they are only building up negative feelings that can eat away the relationship. Letting each other know what you do not like gives both partners practice at accepting a negative response without feeling devastated.

If the touch is in any way negative, the receiver is to let the giver know in a positive way. In other words, rather than saying "Ouch!" "Stop," or "No," that hurts,"let the giver know not only what to eliminate but how the touch could be made more pleasurable. For example, you could say, "Could you please do that more firmly, that tickles." "The scratching of your nails on my skin is too rough, could you use your fingertips instead?" It is just as important for the *receiver* to be honest about any discomfort, as it is for the *giver* to be honest about beginning to tire of the experience.

Except for correcting your partner's touch, the receiver's role in this caress exercise is to just relax and thoroughly enjoy being ministered to. As receiver, empty your mind of all worries and concerns. Forget business and children's problems, the phone calls you did not return, and the errands left undone. If you are having difficulty blocking out distracting thoughts, you may find it helpful to direct your attention to the exact place on your body your partner is caressing. Then focus on discovering exactly how your skin and muscles respond to the different ways your partner touches you. Think of words to describe the feelings—such as "tingling," "warm and smooth," "firm and strong." Concentrate on the moment. Attend completely to the touch your body is receiving.

Feedback

Once either the giver or the receiver is ready to terminate the body rub, or the time allotted has elapsed, the physical part of the exercise is over. However, it is very important to spend at least 5 minutes afterward discussing the experience. This feedback time provides an opportunity to review the event and become aware of aspects that may have been missed the first time around. This is the time to check out any of your worries or concerns. The giver can ask which types of touch the receiver liked best and which specific areas of the body the receiver most enjoyed having touched. The receiver can feel free to question whether the giver was truly interested in the experience or if the giver's interest began to wane at any particular point in the caress.

All concerns should be responded to honestly. In the long run, it is far more important to build a sense of trust than it is to be polite. The expression of negative feelings gives greater credibility to the positive ones. It is hard to trust feedback when it is only positive and glowing. A balanced report is more believable.

Talking over the exercise is a first step in learning to discuss other and more intimate sexual preferences. Such discussions also enhance intimacy. Every conversation in which you share something about yourselves deepens your knowledge of each other, which then fosters caring.

Reminder: If the exercise is successful, the receiver may feel relaxed and turned on afterward. Although it may be difficult to refrain from having sex when both of you feel sexually interested, this is not the goal of the exercise. The purpose of the exercise is to create the foundation for greater sexual interest and response on your part in the future and not necessarily to produce an orgasm today.

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Chapter 9
Helping Children to Cope when a Mother Has Cancer

Husband: One of Craig's few words that he knows how to say is 'hospital.' He also says 'Momma's sick.' He doesn't dwell on it much but it hurts me to think that he's growing up with a mom who is really sick—it makes me sad.

Wife: I used to be with the kids 24/7—I quit work to spend time with them but now I can't because I'm at the hospital every day for treatments. I feel terribly guilty about this.

Most parents would readily agree that raising children can be extremely challenging at times. But when cancer enters the picture, being a mother can also provide a deeper sense of meaning and purpose in life. Despite a mother's best intentions to continue her normal caregiving activities, cancer treatments may diminish her abilities to fulfill her parenting role. Women with cancer have identified three primary challenges of being a mother:

1. Dealing with thoughts and anxiety about what would happen to the children if she were to die.
2. Attending to her personal needs while caring for the children, who have their own needs to be met.
3. Finding a balance between talking openly to the children about the illness and protecting them from information that may be overwhelming (Billhult & Segesten, 2003).

The diagnosis and treatment of a mother's cancer will impact her children, regardless of their ages. The degree of impact will depend primarily on how intrusive the medical treatments are in the patient's life and the developmental needs of the children. At the very least, children will need to adapt to new routines and responsibilities. No longer will they be able to expect their mother to do all the things that she did before the diagnosis. New demands and responsibilities will be placed on them or shifted to the father or other caregivers. The father will be challenged to take over many of the tasks normally handled by the mother, caring for her, and fulfilling his work responsibilities outside the home. There is very little research that focuses on fathers' concerns with parenting when his wife has cancer. Yet the father may feel as much distress as the wife, given the physical and emotional demands of

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caring for the mother and the children. If the mother's illness becomes terminal, the demands can become even more overwhelming.

The level of adjustment of children and adolescents to a mother's cancer will depend in part on who is doing the reporting. In one study, parents reported little or no evidence of emotional distress or behavioral problems in their children, regardless of the children's age or sex (Welch, Wadsworth, & Compas, 1996). Yet the children of these parents gave a significantly different assessment. Adolescent girls reported the highest levels of symptoms of anxiety/depression and aggressive behavior. Children reported emotional distress during the first 10 weeks after the diagnosis but very little distress 4 months later. The parents' reports of distress did not change with time. Based on these findings, practitioners need to assist parents in recognizing and dealing with their children's distress when it is present (Welch et al., 1996).

We begin this chapter by describing the coping responses of children whose mothers have cancer. Using a developmental framework, we identify the social, emotional, and physical needs of children. We provide interview questions to help parents recognize the impact of the cancer on their children and offer suggestions for helping children deal with their fears, sense of loss, separations, and other concerns. Although the focus of the chapter is on the diagnosis and treatment phases of cancer, we have included a section on helping children and parents during the terminal phase of cancer, which is usually the most stressful time for loved ones.

Children's Reactions to Their Mother's Cancer

During the initial phase of learning about the mother's cancer diagnosis, children may experience increased levels of stress, anxiety, and depression. A child's response to a mother's diagnosis of cancer, however, will depend on the age of the child. Young children (under 10 years) may not show high levels of stress as openly as older children, who may demonstrate their anxiety, depression, and anger in a more straightforward way. Infants and toddlers may only sense that their routines are being disrupted and that their primary caregiver, who is likely to be their mother, is not always there for them. They may show that they are upset by fearful behavior, anger, and loss of skills such as toileting and dressing themselves.

Young children (aged 7–10) commonly experience an array of concerns and feelings including confusion, sadness, fear, loneliness, and, at times, anger. Their worries are focused on whether the mother will die, whether something bad will happen to the family, changes in their mother's physical appearance, financial problems, and their own vulnerability to cancer. In one study, the most frequent worry mentioned by children was that their mother was going to die (Zahlis, 2001). Open communication can minimize the worries and misconceptions that children at this age may have (Rittenberg, 1996). However, it may take time to assimilate so much information about the cancer, so that initially children may be quite confused.

With slightly older children (11–13) there is more of a preoccupation with their own lives. These children may worry about taking on additional chores and responsibilities and about being rejected by their peers (Northouse, Cracchiolo-Caraway, & Appel, 1991; Rittenberg, 1996). Parents can help children in this age group by (1) providing them with an opportunity to talk to doctors and nurses, (2) working with teachers to facilitate a supportive environment at school, and (3) assigning chores at home that they are able to fulfill (Veach, Nicholas, & Barton, 2002).

Adolescence has often been overlooked in the psychosocial research on cancer. However, the emotional impact of a mother's breast cancer on an adolescent is significant. Adolescents report that they often do not get the support and information they feel they need (Kristjanson, Chalmers, & Woodgate, 2004). For many adolescents, their concerns will stem from the conflict between autonomy and attachment to their parents. The crisis of the illness may pull the adolescent back into the family at the time when developmentally he or she wants to become more independent (Veach et al., 2002). Some teens may become preoccupied with illness and their own mortality. Adolescent daughters, in particular, are likely to have increased anxiety about their own health and futures. Another reaction among some teens is to withdraw completely from the family and attend to their own developmental need to be with their peers (Veach et al., 2002).

Although there are studies that support the idea that adolescents are adversely affected by a mother's cancer, very little attention has focused on meeting the adolescent's needs for the informal and formal types of support that may be helpful to them. In one study using focus groups of adolescents, the teens were asked about the types of support they needed and from whom they received support (Kristjanson et al., 2004). These adolescents felt that providing a sense of hope was a significant component of support. They considered support from their peers and teachers at school to be valuable, because it enabled them to continue with the normal routine of their lives and to feel hopeful. Having a health care professional's phone number to call was helpful, even if they never used it. Relatives were considered helpful and supportive when they offered practical help such as meals and cleaning and were not "bugging" the adolescent. Adolescents who were participants in support groups described these groups as helpful, because the members were caring, did not pressure them to participate, and shared common experiences. As mothers became sicker, the teens' needs for information and support were that much greater.

Many of the adolescents in the Kristjanson et al. study reported that their information and support needs were not being met either within the family or outside the family. In particular, they felt that they were not included in illness-related discussions and that their needs were overshadowed by their mother's need for support. In addition, the adolescents perceived that their mothers were trying to protect them by hiding information about the cancer from them. Fathers were often reported to be useful in interpreting information about the disease and treatments. The parents' openness with their adolescent children was an important factor in determining whether their information needs were being met (Kristjanson et al., 2004).

Adolescent girls, in particular, may have difficulties when their mothers are diagnosed with cancer. The more vulnerable the daughter feels about her risk of getting cancer, the more likely she will experience psychological symptoms (Wellisch, Gritz, Schain, Wang, & Siau, 1991). However, adolescent daughters who are more involved in the caregiving role tend to feel less anxious about their mother's illness. Giving daughters a concrete way to be helpful may be a way to alleviate some of their worries. In contrast to daughters, adolescent sons may avoid communication and try to conceal information about their mother's illness from others outside the family. Their feelings are more likely to be acted out with inappropriate behaviors, rather than through open communication (Northouse et al., 1991).

Adult children of cancer patients can also experience symptoms of anxiety or depression (Compas, Worsham, Ey, & Howell, 1996; Compas et al., 1994). Although adult children may not be living with their parents, they may be extensively involved in their mother's care and provide emotional and social support to her. We know most about daughters of breast cancer patients—perhaps due to the possibility that a daughter will develop breast cancer and also due to the role they often play as a caregiver. Caring for a mother can be a very rewarding experience for mothers and daughters. At the same time it can create extra stress for a daughter who is likely employed outside the home and may already be balancing the responsibilities of work and caring for her own children. In one study, daughters who were more involved in caring for their mothers with breast cancer experienced higher levels of cancer-related distress than daughters who were not involved with caregiving (Erblich, Bovbjerg, & Valdimarsdottir, 2000). Daughters who viewed the caregiving as a burden were particularly susceptible to high anxiety and depression (Raveis, Karus, & Pretter, 1999; Raveis, Karus, & Siegel, 1998). Daughters who both participated extensively in caregiving and experienced their mother's death from the cancer understandably felt the highest level of distress (Erblich et al., 2000).

Children's Ways of Coping

There seems to be a paucity of research that focuses on the specific coping strategies that children use to deal with a parent's cancer. We found only one study (Issel, Ersek, & Lewis, 1990) that identified multiple ways that children coped with a mother's cancer. Four distinct coping strategies were conceptualized: (1) In Her Shoes, (2) Business as Usual, (3) Group Energy, and (4) On the Table. "In Her Shoes" was a way that children tried to understand what their mother would want if they were in their mother's shoes. Children who used this strategy would try to be more considerate and take care of the mother by helping with chores and trying to be nice. Children who minimized the illness by acting normal and doing regular things coped by trying to go about "Business as Usual." "Group Energy" occurred when children coped by seeking comfort and support from others. "On the Table" was a type of problem solving which involved expressing their thoughts and feelings openly through family discussion and personal reflection. It was more common among older children (Issel et al., 1990).

Communicating with Children: How Much Information Can a Child Handle?

Communication has been identified as the most critical factor in the family's adaptation to cancer. Despite the key role that parents can play in communicating information, they often feel inadequate about this role and unprepared to take it on. While parents may perceive that they have talked to their children about cancer, they may not communicate in a timely fashion or in ways that are understandable and address children's specific concerns. Most children are told about their mother's illness after the diagnosis has been confirmed by biopsy, but some are not told about it until after surgery. Some are not told at all. Regardless of the children's ages and the level of the mother's education, all mothers are likely to benefit from professional advice about communication. This is true during all stages of their diagnosis and treatment, but particularly early on, when they are hesitant about initiating discussions with their children (Barnes et al., 2002). Again, a developmental perspective on ways to discuss their illness in relation to children's understanding is necessary. Box 9.1 offers specific suggestions on telling children about cancer.

How parents cope with the illness will influence the child's coping behavior in a major way. One study looked at how parents shielded or protected their children from the diagnosis and treatment effects and then looked at how children shielded or protected themselves from their thoughts and feelings (Hilton & Gustavson, 2002). The researchers discovered that children generally found it difficult to hear the news of the mother's illness, but when they were told that she was doing well and that "she isn't going to die," they felt relieved and often did not want to know more. In this way they shielded themselves from further information. Shielding is different from denial, in that shielding is a conscious attempt to protect oneself from emotional upset. Shielding is a way to alleviate fear about the future and allows children to get on with life. In itself, shielding and being shielded is neither positive nor negative, especially when it is used in moderation. It becomes problematic when it is overused or underused.

How much information to give a child is a common question of parents. Professionals differ over the protective approach, which seeks to shield children from bad news, and the open approach, which suggests that children should be told everything. However, most professionals agree that children should be told bad news even though it is distressing to hear it. It may be less distressing, however, if the information is given in a clear and honest manner (Hilton & Gustavson, 2002). Based on a review of the research literature on the impact of cancer on children and adolescents, Faulkner & Davey (2002) offer these additional suggestions for parents:

- If the mother is in the hospital for any extended period of time, the mother should reassure the children that her absence has nothing to do with how much she loves them.
- Answer questions honestly.
- Prepare children and adolescents for the effects of treatment (physical changes like loss of weight and hair loss).
- Let children and adolescents help but do not overburden them with responsibility.

Helping Children During the Terminal Phase of Illness

If a mother's disease enters the terminal phase, the reactions of children that are mentioned above tend to be intensified. For example, children with a terminally ill parent are more likely to report high levels of depression and anxiety, and lower levels of self-esteem. Behavior problems may increase and social competence may be diminished (Siegel et al., 1992). Children may have particular difficulty coping when the illness lasts for an extended period of time, with frequent remissions. The repeated cycle of deterioration followed by periods of health can take a heavy toll on a child's emotional life (Christ et al., 1993). The relationship with their parents plays a significant part in determining how children will adapt to the loss of a parent. Consistent and stable parental care both during the terminal phase of the illness and during the years following death facilitate the child's adjustment (Siegel et al., 1990).

Given the heightened emotional distress during this phase, children need additional emotional support, communication, and physical care. Yet the father may be so preoccupied with the needs of his wife and so overwhelmed by his own emotional state that he may be unable to attend to the emotional needs of his children. Further, spouses in this situation do not always have the energy to maintain standards of behavior, reinforce limits, and discipline their children (Siegel et al., 1990). It is important for practitioners to (1) assess possible role strain for the father, (2) ensure that the father receives necessary instrumental and emotional support, (3) encourage him in his caregiving and parenting abilities, (4) facilitate the parent–child relationship during times of intense patient care, and (5) help provide a stable and consistent home environment (Veach et al., 2002). It is critical that parents draw on all available social resources to deal with chronic stress and to avoid burnout.

When a mother's cancer is in the terminal phase, it is also critical for practitioners to help with the emotional needs of the children. Practitioners can create a safe place for children to express their concerns and fears. Again, the age and developmental needs of the children should be considered when working with families and death (see Veach et al., 2002, for more information on working with children when a parent is dying).

Ultimately, children make a healthy adjustment when they are (1) given information about events and expected changes in the parent's health status, (2) prepared, as much as possible, for the parent's death, (3) encouraged to discuss their fears and concerns regarding their parent's illness and death, and (4) allowed to follow predictable daily routines (Siegel et al., 1990).

After a parent dies, the challenge for the remaining parent is to attend to the physical and emotional needs of the children while dealing with personal grief. This is when the family's social network plays a crucial role in helping alleviate some of the pressure on the parent, so that he or she can spend time with the children and take care of social and emotional needs. A major question for children after a parent's death is "Why?" Practitioners can help parents be prepared for such discussion which can help make meaning of the mother's death. Clergy may be helpful in providing answers and comfort to the children. The website www.kidsource.com/sids/grief.html contains an essay, "The Grief of Children," (written by Susan Woolsey, Associate Director of Maryland SIDS Information and Counseling Project) that concisely describes children's common expressions of grief and suggests ways to help children. It is a good resource for parents and practitioners.

Helping Children to Cope with Their Mother's Cancer

The purpose of this session is to address the social, emotional, and physical needs of the patient's children. The focus is on helping the child(ren) deal with fears and concerns related to their mother's diagnosis, treatment, and treatment sequelae. This is accomplished mainly through discussion as a couple and suggestions from the clinician. An attempt should be made to view the child in the context of normal development, to make inferences about the child's understanding of illness, and to suggest what he or she needs given his or her developmental stage. The specific objectives for the following interventions are to

1. Assess the child(ren)'s social and emotional adjustment to the mother's cancer.
2. Provide information on developmental issues and a child's adjustment to a parent's illness.
3. Help the couple view the illness from the child's point of view.
4. Assist the couple in developing a common approach to their child(ren)'s fears and concerns.

Technique 9.1 Assessing the Impact of Illness on Children

Introductory Remarks "The purpose of this session is to discuss how your child(ren) is/are coping with their mother's cancer and how you, as parents, can help them deal with fears and concerns related to their mother's diagnosis, treatment, and treatment side effects. We will view each child according to what is normal development for his or her age. I'll begin by asking some

general questions about the cancer and your child's understanding of it. First, what are the ages of your child(ren)?"
[Note: The clinician may have already been given the answers to some of these questions during the initial assessment session and subsequent sessions. If this is the case, confirm the answers with the couple instead of repeating all of them.]

Questions for Parents (Children of All Ages)

(Be sure to ask *each partner* what they think)

1. "In what ways has the cancer affected your relationship with your child(ren)?"
   [Ask about the following areas: amount of closeness, time spent in play or recreational activities, the way discipline is handled (for younger children), amount of time you spend caring for them, the amount of support you give to them, and the amount of support you receive from them. If changes that have been mentioned are of concern to the parents, discuss them and problem solve around the concern.]
2. "How have the children been involved in the cancer experience?"
3. "What has your child been told about the cancer?"
   a. "How was he or she told?"
   b. "Do you use the word cancer?"
   c. "Are there areas that are difficult to talk about? If so, what are these areas?"

   Remind the parents of the following: "Whatever your children's ages, there are three things you need to tell them about your diagnosis (McCue, 1994):

   - How serious the illness is,
   - The *name* of the illness,
   - Your best understanding of what may happen in the future."

   [Remind them to try not to impose too much information on a child.]
4. "Has there been anybody important in your child's life who has had cancer (e.g., friend, classmate, teacher, relative, friend's parent)?"
   [If yes, probe for their child's reaction. Sometimes children will be using a prior experience with cancer as a reference point for their mother's cancer.]
5. "From whom do the child(ren) receive support? What were your expectations regarding support for your child(ren)? Have they been met?"

Technique 9.2 Assessing the Impact of Illness According to Developmental Stages

"Children respond to stress in a variety of ways, depending on their developmental level. Understanding reactions of children at various ages will help parents and professionals make good decisions about how to help youngsters. I would like to show you a chart that can be used as we discuss your child(ren)."
[Refer to Box 9.2: "When Children Need Help."]

"Let's look at the needs of your child(ren) at their ages and how stress is shown at each phase of development. I want to emphasize that the signs of stress are typical reactions. However, sometimes a child's symptoms are particularly severe or extend over a long period of time or interfere with a child's normal activities, such as school performance, interaction with friends. In those situations, professional help may be needed. If any of your child(ren)'s behaviors have created a problem, let's discuss what you have tried and what has worked or hasn't worked."
[If problems are identified, help the couple generate alternative approaches.]

Questions for Parents of Young Children (Younger than 13 Years)

1. "Has the treatment disrupted the child's daily structure? Who is there to help the child?"
2. "Since the diagnosis, have you noticed any changes in their developmental tasks such as toilet training, learning to walk or talk, attending daycare or school?"
3. "What is the child's coping style? Are you seeing any differences in behavior (especially younger children)? Do you have any concerns about how he or she is coping?"
4. "If school age, have people at school (teacher, principal) been told?"

Questions for Parents of Adolescent and Adult Children

1. "Has the cancer disrupted your daughter's or son's life? If so, how?"
2. "Does the adolescent feel comfortable talking about the site of the cancer, e.g., the breasts, uterus, ovaries?"
3. (If couple has a daughter) "Does your daughter(s) have worries about getting gynecological or breast cancer?"

If the clinician, along with the parents, feels that the children could benefit from help outside the family, provide the parents with a list of resources. Keep in mind the following three levels of help: (1) family and friends, (2) social context (school counselor, pastor, or rabbi), and (3) mental health professional (oncology social worker, psychologist, family therapist, support group).

Homework Assignment *For Parents of Younger Children (Toddler to School-Age):* "If you haven't already done this, I suggest that you find a quiet time with your child(ren) to read an age-appropriate children's book on coping with a parent's cancer. This activity offers the child an opportunity to ask questions and talk about their feelings. It may also help you to understand how the child is coping and the child's level of understanding of the illness." [Give them a copy of Box 9.3 which contains a list of children's books and other audiovisual resources].

> "Children can communicate their thoughts and feelings through play and drawings. Using puppets may be a good way to help a young child express how he or she is feeling about their mother's illness." [Box 9.4: provides other examples of how children express their feelings through play].

For Older Children and Young Adults: "With older children (older than 9 years), I suggest a family meeting as an opportunity to 'check in' with the children and to discuss how the cancer has affected their lives and how they are dealing with it. The meeting can be incorporated in another activity such as dinner, weekend brunch, etc. You can decide how you want to set up the meeting. Distractions should be eliminated as much as possible during the meeting, for example, don't answer the phone and turn off the TV."

You may begin the meeting by providing information about what to expect with the mother's treatment, such as its length, possible side effects, how she may feel, and what changes can be expected (e.g., more naps, more physical limitations, such as not being able to lift heavy objects, and so on). If these things have already been discussed with the children, you can give them an update on the treatment. Then, begin a discussion by asking the following questions:

"How have things changed for you since Mom got cancer?"
"Do you feel that you are receiving the support (or help) that you need to deal with it?"
"Do you have any concerns or worries?"
"Do you have any concerns about getting cancer?"

Case Illustrations

Doug and Kathy and Their Two Adolescent Sons

Kathy was in the middle of her course of chemotherapy when the social worker met with her husband and her to discuss concerns about their two teenage sons who were 18 and 21 years old. Kathy complained of constantly feeling nauseous and being tired of wearing a wig that was itchy all day. She worked as a fashion designer and looked very attractive even when she did not feel well. She claimed that this was a detriment because everyone assumed that she was feeling well and treated her as a well person. Kathy also had difficulty asking for help. Several times during the session she stated, “If you have to ask for help, it’s not worth it.”

These attitudes about coping and support also emerged as she described her relationships with her sons and how they were handling the cancer. First, she made an effort to protect and buffer her sons from the stress of the cancer. The older son had a history of depression and Kathy felt that he could not handle the news of her diagnosis. She called him “Mr. Pessimistic.” She also described him as very self-centered and inconsiderate of her situation, given that it was a very stressful time for her. To illustrate this, she reported that he did not do his own laundry even though she has asked him to do it several times. She complained that he added more stress to her life. The social worker was not sure whether this son was simply not interested in helping his mother or if he was unaware of his mother’s needs. Perhaps it was a combination of both things. Kathy thought that the son blamed himself for her cancer. She perceived that he felt some guilt over his own battle with depression, which might have created a lot of stress for her and might have led to her getting cancer. Although he was 21 years old, this son’s coping behaviors seemed in some ways more appropriate for an adolescent than a young adult.

Kathy described the younger son as being the “opposite” of the older son. He was very sensitive, supportive, and overall was a “great kid.” He was an outstanding student and played two varsity sports. He had been accepted at an Ivy League school for the coming fall. However, whereas the older son openly expressed his anxieties and worries, the younger son was withdrawn and very private. The social worker was concerned about this, because sometimes the quiet child—the so-called “perfect child”—is actually the one having the most difficulty coping with the diagnosis. In fact, his teachers noticed that he seemed disturbed and preoccupied in the classroom. Even his coaches noticed that his athletic performance was not “up to par.”

Kathy dominated the session, so the social worker had to make a concerted effort to bring Doug into the conversation. Doug stated that he was very disappointed in the older son’s reaction to his wife’s cancer. He felt that he was very self-centered and immature for his age, whereas the younger son was mature beyond his years. He stated that his wife’s illness had helped him to change his priorities regarding the children and work. He was now trying to give more time to them and less to his business. He wanted his sons to have a normal adolescence and encouraged them to go out with their friends and enjoy themselves.

When asked how involved their sons had been in the cancer experience, Kathy replied that they have not been very involved. Although both of them had offered to accompany her to the hospital for her treatments, she has never brought them with her because “it’s too scary.” Despite the ages of her sons, Kathy wanted to protect and buffer them from the cancer. But at the same time, shielding them did not allow the children to talk freely about the cancer experience or understand what she was going through. Several times Kathy stated that she did not want her children to remember her this way—as a mother with an illness. “I don’t want them to have bad memories." However, protecting them from bad memories may have been preventing them from dealing with the current realities of their mother's disease. The social worker concluded that it was probably difficult for the sons to talk openly about the cancer, to ask for emotional support, or to provide it.

At the end of the session, the social worker gave the couple a homework assignment of a family meeting. When looking over the questions to discuss with her sons at the meeting, Kathy said that she did not want to ask the question about her sons having any concerns about getting cancer. She said that she did not want them to think that inheriting cancer was a possibility or to worry about it. The social worker suggested that this concern may be on their minds already and that bringing it up may help them to deal with their fears and get accurate information. She also suggested that Kathy talk to her oncologist about the risk of cancer for her sons before deciding whether it is too frightening to discuss with them.

Although the focus of this intervention was on enhancing the communication between parents and children, it was clearly going to be a challenge for Doug and Kathy to engage in an open and honest discussion with their sons. In anticipating this, the social worker asked if there were other people that the sons could talk to about the cancer. The parents mentioned that the younger son was close to an uncle and that the uncle had already talked to him about the cancer. They said they would encourage the son to talk to him again. The older son had been seeing a psychiatrist to monitor his anti-depressant medication. Doug and Kathy agreed to encourage him to schedule an appointment with the psychiatrist to discuss the illness. The social worker mentioned that there were support groups for adolescents at the hospital in case their sons would be interested in attending. Since the older son was returning to college soon, the parents said they would find out if the university had cancer support groups for students.

John and Mary and Their Three Children (Pre-school and School Ages)

In this brief case illustration, the father had been minimally involved in the children's lives prior to his wife's cancer (except as the oldest daughter's basketball coach), but was now the primary parent to care for the children. It was a particularly stressful time in Mary's treatment. John and Mary had three children: a son (3 years old) and two daughters (8 and 10 years old). Mary reported that all three children were worried and afraid of what was happening to her. They also felt stressed out because their father was always angry with them. Their primary concern was who was going to do the "mommy" things. While John was trying his best to fill their mother's shoes, Mary stated that he just did not know the routine like she did—e.g., what they liked to eat, the clothes they wore, and the books they read. The level of stress had been very high because John tried to do all the childcare while he continued working full-time at a job that required him to work late into the evenings. He admitted that he had a short temper and yelled at the kids when they made requests that he could not fulfill. The time he spent with the children was very disappointing to him—the children were worried about their mother and angry that she was not there to take care of them. The cancer experience had provided John with the opportunity to connect with his children, but this had not quite happened. This family exemplifies a family that has to shift from a two-parent structure to a single-parent arrangement, with an added dependent family member—the illness itself (Rolland, 1994).

Each child had reacted in ways that were appropriate developmentally. The older daughter (10 years old) asked a lot of questions and, among the three children, had the best connection with her father, since he coached her basketball team. John and Mary expressed most concern about their younger daughter who was 8 years old. She was not as close to her father and had been spending a lot of time reading in her bedroom. She did not want to hear the word, "cancer." John and Mary were trying to connect her with another girl whose mother had cancer. The teachers at both daughters' schools were told about Mary's cancer so the school had become a stabilizing and a normalizing place for the girls. The 3-year-old son had been the most demanding of their attention. Although he had been toilet trained for several months, he had now regressed and gone back to wearing diapers.

The social worker suggested that the parents read age-appropriate books about cancer with the children. Mary stated that she had already read some books with the kids, but perhaps her husband should read some with the children, too. The couple brainstormed with the social worker around other ways the husband could build connections with the kids and transform the cancer experience into something positive for their relationship. The social worker also referred back to their list of family tasks to see if there were any tasks that could be delegated to other people or even eliminated for the time being. Since the daughters were not involved in any household chores, the parents decided that they were old enough to be assigned simple tasks like loading and unloading the dishwasher, sweeping the kitchen floor, and feeding and walking the dog.

What to Do if . . .

The Couple Wants to Hide the Cancer Diagnosis from Their Children

Some parents may not want to tell their child(ren) about the illness at all or avoid using the "cancer" word if they do tell them. Explore why they think the approach of being open would be inappropriate for their children. Discuss the meaning of the illness for the children and parents. If the couple does not know *how* to tell the child(ren), help them develop a way to tell the child that is age appropriate. Role playing the scenario with the practitioner (or other parent) will give the parents practice in explaining the illness to the child(ren). Remind the parents that children are often very perceptive and can feel when something is different in the family. This can lead to their children's own imaginations running wild and creating even worse thoughts.

The Couple Wants to Involve the Children in Age-Inappropriate Ways Such as Exposing Young Children to Medical Situations that May Be Too Overwhelming

Again, discuss with the couple the normal developmental needs of the child and what the appropriate responses are to those needs. Box 9.2 will help remind them of this important information.

When the Support Person Is Not a Partner

Naturally, the nature of the relationship that the support person has with the child(ren) is an important factor that will dictate to whom the therapist directs most of the discussion in session. In dyads the support person may have no role or minimal involvement and contact with the child(ren). In these instances, much of the focus of the discussion within the session will be with the mother. However, it is important that the support person is aware of the woman's goals for discussion with the child(ren) so that if they do have interactions with the child(ren), they discuss information in a manner and depth that is consistent with their mother's.

Sociocultural Considerations

Although these interventions were developed for practitioners working with two parents, many of the same issues and questions can be discussed with single parents and/or a support person. Single-parent families may be different, in that children often assume more of a caretaking role. The need for involvement by extended family members and by the parent's support network (friends, neighbors, co-workers, etc.) is more critical for single-parent families.

In working with low-income couples, the practitioner may also suggest seeking instrumental help within their communities. Churches, schools, community clinics, hospital social services, free programs sponsored by Public Health Departments, the American Cancer Society, Australian Cancer Society, or other non-profit organizations can all be of great assistance.

Since families come in many forms, there may be specific issues to address when working with blended families, single-parent families, or GLBT-headed (gay, lesbian, bisexual, transsexual) families. For blended families, the threat of loss may be even more intense for children. A child may have already experienced the loss of a parent through divorce or death, making the possibility of another loss much more stressful. Further, depending on the length and nature of the relationship with a step-parent, the new parent may not be able to replace the biological parent in terms of caregiving. The child may also feel less comfortable asking for help.

For GLBT families, issues of support outside the family need to be addressed. Does the family have a strong support network to rely on? If the well partner does not have legal parental rights, this may be a concern. What will be the consequences for the child if the legal parent dies?

Box 9.1 Telling Your Children About Cancer[1]

All children, all ages
Tell them these three things:

- How serious the illness is.
- The *name* of the illness.
- Your best understanding of what may happen in the future.

Pre-school age
Explain the disease on the child's level:

- Use dolls or puppets to help.
- Stay within the child's attention span.
- Keep within the child's ability to understand.

School age
Tell them three things, and keep telling them:

- Nothing they did caused the disease.
- They cannot catch the disease from you.
- Who will help with taking care of them—the things that mommy normally does.
- If possible, let them talk to the doctors and nurses and see when and how mom or dad will be treated.

Teen age

- Give detailed information; answer questions as completely as possible.
- Make sure there is someone outside the immediate family with whom they can talk on a continuing basis.

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[1] Reprinted with the permission of Kathleen McCue from *How to Help Children Through a Parent's Serious Illness,* K. McCue & R. Bonn, St. Martin's Press, 1994.

Box 9.2 When Children Need Help

	Normal needs	**Signs of stress**	**Ways parents can help**
Infants	Trusting relationships, consistent routine	Upset, fearful behavior, problems in eating or sleeping	Closely follow routine schedules of eating and sleeping. Encourage contact between ill mother and child
Toddlers	Parental guidance, opportunities to exert some control	Angry, acting-out behavior, loss of skills such as toileting, self-dressing, sleeping alone, magical thinking (e.g., they caused the cancer)	Continue with consistent discipline. Maintain routine regarding eating, sleeping, and playing. Reassure the child that he or she will not be abandoned
Pre-schoolers	Simple explanations for new or unexpected situations, identification of feeling	Sleeping, eating disturbance, exaggeration of fears and anxieties, being “too good,” quiet, withdrawn, clinging, baby-like behavior	Keep bedtime a calm time focused on child. Do not focus excessively on eating if the child’s eating habits change. Set aside time to talk. Encourage plenty of physical activity
School-age	Accurate information, reassurance about own health, clear rules and expectations	Worry and sadness, complaints of physical illness, anger, school problems, isolation, abnormal and continuing fears	Set aside time to talk and help them talk about what is bothering them. Encourage plenty of physical activity. Notify teachers and school counselors about the breast cancer
Adolescents	Privacy and respect, complete information and involvement in family decisions, strong peer relationships	Unusual hostility, defiance extreme mood swings, trouble with friends, withdrawn and significantly non-responsive, taking risks	Be open and honest about the cancer. Make sure school (teachers, guidance counselors, coaches, nurse) know what is going on. Give them concrete tasks to do. Schedule time to talk (e.g., dinner together, family meeting). Make sure they have a confidante (friend or family)

Source: Barbarin, O. A. (1988). *Childhood cancer project treatment manual*, University of Michigau, Ann Arbor.

Box 9.3 Resources for Parents with Cancer

Books

For professionals

Rudman, M.K., Gagne, K.D., Bernstein, J.E. (1994). *Books to help a child cope with separation & loss: An annotated bibliography*. (4th Ed.) Publisher: Libraries Unlimited.

For parents and caregivers

Brack, P. & Brack, B. (1990). *Moms don't get sick.* Aberdeen, South Dakota: Melius Publishing.
Harpham, W. S. (1997). *When a parent has cancer: A guide to caring for your children*.
LeShan, E. (1986). *When a parent is very sick*. Boston: Little, Brown & Co. (Joy Street Books).
McCue, K. and Bonn, R. (1994). *How to help children through a parent's serious illness*, New York: St. Martin's Press.
Runowicz, C. D., Petrek, J. A., & Gansler, T. S. *Women and cancer: A thorough and compassionate resource for patients and their families* (Available through the American Cancer Society).
Russell, N. *Can I still kiss you? Answering your children's questions.*
Heiney, S., Hermann, J., Bruss, K., & Fincannon, J. *Cancer in the family: Helping children cope with a parent's illness* (Available through the American Cancer Society).
Strauss, L. (1986). *What about me? A booklet for teenage children of cancer patients.* Cincinnati, OH: Cancer Family Care, Inc.
Weingarten, K. *The mother's voice: Strengthening intimacy in families.* New York: Harcourt Brace & Co. (for adult children).
Weingarten, K. *When someone in your family has cancer*. NIH, National Cancer Institute. (www.cancer.gov)

For adolescents

Brack, P., & Brack, B. (1990). *Mom's don't get sick.* Aberdeen, South Dakota: Melius Publishing.
Clifford, C. *Not now . . . I'm having a no hair day.*
Stauss, L. L & Rosen, R. *Coping when a parent has cancer.*
Vogel, C. *Will I get breast cancer? Questions and answers for teenage girls.*

For children

Blake, C. *The paper chain.*
Clifford, C. *Our family has cancer too!*
Ganz, P. & Scofield, T. *Life isn't always a day at the beach: A book for all children whose lives are affected by cancer.* (A workbook that helps children express their feelings and facilitates family communication)

Karu, Tyler. *Henry and the white wolf.*
Parkinson, Carolyn. *Mommy's in the hospital again*. Solace Publishing.
Saltzman, David. *The Jester has lost his jingle.* (www.jesterbook.com)
Steele, D. W., & King, H. E. *Kemo Shark* (www.kidscope.org)
Voirst, J. *Alexander and the terrible, horrible, no good very bad day*.
Kohlenberg, S. & Crow, L. (1993). *Sammy's mommy has cancer*, Magination Press.

Videos

For parents and caregivers
"Talking about your Cancer: A Parent's Guide to Helping Children Cope" (Fox Chase Center)
"We Can Cope: When a Parent Has Cancer" (Inflexxion)
"When Cancer Hits Home" (PBS Video)

For adolescents
"Hear How I Feel" (Northeastern Ontario Regional Cancer Centre)

For children (school age)
"My Mom has Breast Cancer: A Guide for Families," Kidscope (www.kidscope.org/video.htm)
"Kids Tell Kids," Cancervive Pharmacie Corp.

Websites
CancerSourcekids.com
http://www.cancersourcekids.com

KidsCope
http://www.kidscope.org

The Cancer Club
http://www.cancerclub.com

Talk About It! Support
www.talkaboutsupport.com/group/alt.support.cancer

National Breast Cancer Centre: My Parent's Cancer (for ages 13–19 years old)
www.myparentscancer.com.au

Box 9.4 Children's Play as Expressions of Their Feelings[1]

The following are examples of messages that children may send Through their play:

- *Signs of fear and anxiety*. Look especially for types of play that were not there before. Children who are worried about a parent's illness, particularly when surgery is involved, may begin to mutilate things, to tear up dolls, destroy toys or lego structures.
- *Fear of separation.* Toys such as a favorite doll may begin to disappear. When asked, "Why?" The response may be something like "She doesn't like me."
- *Anger*. Watch for new aggressive play, games of war and gangsters or a sudden interest in death and killing.
- *Death.* Listen to what they tell dolls, stuffed animals, or imaginary friends. In their play is someone sick? Is someone dying? Is someone never coming back.
- *Self-blame.* Are they blaming themselves for the cancer. "I have cancer, and now you're going to get it too." "You were a bad dolly, and now I'm sick—see."

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[1] Reprinted with the permission of Kathleen McCue from *How to Help Children Through a Parent's Serious Illness,* K. McCue & R. Bonn, St. Martin's Press, 1994.

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Christ, G., Siegel, K., Freund, B., Langosch, D., Hendersen, S., Sperber, D., et al. (1993). Impact of parental terminal cancer on latency-age children. *American Journal of Orthopsychiatry, 63*(3), 168–178.

Compas, B. E., Worsham, N. L., Ey, S., & Howell, D. C. (1996). When mom or dad has cancer: II. Coping, cognitive appraisals, and psychological distress in children of cancer patients, *Health Psychology,* 15, 167–175.

Compas, B. E., Worsham, N. L., Epping-Jordan, J. E., Grant, K. E., Mireault, G., Howell, D. C., et al. (1994). When mom or dad has cancer: Markers of psychological distress in cancer patients, spouses, and children. *Health Psychology, 13*(6), 507–515.

Erblich, J., Bovbjerg, D. H., & Valdimarsdottir, H. B. (2000). Looking forward and back: Distress among women at familial risk for breast cancer. *Annals of Behavioral Medicine, 22*, 53–59.

Faulkner, R. A., & Davey, M. (2002). Children and adolescents of cancer patients: The impact of cancer on the family. *The American Journal of Family Therapy, 30*, 63–72.

Hilton, B. A., & Gustavson, K. (2002). Shielding and being shielded: Children's perspectives on coping with their mother's cancer and chemotherapy. *Canadian Oncology Nursing Journal*, 12(4), 198–206.

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Kristjanson, L. J., Chalmers, K. I., & Woodgate, R. (2004). Information and support needs of adolescent children of women with breast cancer. *Oncology Nursing Forum, 31*, 111–119.

McCue, K. (1994). *How to help children through a parent's serious illness: Supportive, practical advice from a leading child life specialist.* New York: St. Martin's Griffin.

Northouse, L. L., Cracchiolo-Caraway, A., & Appel, G. P. (1991). Psychological consequences of breast cancer on partner and family. *Seminars in Oncology Nursing, 7*, 216–223.

Raveis, M. H., Karus, D., & Pretter, S. (1999). Correlates of anxiety among adult daughter caregivers to a parent with cancer. *Journal of Psychosocial Oncology, 17*, 1–26.

Raveis, V. H., Karus, D. G., & Siegel, K. (1998). Correlates of depressive symptomatology among adult daughter caregivers of a parent with cancer. *Cancer, 83*, 1652–1663.

Rittenberg, C. N. (1996). Helping children cope when a family member has cancer. *Supportive Care Cancer, 4*, 196–199.

Rolland, J. S. (1994). *Families, illness, and disability: An integrative treatment model*. NY: Basic Books.

Siegel, K., Plamara Mesagno, F., Karus, D., Christ, G., Banks, K., & Moynihan, R. (1992). Psychosocial adjustment of children with a terminally ill parent. *Journal of the American Academy for Child and Adolescent Psychiatry, 31*(2), 327–333.

Siegel, K., Raveis, V., Bettes, B., Plamara Mesagno, F., Christ, G., & Weinstein, L. (1990). Perceptions of parental competence while facing the death of a spouse. *American Journal of Orthopsychiatry, 60*(4), 567–576.

Veach, T. A., Nicholas, D. R., & Barton, M. A. (2002). *Cancer and the family life cycle: A practitioner's guide*. New York: Brunner-Routledge.

Welch, A. S., Wadsworth, M. E., & Compas, B. E. (1996). Adjustment of children and adolescents to parental cancer: Parents' and children's perspectives. *Cancer, 77*(7), 1409–1418.

Wellisch, D. K., Gritz, E. R., Schain, W., Wang, H. J., & Siau, J. (1991). P'sychological functioning of daughters of breast cancer patients: Part 1. Daughters and comparison subjects. *Psychosomatics, 32*, 324–336.

Zahlis, E. H. (2001). The child's worries about the mother's breast cancer: Sources of distress in school-age children. *Oncology Nursing Forum*, 28(6), 1019–1025.

Chapter 10
Living with Cancer After Treatment Ends

> *"I thought, ok, where do we go from here? Gwen had finished treatment and I guess we felt insecure about that. We kept wondering, are there things we should be doing?"*
>
> *"I often think about the other people I met while having treatment and wonder how they are doing."*
>
> *"I expected things to be back to normal straight away, and some things were. But it took about year after chemo finished before I could say my energy was completely back to normal. I used to get really tired in the first year, and that was frustrating."*

Most women and their loved ones experience a transition period after treatments end. They need to come to terms with their cancer experiences cognitively, emotionally, and physically. However, there is considerable variation among people in the duration, intensity, and nature of the transition period. The course of the disease certainly plays a large role in the type of challenges people are likely to face. Some women will enter a phase where they are disease-free and go on to become long-term cancer survivors. For other women the disease will progress or recur sometimes despite being free of symptoms for some time. This group of women often face another round of treatments, sometimes delivered with the aim of curing the recurrence. More commonly, recurrence involves concomitant spread of disease (called *metastases*) to distant anatomical sites. In such cases treatments aim to reduce the symptoms associated with disease progression. Recurrence is a poor prognostic sign. Life expectancy in advanced disease is less than 5 years, and in the case of terminal disease, less than 12 months (Lenhard & Osteen, 2001).

In this chapter we discuss the psychosocial issues of two phases of the cancer experience: first, the transition after cancer treatments have ended and second, when there is a recurrence and further treatments, if tried, have failed. We present several techniques intended to help couples in the first phase normalize their lives while living with the uncertainty of recurrence and the possibility of further treatment. We also describe how these techniques can be adapted, if appropriate, for couples in the second phase, when the couple is facing the woman's death. Our interventions Partners in Coping and CanCOPE focused primarily on living with cancer after successful treatment, as opposed to when the cancer becomes terminal. However, we recognize that when couples confront terminal illness, the situation presents difficult challenges to the clinician. There have been two published

K. Kayser, J.L. Scott, *Helping Couples Cope with Women's Cancers,*

randomized clinical trials (RCT) of couple-based interventions for couples facing terminal cancer (Kuijer, Buunk, De Jong, Ybema, & Sanderman, 2004; Northouse, Kershaw, Mood, & Shaughenacker, 2005). Both studies included couples coping with breast cancer and reported benefits for women's mood and caregivers' burden. In this chapter, the techniques pertaining to fostering couples' adjustment to terminal disease are informed by the results of these two RCTs and from our clinical experience in the field.

The Transition to Life After Cancer Treatments End

> *"I was impatient with myself and went back to work too early. I learned pretty quickly that was a mistake. I needed to be kinder to myself. . .pace things. . .instead of trying to do everything all at once."*
>
> *"We've re-evaluated our lives quite a bit. I retired so we could spend more time together. We travel a lot now . . . go to visit the kids . . . get out and see the world while we can. Joan's cancer taught us—you never know what's around the corner."*
>
> *"I went through a period where I felt I had another lump . . . well I wasn't sure about it. . . and Jack, my partner was worried too. It was a hard time waiting for test results to come back. We were both a bit on edge and snappy with each other to be honest."*

Return to Work and Social Activities

Women's return to previous social and vocational roles is variable. A recent, comprehensive review of the employment status of people after cancer treatments found that around 30% of survivors were not able to return to the jobs they had before cancer (Spelten, Sprangers, & Verbeek, 2002). Obstacles to recovery of role function involve discomfort in disclosing the cancer diagnosis to colleagues, and difficulty managing treatment-related side effects, such as pain, fatigue, or restricted mobility (Andrykowski, Cuuan, Lightner, 1998). Some of the concerns reported by women with breast cancer include uncertainty about the best time to resume activities, changes in career goals, and worry about financial security posed by unemployment or reduced income (Satariano, 1996). Women's financial concerns can be exacerbated by difficulty obtaining medical and life insurance following their diagnosis, a problem commonly encountered by cancer survivors (Ehrmann-Feldman, Spitzer, Del Greco, & Desmeules, 1987; Greaves-Otte et al., 1991).

This suggests that women's role functioning can be assisted by strategies that help them to pace the resuming of activities to match their energy levels, challenge unhelpful thoughts about return to work, and prioritize their personal and career goals. Working on communication skills that help women share their feelings about their goals and the kinds of support they need from the people around them should assist women in their role functioning.

The Existential Journey After Cancer

Confronting a potentially life-threatening illness such as cancer often leads people to re-evaluate important life priorities. The psychological sequelae that can follow an increased threat to mortality has been termed "existential plight" (Weisman & Worden, 1976). This experience is associated with a range of emotions, including uncertainty, vulnerability, a sense of alienation, and redefinition of the self and life goals (Halldorsdottir & Hamrin, 1996). The process of redefinition often involves a review of priorities, particularly those that relate to close relationships. This transition phase can entail challenges to the very essence of women's personal identity (Kayser & Sormanti, 2002; Little, Paul, Jordens, & Sayers, 2002). A large part of integrating their cancer experiences and coming to terms with life after cancer involves finding answers to the question "who am I now ?" (Redd et al., 2001). A common dilemma for women seems to be the degree to which being "a cancer survivor" defines their new self-identity (Little et al., 2002). The partners of women with cancer also experience existential difficulties which can contribute to reductions in perceived emotional closeness in the relationship (Friedman et al., 1988; Skerrett, 1998).

Clinical work that helps couples make sense of their cancer journey will also help them to integrate their experience into their overall sense of identity. Activities such as sharing thoughts and feelings with loved ones, or writing about them, have been shown to facilitate this process in people recovering from a range of traumatic events, including cancer (Kennedy-Moore & Watson, 2001; Zakowski, Ramati, Johnson, Morton, & Flanigan, 2004). However, for such activities to be effective, they must not merely be a venting of emotions, but also involve an analysis of their thoughts and feelings, so that they reach a deeper understanding of them (Kennedy-Moore & Watson, 2001). The cognitive techniques described in Chapters 5 and 8 can help women and their loved ones analyze their responses to their cancer experiences in this way.

Living with Ambiguity and Fears About Cancer Recurrence

Following the end of initial treatments, there are certainly no guarantees about recurrence. Of course, some women will have a much better prognosis than others. But all women and their loved ones face, to some degree, a sense of ambiguity about long-term survival. Women report being more hyper-vigilant to bodily symptoms that they fear might herald cancer recurrence (Polinsky, 1994). Women and their partners' level of nervousness often heighten around the time of medical checkups. They may find that certain things, like hearing about someone else's cancer diagnosis or seeing a story about cancer on television, catch them off guard. Fears and memories about their cancer experiences can be reawakened. Scanning one's world more closely for potential threats is a common and understandable phenomenon after traumatic event, perhaps driven by the assumption that "if something bad has happened to me once, it can happen again" (Foa, Ehlers, Clark, Tolin, & Orsillo, 1999). For cancer survivors these issues can persist for decades (Polinsky, 1994). An important skill for managing life after cancer, no matter how long that life might be, is to learn how to cope with uncertainties while living as fully and as possible.

Attempting to suppress thoughts about recurrence, unpleasant images, or memories of the cancer experience is a "Catch-22" or no-win situation. The more the person tries to remove unpleasant reflections from their conscious awareness, the more these thoughts rebound and intrude into their consciousness (Page, Locke, & Trio, 2005). Recent research suggests that cognitive therapies that include mindfulness (MBCT) or stress-reduction techniques (MBSR), or that are acceptance-based (ACT), might be helpful to people who cope with a range of physical and mental health problems, including cancer, and are managing the intrusive thoughts associated with these problems (Grossman, Niemann, Schmidt, & Walach, 2004; Smith, Richardson, Hoffman, & Karen Pilkington, 2005)

These approaches focus on the *process* of thinking, rather than targeting the content of specific thoughts (Hayes, Luoma, Bond, Masuda, Lillis, 2006). MBCT or ACT are sometimes called *meta-cognitive* approaches because they examine our "thinking about thinking." The clinician helps the person accept the fact that unpleasant thoughts that arise from events in their life are unavoidable; intrusive cancer-related thoughts are part and parcel of life after cancer. The clinician works with the person to reduce the power of these cognitions to upset them. They teach the person to not be fearful of these thoughts, but to habituate to them in a way that allows emotional disengagement (Teasdale et al., 2006). This is a technique similar to *prolonged exposure*, a method used in the treatment of phobias or posttraumatic stress disorder, whereby the person learns to confront the feared stimuli and to stay present in the feared situation until their anxiety levels decrease (Foa et al., 1999). Thus, the person coping with intrusive thoughts about cancer learns to notice them, but to not give them any special credence. In essence, the goal is to *not* fight the thoughts and actively try to change their content. Instead, the person accepts their presence (but not their premise) and lets these thoughts come and go through their stream of consciousness. Importantly, the approach is not about passive resignation to the flow of thoughts. Rather, the aim is to remove the debilitating impact of the intrusive thoughts, so that the person can strive toward valued goals and get on with their life.[1]

In this chapter, we describe a mindfulness-based cognitive therapy (MBCT) technique, used in the CanCOPE trial protocol (Scott et al., 2004). In the CanCOPE program, mindfulness-based cognitive strategies were taught to couples in later sessions of the therapy program. The technique was employed specifically to help people (usually the women) manage upsetting and frequent thoughts about cancer recurrence or death, thoughts that they had not been able to reduce using conventional

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[1] For information about nine randomized clinical trials (RCT) of MBCT or MBSR interventions, see Smith, Richardson, Hoffman Pilkington (2005). The research team of Antoni and colleagues (2006) has found that a traditional or convention CBT stress-reduction approach was effective for reducing intrusive cancer thoughts in women after breast cancer.

cognitive restructuring strategies. Intrusive thoughts about cancer recurrence may be particularly difficult for women to challenge because they face the harsh reality that there is no certainty to their situation; the cancer *may* come back. Hence, the MBCT skills not only build upon couples' broader knowledge of cognitive restructuring (covered in Chapter 5), but aim to help them accept and defuse intrusive thoughts about recurrence, rather than try to fight or change the content of the thoughts.

Finding Positives After Cancer

As we mentioned in Chapter 1, there can also be positive existential changes associated with the cancer experience—for the woman, her partner, and also for their relationship. In psychological literature these positive outcomes have been referred to by various names, including "benefit finding," "meaning making," "posttrauma growth," and "personal growth" (Helgeson, Reynolds, & Tomich, 2007; Stanton, Revenson, & Tennen, 2007). Just as medical variables, such as the type or extent of cancer treatment, do not predict distress after cancer, they also do not predict positive outcomes. Women and their loved ones, in the early stage of cancer as well as the terminal phase, report unexpected benefits and positive effects from their cancer experience.

For many couples, one of the benefits arising from their cancer experience is the positive impact it has had on their relationship. A recent study that followed the trajectory of recovery in 282 Canadian couples coping with breast cancer found that almost half the couples felt that cancer had brought them closer. The husbands in these couples reported showing more physical and emotional engagement with their wives during the illness experience. The men said they tended to look to their wives and follow their lead as to how to cope and were active in providing support during treatments (such as accompanying their wives to medical appointments) and their wives reported their partners showed them more physical affection (Dorval et al., 2005).

However, the relation between benefit finding and adjustment is not well understood. It seems to be dependent upon when the cancer patient's adjustment is being assessed in the course of their disease (Stanton et al., 2007). For example, in women with breast cancer, finding positive meaning in their experiences in the first few years post-diagnosis predicts positive affect, lower distress, and reduced depressive symptoms up to 5 years after diagnosis (Carver & Antoni, 2004). Similarly, Lewis (1989) found that meaning making predicted reduced anxiety and higher self-esteem in people diagnosed with advanced stage cancers. In contrast, when benefit finding is assessed earlier in the person's disease experience, it has been found to have either a negative relationship or no relationship with psychological adjustment to cancer (Tomich & Helgeson, 2004).

In summary, cognitive processes are not only important for the prevention of distress, but also for promoting positive outcomes after cancer. Strategies that seem particularly important for positive outcomes are those that help people develop realistic and balanced attitudes about their intrusive thoughts and that facilitate emotional processing of the meaning of their experiences. Techniques that help with cognitive processing, such as writing or talking about feelings, are useful for reducing distress when facing stressful life events (Lyubomirsky, Sousa, & Dickerhoof, 2006) and may encourage positive emotional states (Lepore & Smyth, 2002; Quartana, Laubmeier & Zakowski, 2006). Writing down positive thoughts and feelings about breast cancer has also been shown to reduce distress in women high in cognitive avoidance (Stanton et al., 2002).

When Couples Face Recurrence or Terminal Illness

> *"I couldn't believe it, I was in shock. . .I'd thought we were in the clear, that we had made it. . .for the cancer to come back after 7 years seemed so unfair."*
>
> *"She just found it so hard to face chemo again. She had a hard time with it the first time around and so the thought of going through it all again was really hard to take."*

Heightened Emotional Stress

The news that the cancer has returned or is spreading can trigger a more intense emotional response than that experienced after the initial diagnosis. Many couples feel disappointed and anxious about the prospect of undergoing treatments again, and struggle to prepare themselves psychologically (McClean & Jones, in press).

Couples coping with advanced and terminal disease also report a heightened need for communication and affection from their spouse (Leiber, Plumb, Gerstenzand & Holland, 1976; Walker, 1997). As we mentioned in Chapter 8, this may be due to the natural desire to defend oneself psychologically against life-threatening situations by seeking solace and protection in one's close personal relationships. Thus, the focus for many people is on strengthening and nurturing relationships with loved ones. For patients in particular, interpersonal concerns often exceed disease-related concerns, such as pain and symptom management (McLean & Jones, in press). As the disease progresses, some of the pressing issues a woman and her caregiver may want to discuss include the woman's wishes for her funeral arrangements, writing a will, saying good-byes, resolving relationship conflicts, and concerns about how dependents will adjust to the impending bereavement. These are sensitive issues that can provoke strong emotional responses. They can be difficult to broach and discuss effectively. Couples who are not confident in their ability to resolve them in a positive way are likely to avoid them. Avoidance, in turn, can mean women and their caregivers experience even greater distress in the terminal phase of the illness. Further, after the woman dies, loved ones may be that much less prepared to face the practical and emotional issues that arise in bereavement.

Challenges of Caregiving

While the terminal phase of the illness is inherently difficult for caregivers, the level of difficulty is intricately tied to the physical well-being of the patient. As the woman's functioning declines, caregiver burden increases (Coristine et al., 2003). Cancer that has metastasized can produce new symptoms due to the site of the disease. For example, a brain tumor may cause paralysis or difficulty swallowing. Generalized symptoms can also develop. These can arise from side effects of palliative treatments, the deterioration in women's bodily functions as the disease progresses, or a combination of these factors. Pain symptoms may increase or be difficult to manage (Murphy, Lawrence, & Lenhard, 1995). During the palliative phase the disease inexorably progresses. However, the length of time the woman experiences a relatively stable pattern of symptoms, before downturns in her general health occur, is unpredictable. These fluctuations in symptoms are unpredictable. The aim of medical care at this point is to manage the patient's pain and ensure dignity and comfort as death approaches.

A common challenge for the partners of women with advanced or terminal cancer is coming to terms with caregiving roles and responsibilities. Couples and families often face a period of adjustment as caregiving roles are absorbed into household routines. Partners often need to learn about a complex or demanding medical regime; this task is often made harder by the emotional stress they are under (Koocher & Pollin, 2001). The side effects of medications, such as constipation, mental confusion, or sedation, are often distressing not only for the women, but also for their loved ones. For the caregiver, it can be emotionally or psychologically overwhelming to witness their loved one in pain or deteriorating physically.

Impact on the Couple's Relationship

The distress that women and their loved ones face during this phase of the illness can be exacerbated by differences in each individual's comfort with the level of intimacy in their relationship. People's way of bonding with others (sometimes called *attachment style*) is thought to be formed from childhood relationships with significant others, and impacts their current intimate relationships (Bowlby, 1988). For example, people who feel confident and secure in their emotional connections with loved ones are highly responsive caregivers. People who have insecure or anxious attachments styles, by contrast, tend to be less competent caregivers and report high caregiving burden (Kim & Carver, in press; McLean & Jones, in press). As death draws near, differences between the patient and the caregiver in their attachment styles can lead to divergent views of the goals of palliative care and intensify the couple's distress. The dying woman may prefer measures aimed at improving her comfort over those designed to extend her life. A caregiving partner, who is insecure in his attachment, may focus instead on ways to maintain and prolong his emotional connection with his spouse. He may feel intense sadness and even rejection as the woman's mental alertness fades or she responds differently from the person he knew. He may want to delay or decrease pain medication because the sedating side effects impede the woman's ability to communicate with him (Jones, Huggins, Rydall & Rodin, 2003). Eventually, people's unmet need for intimacy may undermine their satisfaction with their relationship, placing an additional strain on their ability to cope with the terminal illness (Kirby, Baucom, & Peterman, 2005; McLean & Jones, in press).

In summary, the main issues confronting patients and their loved ones during the terminal phase of cancer revolve around intimacy and communication needs, and caregivers' efficacy in their roles. Providing couples with the opportunity to discuss sensitive topics in a private and emotionally safe environment is important. The supportive communication and shared cognitive coping techniques presented in Chapters 5 and 6 will help couples understand each other's emotions and enhance their ability to support each other in this difficult time. Further, some caregivers may benefit from cognitive strategies that help them acquire an understanding of the deeper emotions that the caregiving experience arouses in them. Expanding the level of practical and emotional support provided to the caregiver is likely to strengthen their reserves for coping with the burden of caregiving. Finally, women may benefit from relaxation techniques designed to manage pain and other symptoms.

Notes to the Clinician

The focus of this phase of treatment is on helping patients and their loved ones to integrate their cancer experiences into their life after cancer. Ideally, they will transform their experience in such a way that they grow from their connection to each other. Most of the techniques presented in this chapter encourage people to reflect on their journey and find meaning in their experiences. They need to contemplate and build a vision for their future lives. Such work takes time. In some instances, just as with personal growth in general, the work is likely to be ongoing and cumulative in its effects (Lecher, Carver, Antoni, Weaver, & Phillips, 2006). Hence, the clinician should view the techniques outlined here only as starting points for clients. Homework assignments are designed to help people define their goals and practice and develop skills for achieving them. It is likely that the clinician will work with the couple on these issues over several sessions. For people coping with terminal illness, sessions may be conducted in the couple's homes, depending upon the nature of the service delivery environment, or the workplace in which the clinician is practicing. In addressing these therapy goals, the clinician needs to be attentive to the timing of the session(s) related to this topic. Patients who have not yet completed their treatments are unlikely to be able to envisage life after cancer. For them, the session content would seem hypothetical and of remote concern. Similarly, people who have only recently been informed that there is recurrent disease are likely to feel upset and thrown back into crisis mode. They are unlikely to be able to engage in reflective tasks at this time. Further, the goals of sessions that focus on living with cancer aim to help couples develop realistic outlooks that balance hope for the future, with acceptance of things that perhaps cannot be changed.

Finally, in working with cancer survivors, the clinician's approach to therapy must take into consideration that the cancer experience is a part of their life story, but it is not their total story (Lecher et al., 2006; Manne et al., 2004). Consider the point in the life cycle of the couple's relationship that the cancer has occurred, and adapt techniques to suit the couple's, or family's, developmental needs (Koocher & Pollin, 2001). For example, there will be some overlap in the emotional meaning attached to thoughts about prognosis by elderly couples compared to younger couples with children. However, the different stages in the couples' relationship history will also produce distinct anxieties. The elderly couple, who have been together a long time, may view the cancer as taking them a step closer to the time when they will one day, inevitably, have to say good-bye to each other. The issues that concern them the most might be about expressing their deepest feelings for each other and ensuring the woman has the opportunity to say farewell to other loved ones. The young couple in contrast may worry more about their children and the impact the loss of their mother will have on them. They may be more concerned about preserving positive memories of the mother for their children and ensuring the children's adjustment to their loss.

Skills for Transition to Life After Cancer

This session will present a number of techniques designed to help the couple move from a pattern of adaptation which is crisis-oriented, to one which attempts to normalize their current situation. It involves the acceptance of the fact that life will never be *exactly* the same as it was before the diagnosis, but challenges them to define what a *normal* life will look like for them as a couple. Although medical treatment(s) may have ended, there are likely to be some emotional aspects of the experience to deal with.

There are four main techniques in this session (1) exploring common emotions after treatments end, (2) managing intrusive thoughts about recurrence, (3) resuming normal activities and setting short-term goals, and (4) sharing the positives and building goals for the future. The instructions are written for clinicians who are working with couples where the women have no sign of disease. However, we provide suggestions and techniques for couples coping with advanced or terminal illness at the end of each procedure.

Thus the objectives of these sessions are to help both partners:

1. Explore their reactions to this next phase of their cancer experience.
2. Identify cancer-related problems they are experiencing and help them devise strategies for coping with them.
3. Discuss the existential impact of cancer on their core beliefs and long-term life goals.

4. State the positive experiences they have had as individuals and as a couple, due to their cancer experience.
5. Explore the impact of their cancer experience on their relationship and identify strengths in their coping and support skills.

To implement these techniques, the clinician should bring pens and two copies for each partner of Box 5.2: Coping Self Talk Forms (p. 99).

Technique 10.1 Exploring Common Emotions After Treatments End

Introductory Remarks "I would like to explore with you how you have been feeling now that treatments have ended. This transition period is different for everyone. Sometimes people feel confused or surprised by their reactions to the finish of their treatment. They may feel mixed emotions, such as feeling relieved but also sad. Often, a bond has developed with people they met during treatments, and they can feel a sense of loss of that comradeship with other patients. They may feel insecure that treatments have ended, because while they were being treated they felt a sense of protection; that is, the cancer was being attacked and something was being done. In the same way both of you explored your feelings when diagnosed, understanding your reactions to this transition period can help you find ways to cope after treatments."

Step 1: Ask each person to identify any emotions that they find particularly hard to accept, or understand.

"People sometimes fear they are slipping back in their progress if their feelings are the same or similar to those they felt when they, or their loved one, were diagnosed. Feelings that are unexpected also make people worry they are not coping. Are there any feelings you have that you find surprising or unexpected, difficult to understand, or remind you of how you felt when you found out about the cancer?"

Step 2: If the person identifies such a feeling, help them to develop a deeper understanding of where this feeling might stem from.

"Think back to a situation when the emotion was particularly strong. What was going on in your mind? What were you thinking?"

Next, help them to complete a Coping Self Talk Form, using the same methods described in Chapter 5. Suggest to them useful alternative thoughts that other people have found helpful to move on and cope with the transition after cancer. Some examples of these include:

- I will talk to myself the way I would when encouraging and supporting a best friend.
- It might feel a little strange going back to everyday things like work or visiting friends, but soon these things will all feel familiar again.
- It is ok to think about my loved one's health, but not to worry. Worry does not achieve anything.
- After treatments, I can show myself the same consideration and understanding I would show someone I loved.

Step 3: Sometimes people's feelings in the transition phase arise from deep core beliefs or assumptions about the self or the world, which have been shattered or altered in some other way by their cancer experience. If there seems to be a theme to the person's emotions after cancer that involve thoughts that they find particularly hard to challenge, then these might stem from deeper core beliefs. In this case, the clinician should use the same *Downward Arrow Technique*, described in Chapter 5, to help the person and their partner to understand the origin of these strong emotions. Bear in mind though, if the persistent thoughts are predominately about fears of cancer recurrence, then we suggest these particularly cluster of thoughts are better managed using a mindfulness approach, whereby their content is *not* actively challenged. Technique 10.2, Managing Intrusive Thoughts About Recurrence, describes this process.

Adapting Technique 10.1 to End-Stage or Terminal Cancer The common reactions that couples experience when they are first told the cancer has recurred or is spreading can include sadness, fear, disappointment, anger, anticipatory grief, and desperation to find a cure. Often these emotions are experienced more intensely than when the person was first diagnosed. Technique 10.1 can be used to explore the couple's reactions. However, the helpful thoughts that couples generate on their Coping Self Talk Forms need to focus on acceptance of the situation, while still retaining hope. The aim is for the couple to make the most out of life, to have a full life without the news overwhelming the quality of the time remaining.

It is understandable the people coping with terminal illness will have thoughts about cancer progression and death. The fact remains, though that news of recurrence does not tell a person how long they will live or how they will die. Often a couple's most distressing thoughts involve catastrophizing the events associated with the "what" and the "when" of the impending death.

Some worries that require the clinician's attention are:

- The pain will not be manageable.
- Loved ones will utterly and permanently "fall apart."
- The news is a death sentence justifying inaction, waiting and worrying, rather than living.

- The patient's care puts a huge burden on loved ones.
- Life has been a failure—failed dreams, hurts caused on loved ones, injustices experienced, etc.

These concerns are understandable, and some worries arise, in part, from lack of knowledge about palliative care services and facilities that can support the patient and the carer. Couples may therefore imagine that they will face the terminal care phase in isolation from medical and/or nursing services. Provision of information about palliative care services and referral to such agencies can help allay some fears.

Technique 10.2 Managing Intrusive Thoughts About Recurrence

In some cases intrusive thoughts about recurrence and/or death are very frequent and the person has not been successful in challenging them using conventional cognitive-behavioral (CBT) techniques. In these instances mindfulness-based cognitive therapy (MBCT) may be more useful for assisting women and loved ones to live full and happy lives.

Introductory Remarks "Being a cancer survivor or someone who has supported a woman through her cancer experience can take some getting used to. Cancer reminds people of their mortality. Most of us avoid thinking about death, and live with an illusion that life goes on forever. People often feel vulnerable after a situation where their life has been threatened. Events like cancer, or other stressful situations like a car accident or a violent crime, can give a person an increased sense of life being fragile or short, and an awareness of their vulnerability. These can be strange or disturbing feelings. If a person does not know how to manage these fears they can start to feel emotionally drained and tense. Learning to accept and manage fears of the cancer returning, that sometimes arise, helps a person to move on and enjoy life after cancer.

Some persistent thoughts about recurrence may be resistant to change and may be part-and-parcel of having had cancer. It may be more useful in the long term to let them come and go, rather than actively trying to change them. The more you try to *fight* them, the stronger they will get. A better way to manage them might be to recognize that they are just thoughts, they do not have power, and do not deserve special attention—let them come and go. Notice these thoughts for what they are—'my cancer worry'—and the let them drift through your consciousness."

Step 1: Explore with the person who is experiencing the intrusive thoughts (usually the woman) their feelings about trying this technique.

"Sometimes unhelpful thoughts about coping make women fearful of trying this technique. For example, some women may hold the superstitious belief that talking about 'recurrence', will make it come true. Do you have any reservations about trying this technique?"

Gently help the woman to challenge negative thoughts about the impact that this technique will have on her overall coping or on her disease outcomes.

Step 2: Give the woman the following instructions about the technique, saying:

- Do not try to block out your fearful thoughts. Do not fear them, they are just thoughts. In fact, try welcoming them as an opportunity to practice letting them come and go.
- When you notice the thoughts say to yourself "these are just 'fear' thoughts," "I can let them come and go," "thoughts are just thoughts, they don't make things real." Then move on.
- Just because you have a particular thought, does not make the content a *truth*. Thinking these thoughts does not mean that they *will* happen or that they *will not* happen. They just are.

Step 3: Next, have the person practice noticing the thoughts, and even noticing the language they use to describe these thoughts. The idea is similar to prolonged exposure techniques used in treatment of PTSD, except that the person is exposed to a feared thought or imagined event that they have been trying to avoid, rather than a feared situation. Humor can be a useful means of defusing thoughts, such as the cancer patient who stated:

> "I used to have these pictures pop into my head. They were like a melodramatic B grade movie. I'd see my own funeral . . .everyone crying. . .it would really upset me. But then I learned to say 'hey they're just thoughts, they're not reality'. Now I can just say to myself – 'seen that movie before, it's boring with bad acting!' – and I don't waste my time with it"

She was able to label her once powerful and upsetting thoughts as her B grade movie. She felt this label also allowed her to laugh at and detach from them.

Say to the person "what often happens when we have these upsetting thoughts is that we mentally turn away, we cast our mind's eye to the side; we dare not look at these thoughts. That's what gives these thoughts the power.

What we are going to do today is to look at the thoughts fully in the face and recognize them as just thoughts and nothing more."

Step 4: Practice these methods of *thinking* about her thinking in the session by reading her the following instructions:

This exercise is quick and easy to do. It helps you to notice your recurrent anxious or upsetting thoughts, and to not fear them, but to let them come and go.

> Close your eyes, and feel yourself sitting comfortably in the chair,
>
> You might notice the sounds in the room, your own breathing. This is Ok.
>
> Breathe in deeply and slowly, counting to 4.
> Then breath out slowly, counting to 4.
>
> Breathe in slowly, counting to 4, then hold your breath for 2 seconds.
>
> Breathe out slowly, counting to 4.
>
> The next time you breath in, I want you to imagine you are in your favorite place, relaxing comfortably.
>
> It may be a place from your daydreams, or a favorite holiday spot.
> But once you have that image—make it as strong as you can.
>
> Hold that image, breathing in the same relaxed, calm way.
>
> Look around you in your safe place. Tell yourself you can come here whenever you want to. This is your safe place, you can feel relaxed and calm here.
>
> In this safe place you can also practice calling in your intrusive scary thoughts, meeting them, watch them traveling by.
>
> But you can also notice other thoughts, random thoughts. Notice them all drift above you, or around you, in your safe place.
>
> Practice noticing all your thoughts—thoughts about what I am saying—thoughts that are about cancer recurrence—thoughts that are about thoughts—thoughts that are about not thinking.
>
> Begin to feel the rhythm of your thoughts while you stay in your special and relaxed place. Just notice them all as they come and go.
>
> When you feel relaxed, begin to notice your pleasant happy place in more detail, make it as vivid as you can.
>
> Notice your breathing and when you are ready, open your eyes.
>
> © J. L. Scott, 1999.

Assignment and Planning Ask the person to practice the techniques and suggestions for homework by saying:

"Remember this takes practice—the idea is not to be good at *getting rid* of these thoughts, but to accept them as background noise in our subconscious, as thoughts that have no power to upset us. One way to do this is to practice letting the thoughts come and go in our mind."

Ask the person to practice twice a week, for about 20 minutes, watching the intrusive thoughts coming and going in their mind. They should pick a time in the day for their practice sessions when they would normally be feeling their best; not a time when they find they normally worry more, such as lying in bed at night. The underlying clinical idea is that they are being given permission to conjure up these thoughts, but in a context of a mood that is incongruent with the mood the thoughts would normally evoke when they come unbidden. When checking on progress with homework, remember, the aim is not for the thoughts to be *less* frequent, but to lose their power to upset the person.

Adapting MBCT Techniques to End-Stage Cancer Some people interpret the news of the return or spread of the cancer as confirmation of their worst nightmare, something they have been dreading all along. For them the feared thoughts *do* have power. It is understandable that they may feel plagued by intrusive thoughts about their death, or about their loved one's death. But it is ultimately pointless for them to ponder such thoughts. No amount of worry will provide them with an answer of when, and how, they will die. The same mindfulness techniques as described in Technique 10.2 can help them cope with their intrusive thoughts and *live* with cancer, rather than *exist* in limbo.

Technique 10.3 Resuming Normal Activities

Introductory Remarks "When treatments finish many women are eager to return to normal routines. There are no hard and fast rules for how quickly this should happen. Each person is different. Often, routines involving medical matters have become normal in a person's life. When treatment finishes, things seem less predictable. It can take time for pre-cancer activities to become familiar again. For example, returning to work or seeing friends again after a break can feel oddly unfamiliar. Some people experience problems with reduced stamina after treatments, take on too much too soon, and feel tired. Another common difficulty for women is to overlook the progress they have made. They focus only on things they have not been able to resume, and overlook the things they have returned to. They start to feel that their progress is slow and feel frustrated or disappointed. The focus of this session is to help people reintroduce activities in a way that is balanced, manageable, and rewarding.

Reintroducing or maintaining valued activities in your life is a skill. The best way to be fair to yourself after treatments is to plan the gradual re-introduction of activities. It is important that you pace yourself so that emotional and physical demands are manageable. Be patient with yourself. Set reasonable and manageable goals and monitor your progress. Recognize your gains, no matter how small they seem. Reward and praise yourself when you achieve a task you have set yourself."

Step 1: Ask each partner to complete the 'Activities Plan Worksheet' (Handout 10.2). Say to the dyad
"This technique will help you to reintroduce activities into your life. Your spouse or partner may feel uncertain about your goals and the best ways to help you achieve them. One way to guide them is to go through the activities plan together."

Step 2: The clinician should help each partner think about the steps involved in doing the activities they listed on their worksheet. For example, starting back to full-time work can be emotionally and physically challenging. Some women feel out of touch with things or anxious about seeing colleagues again. Many women are unsure how their work will affect them physically. Help the woman consider her physical abilities, such as mobility, stamina, and strength. Are there ways they can break the tasks down into manageable steps? Some steps to suggest to them include

- Talking on the phone to colleagues.
- Visiting with work colleagues at morning tea time or at coffee breaks.
- Speak with the boss about ways job roles might be temporarily adjusted to suit your physical capabilities.
- Some colleagues might be uncertain as to how to behave on your return. Speak frequently to colleagues with whom you will be interacting a lot. Give them a hint about what type of support you would find helpful.
- If possible, work one or two half-days, build up to one or two full days, and then try a full week.

Step 3: Help the couple manage negative thoughts that might hamper their progress with reintroducing activities successfully. Common unhelpful thoughts concern their fears about other peoples' reactions to their return, holding high standards for their performance, and being overly critical about their rate of recovery. Help the person challenge these negative thoughts using the Coping Self Talk Form and the techniques described in Chapter 5. They might also find it productive to look over Handout 10.3 'Helpful Thoughts for Activities Planning.'

Assignment Planning Ask the woman to place the "Activities Plan Worksheet" some place where it is accessible to her and her spouse/partner. Sometime during the week, complete the worksheet.

"Pick one or two steps toward your goals that you can reasonably attempt in the next week. Write these steps down on your worksheet. Place a check next to activities after you have completed them. Remember to praise and reward yourself for the things you achieve—even the small things count. Remind your spouse/partner to acknowledge your achievements, if they forget."

Adapting Technique 10.3 to End-Stage or Terminal Disease This technique should be equally useful for couples coping with advance or terminal illness. However, the focus will be slightly different. For women it may be about finding ways to keep treasured activities in their lives for as long as they are physically capable. The clinician should help them to problem-solve on how to pace activities, and to match their activity to the times of the day when their energy levels are best, or when their pain is relatively low. Patients often know the pattern of fluctuations in their energy across the day. Ask the women, "Are there particular times of the day where you notice your energy is better, (or you pain) is less problematic?" The activities that people may be trying to accomplish may seem mundane to the casual observer, but for the patient or their caregiver may hold great personal significance. For example, being able to sit at a dinner table to eat a meal may signify to the woman that she is still capable of some independence and be a source of self-esteem. For the caregiver, this activity might signify a sense of normality in his life, which otherwise feels overwhelmed with unfamiliar routines, such as nursing and caregiving activities. For many couples, planning activities is a balancing act between striving for goals and knowing when to accept that goals are now unattainable. It can be hard to know when to let go of them and move on. Helping couples find this balance is challenging, but one solution is to redefine the scale and scope of the activities that they are striving to maintain. Here is how this can unfold in therapy.

Case Illustration

Peter (77) and Louisa (73) had been married almost 50 years. Louisa's endometrial cancer had spread to her liver and she was becoming increasingly weak and fragile. During the session they expressed their sadness about the recent loss of a valued ritual.

Louisa	I felt sad this week because I realized I will not be able to go to the coffee bar at our local shopping center with John anymore. That part of my life is lost. I just can't—I feel too ill, it takes too much out of me now
Peter	Yes, we had to turn around and come home last time. It is a real shame as we loved our little place (turns to Louisa), didn't we. (Looks back at therapist) She's been quite down about it really.

Louisa Well, I don't want to make a big deal about it, it's such a silly thing—it's just I looked forward to that little trip together

Therapist Louisa, it sounds like the coffee outing meant more to you than just a chance to have coffee. Describe for Peter and me what was important for you about that trip. Help us understand what it meant for you

Louisa I guess it was our special time together—I'm usually in our bedroom with all my medical stuff around me—Going to our coffee place . . . I felt more normal. We used to call it "our date". . . It was our special treat time. . . I looked forward to it I guess.

Therapist What ways can we think of to make having coffee together at home your special time?

Peter (turns to Louisa) well you know love, we have your mum's china tea-cups you inherited. . .we never use them because we're always scared of breaking them, and that's a waste really "cause they are really lovely".

Louisa Well that is right, they're just sitting there

Peter I can get those out for us—we can have our own little tea party sweet heart, probably be quieter than the shopping center too—without all that elevator type music playing

Louisa You're such a romantic old softy aren't you—having a tea party with your girl

Therapist This sounds like a good idea. I also suggest Peter that you set the tea party up in a place in the house where you don't do nursing care activities—so that the environment also feels special for you both.

Peter Our sun room is ideal—I can make sure there is a clear path through our lounge room so Louisa can get there on her walking frame. I can set it up to look nice too

Louisa I have nice embroidered table cloth we can use to put on that old coffee table too

Therapist Ok, so how's this for really hard homework. . .I am going to ask you to have a tea party together on the day you would normally have gone out

Technique 10.4 Sharing the Positives and Building Goals for the Future

This technique is about helping people to explore any positives that have come from their cancer experience and build on them for the future. The practitioner explains that when a couple faces a serious illness, it often causes them, at some point, to review their life and where they are going. The practitioner should facilitate a discussion with the couple around this theme. An objective is for them to articulate how the cancer experience has affected their lives, or core beliefs, and what remains important to them. Some times the cancer experience reaffirms things that were already important to them, other times it gives them new insights.

Introductory Remarks “Through their cancer experiences people often identify some positive things they have learned or rediscovered. For some, their experiences have been a journey of personal growth. For others, their experiences remind them of the things in life they value or hold dear.

Moving on after cancer is about adjusting to experiences and changes. All changes in a person’s life, even positive ones, take some getting used to. Someone’s experiences and memories become part of what makes them who they are as a person. To move forward, it helps to be able to look back and understand your experiences with cancer. Identifying positive aspects of your experiences can help make the process of recovery smoother and helps you come to terms with who you are now.”

Step 1: Now review these issues with both individuals in a more structured way by having each partner write down some of these positives. Handout 10.4 can be useful in helping them do this.

Step 2: Now help the couple identify the positive experiences and skills associated with their cancer experience that they would like to keep in their lives. Help them to identify how their experiences have influenced their planning or goals for their future, as a couple and individually. Instruct each partner to put their personal coping goals into perspective by completing Handout 10.5 ‘Looking at the Bigger Picture.’ An example of goals from one young woman following treatment for breast cancer included:

> I’d like to be a more confident person, try different things that are new for me.
> “I also think my experience has taught me patience, so I’d like that to stay with me, be more understanding of others”.

Goals for her and her partner included:

> I’d like us to remain close, spend more time together,
> I think we share a special bond, this has brought us even closer.
> To know we can come through this together will make us feel strong.

Adapting Technique 10.4 for End-Stage or Terminal Illness Step 1 of this section is appropriate for people coping with end-stage or terminal illness. However, Step 2 and the Bigger Picture Form are not suitable as the 5-year goals are likely to be asking women to think beyond their probable life expectancies. For partners this projection task would also be painful.

At this stage, an important task is to mobilize practical and emotional support and respite for the caregiver. One way to help couples do this is by reviewing their social networks using the genogram that was drawn with the couple during the assessment session (see Chapter 5). The genogram helps couples identify people who potentially are able to provide support and helps them identify any obstacles to their seeking support. Sometimes people hold unhelpful thoughts (e.g., "I am being a burden") or core beliefs (e.g., "If someone really loves you they should instinctively know what to do") that stop them from seeking potentially helpful sources of support.

Case Illustration

Jessica (42) and Chris (44) have been married 8 years and have a son Nicolas (5). Jessica has been diagnosed with ovarian cancer and has undergone a hysterectomy and chemotherapy. She has been away from work for almost 8 months while undergoing treatments. As treatments drew to a close she began looking forward to getting back to work, saying that this represented "normality" for her. Chris stated that work had always been important to Jessica and that "before cancer you could not get her to slow down." However, Jessica was surprised to find that upon returning to work, her job was not the source of enjoyment she had imagined it would be. Instead she felt "different" and "not as close" to the people she worked with anymore. She was surprised by the subtle ways she had changed after cancer. She felt "less willing to put up with moaners and idle gossip now. I think, 'just get on with it and focus on important things'." Jessica worried that this meant the cancer experience had made her "hard and uncaring."

Chris' reactions to life after cancer were similar to Jessica's in that he said he felt less obliged to be "the person who always volunteers for things at work." He said he felt he wanted to spend more time with Jessica and Nicolas and "not work the incredibly long hours" he did before Jessica was diagnosed.

The therapist worked with Jessica and Chris to explore Jessica's thoughts about her job, using the Coping Self Talk Form. Through this process Jessica and Chris began to realize that the notion of "being back to work" held a deeper meaning for Jessica, that it had come to represent being back to exactly the person she was before cancer. She had thought that once she was back at work she would have been able to put cancer completely behind her, as though it had never happened. Instead, seeing her colleagues chatting together as they always had, only served to remind Jessica that she was different now. Her values and the things she wanted to spend time doing and talking about were different after cancer. Jessica worked with the therapist to explore these thoughts. She also began to keep a diary where she records her thoughts and feelings about her cancer experience. In sessions, she shared her feelings with Chris and her therapist. With time she came to realize that cancer did not have to be blocked from her memory for her to get on with her life. She also discovered that she was writing about positive things that had come out of her cancer experience, like the fact that she felt closer to Chris. She said she felt "proud" of how they had coped as a couple. She said that she came to accept that cancer was a part of her life story.

Jessica felt this process was also helping her to see herself with less critical eyes. She realized that cancer had not made her a hard person. In fact in some ways she felt more compassionate about others' problems. Through the goal setting exercise she identified that she would like to try to give something back to people who were struggling in society. She took up a volunteer role one afternoon a week as a helper at a respite care center for disabled children.

In analyzing his thoughts after cancer, Chris came to realize that before cancer, a great deal of his sense of self-worth and confidence had stemmed from his work. He felt one of the positives from his cancer experience was "seeing that work did not make me a good husband and father." He felt he was a better partner after cancer because he now realized the importance of sharing the emotional journey with his spouse. He felt he was a better parent as well and had come to realize just how much he enjoyed having more time with his son, "do all the little things." Chris said he felt proud of how they had coped as a family and that he did not want to lose that by "getting back into over-work routines."

Jessica and Chris also started to embrace the changes in personal goals and priorities that they had both experienced as a result of cancer. They stated "cancer has helped both of us to get a better balance of work and play in our lives." They started to work toward new goals they had as a couple, such as a family holiday to visit out-of-state relatives and more frequent family outings.

What to Do if . . .

Partners Allude to Sensitive Topics, but Do Not Openly Discuss Them

Clinicians need to manage these discussions with compassion and in a way that does not strip couples of protective psychological mechanisms such as hope (Mohr et al., 2003). Sometimes partners and families talk quite openly about important issues, but one person will refer to the impending death in a hypothetical way. This may be a psychological protection. As long as this coping strategy does not interfere with people being able to discuss important issues, stripping the person of this protection is unnecessary.

There are no hard and fast rules about how, and when, to begin a discussion about a poor prognosis and what it means for each person. The therapist must use his or her clinical judgment to decide when the time is right. Sometimes people will allude to the topic, but not speak about it openly. One way for the clinician to introduce the topic is to model open communication and to normalize feelings associated with talking about death. The following is an example:

Many people feel uncertain about when and how to raise sensitive topics to discuss. Sometimes people make a vague reference to sensitive topics but feel uncertain as to how to take the discussion further. Common topics that people find hard to broach are wills, funeral arrangements, sharing feelings about each other and what they mean to each other, or resolving past hurts in relationships. Open, supportive communication about these sensitive topics is important for coping, not only in the present but also during bereavement. That is not to say that conversations have to be about these topics all the time. But it is important that couples and families have an opportunity for such discussions. Part of my role is to help families start the conversation and take the opportunity to discuss important and sensitive topics.

The clinician needs to be mindful that pursuing such discussions is also a balancing act between what would be therapeutically ideal to achieve and what is realistic in the time the woman has left. Be mindful of the depth of psychological healing that old wounds may require before partners and family members can come to terms with issues. Decisions about the pacing of therapeutic goals for family communication need to be based upon a realistic and empathic understanding of the cost and benefits associated with opening old wounds for discussion if there is not time enough time to heal them.

The Woman Diagnosed with End-Stage Disease and Her Partner Hold Different Expectations About Prognosis and Survival

It is the physician's role to communicate medical facts about the prognosis, not the clinician's. However, the meaning that each person attributes to this information often does need to be discussed with the clinician. Different expectations have implications for their mutually supportive behaviors and their psychological adjustment. In our clinical experience, the objective signs of disease progression reach a point where there is no denying the inevitable. However, discussion about death or other sensitive topics should be encouraged before the disease progression and pain medication significantly impair the patient's cognitive functioning. The patient's active involvement in decision-making takes the pressure off the caregiver to make these decisions on their own at some later point.

The Therapist Becomes Distressed

Palliative care issues usually challenge the clinician to cope with a heightened sense of their own mortality. The clinician often feels very close to couples and is saddened when the woman dies. Often, "practicing what one preaches" and engaging in stress management and helpful self-talk can help clinicians manage strong emotions associated with their work.

Palliative care counseling is not for everyone. The beginning clinician will be challenged in making clinical decisions and facilitating discussions. Some clinicians are not always comfortable working in palliative care. If a clinician is going through a particularly stressful time in their own lives, particularly one involving terminal illness of a loved one or bereavement, then working in this area becomes especially difficult and respite from the work is advisable. In this case the clinician may decide that referring the couple or family to a professional who specializes in palliative care counseling is preferable to him/her undertaking the role.

The Woman's Cognitive Deterioration Prevents Her from Giving Emotional Support to Her Partner

There are two strategies that are useful in this situation. One, the therapist might help the caregiver to identify a key person from within their social network who they can confide in and receive emotional support from. Second, the caregiver could keep a diary of his/her thoughts and feelings, which could then be analyzed in an individual session with the clinician.

When the Support Person Is Not a Partner

Most of the mutual support and coping skills described in this chapter are also applicable to other types of dyadic relationships. However, the clinician needs to adapt them to match the natural roles and levels of emotional intimacy in the dyadic relationship. For example, a mother–daughter dyad may be quite comfortable with support interactions that involve provision of nursing or practical support. In contrast, provision of some practical support, such as helping with toileting and showering, is something that some dyads will not engage in. Non–spouse dyads, particularly those where the members of the dyad are not related, may find these tasks more uncomfortable to discuss and negotiate, and more disturbing to perform, than spouse–patient dyads. This may be because the tasks breach boundaries applied to privacy when undressed, or when carrying out bodily functions, that exist between friends but are less rigid in spousal relationships (Coristine et al., 2003).

Handout 10.1 Useful Ways to Manage Cancer Fears

Put your fears into perspective. It is natural to have thoughts about "what if." They are very common after cancer and they are to be expected.

Change your train of thought and think of pleasant things. Do pleasant things to give your mind nice things to think about.

If you find yourself imaging frightening scenes, stop the image. Practice imagining positive and pleasant images.

Plan a special reward or treat for yourself on anniversary or checkup dates so that you have something nice to look forward to.

Practice relaxation exercises in the days before a follow-up appointment. This helps control feelings of irritability or anxiety.

Share your fears and concerns with your support person. Ask them to help you identify and challenge any negative or unhelpful thoughts you have about the impending event.

Do things that you find enjoyable. This helps you distract your thoughts and think of pleasant things.

It is also important to accept that some feelings of anxiety are to be expected. Remind yourself that once the event (news report, medical checkup) is finished, your feelings will return to normal.

Handout 10.2 Activities Plan Worksheet

1) Make a list of activities or tasks you would like to reintroduce gradually or to keep in your life.

Some activities other women wrote on their Activities Plan Worksheets are:
driving, hanging washing on the line, grocery shopping, sporting activities, looking after grandchildren, exercise classes, returning to work, gardening, study, resuming roles in social clubs or other organizations, vacuuming, walking.

Some activities partner and other support persons wrote on their Activities Plan Worksheets are: sporting activities, looking after grandchildren, exercise classes, returning to work, gardening, study, resuming roles in social clubs or other organizations.

Write down the activities you would like to begin or return to.

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2) Check √ those activities you wish to start first.

Handout 10.3 Helpful Thoughts for Activities Planning

I can take it one day at a time. I will take it slowly and gradually to get back to my routines.

Having a day when I feel a bit down does not mean I am coping poorly. Everyone has days when things do not go exactly as they would have liked.

To feel good about myself I can do nice things for myself. Give myself a little treat.

Healing takes time, but it does happen.

Feeling a bit tired or run down is understandable after what I have been through. I need to let my body heal.
There is no point in being impatient. My energy will gradually return.
I do not need to do everything I want to do straight away. I need to give myself time to get back my strength.
I am doing better than I was. Improvement may be slow but it is happening.

Handout 10.4 Some Benefits from My Cancer Experience

Some examples of the positive things that other people have learned or rediscovered through their cancer experiences are:

- Learning more about themselves
- Becoming closer to their support person
- Realizing personal or inner strengths
- Greater appreciation for the little things in life
- Being more spontaneous, doing the things they want to do
- Finding new priorities and goals
- Reminded of the value of relationships with friends and family
- Greater involvement in their own health care
- Reminded that others care about them
- Becoming more assertive or confident
- Learning how to communicate with medical professionals
- Less worried about minor irritations in life
- More understanding or empathy for other people's experiences

Write down the positive things you have learned through your experiences.

Positive aspects of my cancer experience

Handout 10.5 Looking at the Bigger Picture

Imagine yourself 5 years from now. Cancer treatments finished a long time ago. Ask yourself.

- If I have coped with my experiences with cancer in the way that I desire, what will I be like as a person in 5 years from now?

- In what ways will I be the same person as I am now? In what ways might I be different?
- Are my current ways of coping helping me to travel my journey in the way I would like?

The personal qualities and coping skills I would like to develop as a person.

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In 5 years from now what impact would I like my cancer experience to have had on my relationship with my partner or loved ones.

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