

**THE STRUGGLE  
FOR LIFE:  
A Psychological Perspective  
of Kidney Disease  
and Transplantation**

*Lyndsay S. Baines  
Rahul M. Jindal*

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# **The Struggle for Life**

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# THE STRUGGLE FOR LIFE

## *A Psychological Perspective of Kidney Disease and Transplantation*

Lyndsay S. Baines and Rahul M. Jindal

Praeger Series in Health Psychology  
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*To the patients found between the pages of this book. They never claimed to lead by example. Their will to go on may have waxed and waned, but their determination to tell their stories in order that others might better understand the plight of patients on dialysis and after kidney transplant never faltered.*

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Sioux Falls, 2003*



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## SERIES PREFACE

The field of health psychology has experienced tremendous growth during the past 20 years. This growth reflects an increasing recognition of the many social and psychological factors affecting health and illness, and the realization that physical health can no longer be addressed solely from a biomedical perspective.

The books in this series focus primarily on how social, psychological, and behavioral factors influence physical health. These volumes will serve as important resources for layreaders, as well as students and scholars in psychology, medicine, sociology, nursing, public health, social work, and related areas.

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## PREFACE

The emotional and psychological manifestations in patients receiving dialysis and organ transplants have been recognized for some time. These disorders have been classified in terms of chronic depression and psychosis or conceptualized in keeping with distortion in body image, fear of rejection of the transplanted graft, and grief for the donor. In keeping with other chronic illnesses, some authors have pointed to the manner in which emotional problems may delay and adversely affect medical management and progress of the illness, resulting in graft loss and even death. However, in contrast to other chronic illnesses, little attempt has been made to provide psychosocial support for these patients either before or after transplantation. Where such intervention does exist, it has been fragmented and intermittent. Our own experience of implementing a ward-based psychotherapy service at the transplant unit in Glasgow has suggested that while renal disease shares many common characteristics with other diseases, some aspects of the clinical manifestation of emotional problems in patients with renal failure and recipients of organ transplants are also unique, multifaceted, and more complex than has been generally realized. Not only was our service designed to support these patients, but also to have a positive impact upon the transplant agenda, defined in terms of individual patient access to and adherence with the transplant process.

Our primary concern has been to gain a deeper understanding of the relationship between the emotional states recalled by patients during ther-

apy sessions and medical adherence, compliance, or concordance with dialysis, and the posttransplant regime. These symptoms often respond to psychotherapy alone, or in more advanced cases to both psychotherapy and pharmacological intervention. Psychotherapy opens up a nonjudgmental, person-centered dialogue with patients, away from the stringent time constraints and formality of the physician's clinic. Given such an opportunity, patients with kidney disease and recipients of kidney transplants often describe themselves as feeling completely isolated with the reality of their illness (often despite having supportive social networks). These patients describe their experience of renal disease as unpredictable, unstable, and dependent upon their own survival. Furthermore, during therapy, medically noncompliant patients will reflect that their behavior is incomprehensible, unfathomable, and as frustrating to them as to the rest to the transplant team.

The prime responsibility of the therapist is to establish a dialogue with a patient that facilitates quiet reflection and the option for individual change in behavior, attitude, perspective, or personal development. Psychotherapists also need to find a way to communicate in a concise and meaningful manner to other members of the transplant team, the laborious and convoluted dialogue of therapy sessions. Indeed, often what is called for on the part of the therapist is a flair for "transliterate prose" in order to permeate the pragmatic ambiguity that characterizes the day-to-day medical management of ongoing renal disease and reconcile it with the emotional world of the patient. A patient who feels unheard and misunderstood and faced with what he or she perceives as a frustrated, ambivalent, or dismissive transplant team, will, in our experience, become increasingly reticent, difficult to manage, and isolated from health professionals, fellow patients, and family.

Our observations suggest that renal patients tend to be self-deprecating and seek to blame themselves for their illness. Therefore, in working psychotherapeutically with these patients, we have encouraged them to consider a transplant as presenting them with *a* chance, as opposed to *another*, or a *second* chance. *Another*, or a *second* chance appears to conjure up connotations of redemption, or relief from a purgatory state. This is particularly unhelpful during therapy, as transplant patient's need little encouragement in selfrecrimination. Indeed, they are, of all the patient groups we have worked with, the most brutal and unforgiving of themselves. Due to surgical and pharmacological advances, staff, patients, and their family's expectations regarding post-transplant emotional, vocational, and relational availability are high. Transplantation is often seen as an instantaneous panacea for social, ca-

reer, or relational problems that may have developed during years of dialysis. However, the reality is that ongoing chronic illness erodes the patient's confidence, while personal development and life goals and ambitions are often stunted. It is not unheard of for recipients of kidney transplant, particularly patients who have dialyzed for long periods through their teens and early twenties, to be without personal and professional focus even years after a successful transplant.

Ongoing references to an organ transplant as a "*gift*" of life are often misconstrued by patients and aligned psychosocially with the assumption that transplantation is synonymous with becoming "*gifted*" in terms of insight, courage, self-esteem, relationship skills, and vocational skills. An underlying theme in psychotherapy after a successful transplant is often patients' self-imposed belief that they need to achieve something spectacular to prove them worthy of the transplant. Often, all that is really wanted (especially after long periods of dialysis), is a quiet, healthy life (defined in terms of longevity of the transplanted organ and minimum side effects of antirejection medication) and the fulfillment of a few quietly expressed and sometimes unexpressed personal and professional aspirations. Patients often need a great deal of support after transplantation to reconcile the past lost to chronic illness, construct a working present, with a view to future aspirations. To appreciate the patient-centered experience of disease we need to go beyond the bounds of the macroquantitative measures of quality of life that many readers will be used to. Much of the book is concerned with quality of life at a microqualitative level that involves patients taking the therapist by the hand (metaphorically speaking) into their world and their reality as opposed to the one imposed upon them and often missed by quantitative measurements and which there is a plethora of data elsewhere. In the qualitative tradition, we have detailed recurring themes recalled by patients during therapy that detail the personal *struggle* defined in terms of individual patient's deliberation, contemplation, and reconciliation of his or her past, present, and future life.

Research into psychosocial issues among this group of patients has tended to reflect the quantitative tradition of medicine. However, psychosocial aspects of chronic illness do not necessarily lend themselves to the definitive confines of quantitative research. Complex psychotherapeutic maneuvers, subtleties of therapeutic intervention, and subsequent change in behavior and emotional states are lost when relying solely on quantitative measurement. This leaves the transplant team unable to translate research findings into practice, or to determine what might be the best intervention for an emotionally distressed patient at a particular



point in time. Moreover, there has also been a concerted effort to utilize these findings in the construction of “scales” and “assessments” to identify emotional distress, or predict posttransplant compliance and subsequently exclude such patients from the transplant process. However, such scales and assessments typify patients emotionally at the point of implementation and do not allow for the process of individual change and intervention. Also, often they do not accommodate the unpredictable manner in which ongoing chronic illness compromises patients socially, politically, and economically.

In the United States, much attention has been given to pretransplant “psychosocial screening” and “candidate selection.” These procedures are often formalized, particularly in patients with a history of non-compliance and/or substance abuse. In such cases, “screening” is often conducted with a view to intervention and tends to be more liberal than in the United Kingdom. This libertarian attitude appears to have prevailed despite the ongoing shortage of organs for transplant and has been attributed to the comprehensive post-care package offered by Medicare and litigation, which has challenged exclusion. This is in stark contrast to the practice in the United Kingdom where the selection process is generally not formalized and does not make allowances for the emotional trauma of ongoing chronic illness. Therefore, transplant teams leave themselves liable to subjective bias regarding individual patients. We suggest that transplant teams might be better placed to consider patients in terms of their psychosocial profiles. Profiling offers a holistic perspective of a patient’s past and present life and aspirations for the future and is always preceded by the offer of appropriate treatment (Chapter Two). Also, if the patient’s problematic behavior should continue, or resurface, the transplant team is able intervene in an insightful and effective manner.

We suggest that one of the main reasons that psychosocial support is not readily available in transplant centers, is because much of the early intervention was developed from a psychiatric or classified standpoint. In turn, this data was utilized to classify psychopathology, as opposed to intervention from a personal developmental perspective. Therefore, much of this work might have been perceived as abstract or distant from the concerns of the transplant team. While we recognize that some symptoms might be psychopathological in nature, we suggest that many of the dilemmas facing transplant patients are emotional states that are unclassifiable and are well suited to the tradition of psychotherapeutic intervention. If such support is to become more widely available to patients, there will have to be a successful alliance between the transplant team

and mental health professionals. This unlikely and largely unprecedented pairing will be much easier to actualize if the transplant team has insight into the work of mental health professionals, along with the thought processes and clinical presentation of their patients in this setting.

If psychosocial aspects of patients with renal disease and transplantation are to be fully realized and effective intervention implemented, then the transplant team and service coordinators who plan and implement the service will need to better understand the aims, methodologies, and philosophies of social sciences. Therefore, this book is written with the transplant team, practice planners, and patients all in mind to offer insight into psychosocial aspects of patients with renal disease and renal transplantation. It is also hoped that our experience will assist physicians in managing psychosocial issues described by their patients. After all, attending to the emotional needs of patients is not the sole prerogative of the psychotherapist; any member of the transplant team can find him or herself face to face with a distraught or agitated patient. When pushed, most health professionals have some repartee of "counseling" skills that they tend to utilize in such situations. Much of this lay counseling is the "think on your feet variety," aimed at surviving the moment and moving the patient on to comply with some vital medical intervention.

Impromptu psychological intervention is often conducted while perched precariously on a scooter that passes as a stool and with only a flimsy line of demarcation between you and the burr and bustle of the ward. Such intervention, when conducted with empathy and compassion, can provide a constructive preamble or incentive to formal therapy. Psychotherapists pay attention to words spoken by the patient and in the context in which they place them, as a means to understand our patient's inter- and intrapsychic worlds, in the same way that physicians monitor creatinine levels, to determine the functioning of a newly transplanted organ.

However, all too often such encounters are avoided by the transplant team whose members feel that they will be under pressure to conduct a complex psychoanalytical interaction for which they are not trained. In truth, on such occasions, medical or nursing staff does not really have to say very much, but just listen and paraphrase what they hear at seemingly polite intervals. This gives patients an opportunity to listen to themselves and often find their own answers in the dialogue that they have with themselves or, rather, the dialogue that they do not have with the staff member. In order to ensure that findings represented in this book are comprehensible to the nonpsychotherapeutically minded reader, we utilize narrative and case studies infused with sociological concepts to

portray clinical dilemmas that will be easily recognizable to members of the transplant team, patients, and their family and friends alike. We hope that the transplant team will feel better able to understand and gain more confidence in dealing with the emotional needs of the patients.

We understand that other transplant teams may be reluctant to develop such a service, given the above-mentioned different philosophies of the two approaches: namely, the qualitative methodologies favored, but not exclusively adhered to, across the social sciences, and the quantitative randomized control design that has determined the transplant agenda. This is particularly important at a time when patients are becoming better informed and utilize complementary therapies as an adjunct to medicine and thereby potentially rendering the control group less sterile, or out of control. However, far from social science being irreconcilable to the medical transplant team, we believe that both medicine and the social sciences have much to learn from each other; they can be interactive, supportive, and complimentary. For example, data collected within a quantitative design can be analyzed both quantitatively and qualitatively. In other words, randomized controlled or comparative studies can often incorporate a more explorative or qualitative arm to the research protocol that serves to advance a more holistic perspective to the understanding of the outcome.

We hope that this book will be of interest to the transplant team (nurses, physicians, surgeons, social workers, physiotherapists, occupational therapists, nutritionists, psychologists, counselors, pastoral ministers, and volunteers as well as patients and their families, psychotherapists, and psychiatrists) whose input was vital to our book. We describe the dilemmas faced by the psychotherapist, itself an emotionally demanding “perilous calling,” while developing effective “front line” intervention, of a profession, more commonly associated with the private consulting room. This is particularly poignant for a transplant center whose catchments area spans the elegant West End of Glasgow, where the moneyed classes hold out against the infamous housing schemes, through the West Coast of Scotland. This large geographical expanse comprises patients across the entire social spectrum. Arguably, on the face of it, given that psychotherapy has largely been perceived until recently as a “middle class” affair, some of the characters you meet in this book might (at first encounter) seem more likely candidates than others for the “talking cure.” But of course, chronic organ failure does not discriminate in terms of social class and therefore, the experiences recalled in this book represent individuals from all segments of society.

We present a full complement of human dilemmas, from substance

abuse, debt, adherence, imprisonment, addiction, depression, anxiety, eating disorders, compromised femininity, gender diversity, relational breakdown, and attempted suicide. First and foremost, you will find between these pages the extraordinary account of ordinary individuals who found themselves diagnosed with renal failure. Identities are disguised, condensed, or interspersed as a means to protect patient's identities. The case reports do not necessarily reflect the time and intensity of thoughts of both the patients and the therapist as played out in the sessions week after week, or the support offered to patients in the short term as a means to bring about emotional, behavioral change, and ultimate survival in the long term. It should be remembered that patients often present a different construct of themselves to the physician than to the psychotherapist. The two are not mutually exclusive and both professionals should have insight into problematic patients. In most cases, this is not an attempt at deception; rather, patients use differing professional titles as a cue to present a different aspect of themselves. However, this self is always candid and most patients with ongoing chronic illness work on a need-to-know basis, with both themselves and the professionals who are trying to help them. It is hoped that our reflections, analysis, ruminations, and research findings as presented here will increase understanding of psychosocial issues among this patient group and lead to a timely and cost-effective intervention.

The first chapter provides an introduction to psychotherapy and forms the basis of the book. The following chapters draw upon the background information presented in this chapter but deal with specific issues and presentations including novel interpretations of issues, adherence, bereavement, and loss, anxiety, phobic states, body image, organ integration, gender, eating disorders, alcohol abuse, transplant among minority populations- and live-organ donation. Also, in order to provide a linkage to other chronic illnesses and thereby add to the texture of the book, we have provided brief overviews in each chapter of pertinent psychosocial findings of our colleagues in the fields of oncology, diabetes, cardiovascular disease, and cardiac and liver transplantation. Issues relating to cardiovascular disease, cancer, and diabetes are all in the public domain, and will therefore be recognizable to the lay reader, while the inclusion of data from studies in cardiac and liver transplantation will provide the opportunity to compare and contrast the unique and common characteristics of patients with renal transplants.

The medically orientated members of the transplant team need to be mindful that the purpose of our book is not to replicate the medical textbook tradition. Those searching for quantifiable data such as end-

points and outcome measures should look elsewhere. While such work provides valuable indications for future research it tends to provide generalizations at the expense of clinical meaningfulness. In short, it does not always represent the real world of the clinician who needs to better understand the subtleties of patient presentation and how to intervene with a specific patient at a particular point in time. Rather, we follow the psychotherapeutic tradition and present our systematic observations based upon our research and experience with patients with kidney failure and kidney transplants and their families. We have described the model of Systemic Integrative Psychotherapy, which we believe to be sensitive to the different emotional and spiritual states recalled by patients and their progress through them, detailed interventions that indicate how staff might intervene with patients at a particular point in time, along with obstacles to resolution and bench marks in treatment. In so doing we aim to contribute to the growth of understanding and stimulate debate on psychosocial issues among transplant patients. We do not necessarily consider the results conclusive; rather they are suggestive and provide an indication for further exploration of these issues.

## **Chapter 1**

# **EMOTIONAL DISORDERS, PSYCHOTHERAPY, AND ORGAN TRANSPLANTATION**

### **INTRODUCTION**

Much of the early work among recipients of organ transplants and patients on dialysis was supportive or psychoanalytical in nature and was conducted by psychiatrists who pioneered the field and who laid the template for future research. Primarily, they identified classifiable disorders such as depression, anxiety, suicide risk, sexual dysfunction, distorted self-image, and psychotic episodes. Recent research has been conducted in the cognitive-behavioral and educational traditions and has served to conceptualize patient's psychosocial experience of dialysis and transplantation. These are generally recalled as fear of rejection, grief for the donor, prolonged adherence to the sick role, and unrealistic expectations after transplant. Classification and conceptualization of the inter- and intrapsychic perspective of transplantation has served to collate knowledge and identify the extent of emotional disorders among this patient group. However, this generic perspective serves to cluster patients as a homogenous group, thereby losing the subtleties and idiosyncrasies of their experiences. Furthermore, these arbitrary classifications do not always accurately represent the experience of our patients. Our experience of working with these patients suggests that therapists are well placed to advance psychosocial understanding of the experience of renal disease and deliver effective intervention when required.

The incorporation of a psychotherapeutic component into the medi-

cally dominated field of renal failure and organ transplantation requires the adoption of an inclusive (combined qualitative and quantitative) research design. This type of research does not lend itself well to the physician's much-favored, randomized control group study. Physicians' skepticism as to the incompatibility of qualitative research with their other ongoing research projects has meant that mental health professionals have adopted a quantitative, as opposed to qualitative, approach. In so doing, much of the clinical meaningfulness has been eliminated, leaving clinicians unsure how to intervene with a particular patient at a specific point in time. In this chapter, we will give a brief overview of psychological problems common to patients with chronic illness before focusing on those who appear to be specific to renal disease and recipients of kidney transplants. We will also discuss the role of the therapist as a means to bring about change in emotional states and research findings as to the effectiveness of various modalities of therapies.

## **PSYCHOSOCIAL PROBLEMS AND CHRONIC ILLNESS**

The etiology, prognosis, and the need for effective intervention regarding psychosocial symptoms have permeated most fields of chronic illness, including oncology, diabetes, cardiac disease, and heart and liver transplantation. The most notable psychosocial presentations among all of the above are those of depression and anxiety. Depression can serve as an independent risk factor to the onset of disease; secondary manifestation as a result of living with the reality of an enduring prognosis and both during and after recovery from a prolonged illness. There is a paucity of data on the exact number of cancer patients who might be suffering from depression and anxiety at any one time; however, studies have consistently indicated that clinical depression was significantly more prevalent among lower socioeconomic groups. It is possible that depression and anxiety in cancer patients have been compounded by negative societal associations and historical attitudes toward cancer and the concerns about the effectiveness of treatment. Depression, anxiety, generalized distress, and fatigue have been especially associated both with secondary screening and prevention programs among high-risk populations (Kash and Dabney 2001), with the reality of living with an uncertain prognosis (Brennan 2001) and adjustment to and survival from cancer (Chan et al. 2001). Kash and Dabney (2001) identified the presence of psychological symptoms in their study aimed at identifying women genetically determined to be at high risk of contracting breast

cancer. Three hundred and ninety-one women from a combination of rural and urban areas were asked to complete a questionnaire on genetic testing, psychological distress, and health beliefs and compared with 382 controls who were representative of the study group in terms of age, geographical location, but who did not have any predetermined genetic susceptibility to breast cancer. Multiple regression analysis revealed that those most willing to undergo screening were those women who had better levels of insight into the concept of genetic predisposition, with a positive attitude to testing and who were genetically more likely to get cancer. However, while high-risk women were more likely to show an interest in testing, they were more likely to display testing anxiety and less likely to comply with screening.

Until recently, little had been known about the intrapsychic or psychosocial “adjustment” process of patients once they are diagnosed with cancer, or how this process might evolve in keeping with the progression of the disease. Brennan (2001) identified what he referred to as the “healthy personal growth” or personal development that can come about as a result of living with an enduring prognosis such as cancer. Also, changes in psychosocial adjustment over time among gynecological cancer survivors has been documented in a longitudinal prospective study conducted by Chan et al. (2001) with a view to providing adequate supportive intervention. Seventy-four patients with gynecological cancer were subjected to semistructured interviews at confirmation of diagnosis and at 6 and 18 months after the completion of treatment and no evidence of recurrent disease. Patients reported on their self-esteem, outlook on life, self-role, depression, and femininity. Neuroticism and anxiety were assessed using the Hamilton Anxiety Scale and social adjustment in terms of vocational capacity or status, leisure activity, marital relationship, and sexual activity. While lifestyle adjustment was not a significant problem for the majority of patients, psychosocial adjustment differed with the mode of medical intervention. Improvement in perceptions of femininity and neuroticism was observed for patients receiving chemotherapy while those who received surgery were more likely to deteriorate. In addition, increased neurosis was associated with lower educational groups while existence of religious belief was associated with family support and increased social activity.

Similarly, among diabetic patients, psychological symptoms were thought to interact with specific psychosocial variables, predominantly anxiety and depression. Lustman et al. (1998) estimated that between 15–20% of patients might be suffering from depression; thought to be a conservative estimate as they suggested that depression might coexist



with other disorders often associated with diabetes such as eating disorders, anxiety, and family conflict. Furthermore, they suggested that only half of this patient group was ever diagnosed, let alone treated. It would seem that the nature of the physician-patient relationship is also determining factor with respect to patient willingness to engage with treatment and the course of the disease (Auerbach et al. 2002). There have been attempts to implement complex screening procedures among high risk populations or those thought to be susceptible to diabetes (Weber & Roth 1997). They found that the process of screening for diabetes was in itself associated with conflict, anxiety, depression, and subsequent family conflict. They speculated that individual patient characteristics such as maturity, emotional stability, personal integrity, and the availability of family support tended to be associated with a more positive approach to screening and better outcome.

There has also been a concerted move toward the development of individual typification of clusters of personality traits with the course of the disease, specifically glycemic control. Lane et al. (2000) conducted a longitudinal study of 105 type 2 diabetic patients who were also undergoing a course of stress management. The NEO Personality Inventory, a questionnaire that measures 5 domains of "normal" personality and was administered at baseline, at 6 and 12 months. Glycemic control was measured by glycated hemoglobin and average glucose control over 7 days of self-monitoring. The results indicated that higher average glucose levels were associated with neurosis, anxiety, anger, hostility, depression, self-consciousness and vulnerability, while lower scores were associated with altruistic personality traits. Similar, although not as marked traits, were also evident at 6 and 12 months follow up. This study appears to have successfully established a link between specific personality traits and glycemic control and subsequently medical well being. These traits could easily be targeted during a course of short-term psychotherapy in an attempt to address the underlying issues in an attempt to bring about a more altruistic attitude to life.

Among cardiac patients, depression is considered an independent risk factor for cardiovascular disease and has been associated with higher mortality and morbidity (Thornton 2001, Burg & Abrams 2001). The severity of the problem among this patient group was further reiterated by Thornton's (2001) suggestion that 8–45% postacute myocardial infarction patients are likely to suffer from a major episode of depression. While Burg and Abrams (2001) have suggested that the figure might be slightly lower at 15–20% of postmyocardial infarction patients suffering from chronic depression and as many as 27% reporting symptoms of

mild depression. While depression has also been considered an independent risk factor in the development and maintenance of heart disease, there is often a degree of comorbidity between cardiovascular disease and depression (Hesslinger et al. 2002). Supporting this position is a recurring theme in the literature pertaining to heart disease suggesting that while any of the above psychosocial factors might impact independently, they are more likely to combine at different stages over the life course. Psychosocial factors are also thought to be prevalent among patients with chronic heart failure who require heart transplantation. This is probably not surprising as the quality of life of these patients is generally considered to be poor as well as the fact that they face certain death without a timely transplant (Gentelli et al. 1997). There has been great emphasis placed upon the presence of such symptoms to assess suitability for a heart transplant (Skotzo et al. 1999), itself an anxiety and stress-provoking experience and also the presence of psychosocial symptoms as a means to predict the outcome.

Nevertheless, psychological well-being after a successful organ transplant has become an ongoing cause of concern. This has prompted a number of studies aimed at identifying patients at risk of developing psychiatric disorders (Dew et al. 2001) and the measurement of post-transplant psychosocial recovery (Triffaux et al. 2001). Dew et al. (2001) studied 191 heart transplant recipients in a prospective evaluation of the prevalence, clinical characteristics, and risk factors for the development of a major depressive episode, anxiety, and posttraumatic stress disorder three years after a transplant. Depressive (22.5%) and anxiety (17.7%) disorders were most prevalent 8–36 months after surgery; posttraumatic stress syndrome (17%) was most evident during the first year after an initially successful transplant. Further factors that were thought to increase the risk of the above disorders included pretransplant psychiatric history, female gender, prolonged periods of hospitalization, impaired physical functioning, and lack of social support.

Similarly, the presence of psychosocial issues among recipients of liver transplants has been considered primarily in relationship to anxiety and depression, both of which have been found to be prevalent among this patient group. As with cardiac patients, evidence of psychiatric problems has been viewed as an independent variable to assess suitability for transplant (Lang et al. 1997) and as a determinant of posttransplant psychosocial well-being (Nickel et al. 2002). Lang et al. (1997) conducted a multiorgan transplant survey among heart, liver, and lung transplant patients awaiting transplant to determine the prevalence and/or differences in the severity of psychiatric disorder among the different patient

groups. The methodology included semistructured interviews and the Transplant Evaluation Rating Scale, with diagnosis made according to ICD-10. The lung transplant group was less likely to suffer from psychiatric problems with 68% of patients surveyed displaying no psychiatric symptoms. While at least 50% of both the heart and liver transplant patients displayed at least one psychiatric symptom. The authors recommended ongoing psychiatric evaluation but did not offer any insight as to why some transplant patients might be less susceptible to the development of psychiatric problems.

The psychosocial considerations among recipients of liver transplants take on a more controversial, ethical, and rehabilitative dimension when one considers liver transplant in patients with alcohol liver cirrhosis (Reeck et al. 1993, Stilley 1999). These patients often need to undergo a course of rehabilitation relating to alcohol abuse before being considered for transplant. In particular, liver transplant candidates with a history of substance abuse might have their posttransplant prognosis hampered by the potential for a return to drinking behavior and the social, legal, and economic consequences associated with ongoing alcohol abuse. In particular, patients with a history of substance abuse tend to differ from their nonalcoholic counterparts in terms of their increased susceptibility to distress, lack of coping skills, and lack of support networks (Stilley et al. 1999). However, despite these obstacles, they reported that resumption of drinking behavior posttransplant is relatively low, particularly when pre- and posttransplant psychological assessment was accompanied by therapeutic intervention. The findings of Reeck et al. (1993) who suggested that survival rate after transplant was not that different in patients with alcoholic liver disease compared with nonalcoholic patients who underwent liver transplant (65% and 71%, respectively) appear to support these statements.

Anxiety and depression as opposed to physical factors (length of prolonged periods in hospital, medical complications, age, and employment) are also thought to influence coping behaviors in relationship to post-transplant quality of life (Nickel et al. 2002). The authors used the Hospital Anxiety Depression Scale, the 36-Item Short-Form Health Survey, and the Freiburg Questionnaire on Coping with Illness respectively. The findings suggested that anxiety and depression were much more likely but not exclusively associated with increased adjustment and well-being post-transplant. The authors established a relationship between depression and anxiety and the above-mentioned physical variables.

It is becoming increasingly clear that there may be differences in severity of depressive, anxious, and neurotic manifestations between dif-

ferent chronic illnesses. However, common to all is that experience and survival of chronic illness run parallel to the medical course of illness and beyond. The very experience of chronic illness erodes confidence and inhibits personal, social, vocational, and relational achievement. Furthermore, the prevalence of depression and anxiety after survival, remission or surgical intervention suggests that if patients are to achieve their maximum medical and psychological potential these issues will need to be addressed in a timely and well-informed manner.

## **PSYCHOSOCIAL PROBLEMS ASSOCIATED WITH RENAL FAILURE**

In keeping with the psychosocial trends discussed earlier, the most commonly sighted emotional disorder among dialysis patients is that of depression, which is reported to be as high as 22% (Craven et al. 1987, Lowry 1979) and commonplace following the removal of a rejected kidney transplant. In turn, depression has been attributed to redundancy, altered life style (Glassman 1970), and the severity of the illness. Depression is closely followed by suicide, anxiety, and phobic responses to treatment (Abram et al. 1971, Abram & Buchanan 1976). However, depression has not just been limited to patients on dialysis. Depression following successful transplantation (Christensen et al. 2000) as well as “paradoxical” depression in donors of living kidneys (Fukunishi et al. 1998) has also been observed. Depression that manifests during dialysis often continues after transplantation if not diagnosed and treated in a timely manner (Locsey et al. 1987, Christensen et al. 2000).

The prevalence of these disorders has frequently been analyzed in keeping with length of time on dialysis (Czaczkes & Kaplan De-Nour 1978), poor social support (Siegal et al. 1987), and individual adjustment to a change in lifestyle associated with ongoing dialysis (Wright et al. 1966). In turn, these factors have been associated with increased incidence of hospitalization (Ziarnik et al. 1977), noncompliance with the medical regime (Baines & Jindal 2000, Baines et al. 2001), and mortality (Shulman et al. 1989). However, other studies have suggested that there is little association between depression and mortality among renal patients. In a study of 97 patients on either hemodialysis or CAPD and recipients of kidney transplant, there was found to be no relationship between depression and survival (Devins et al. 1990). In contrast, those patients who described themselves as “happy” overall had the shortest survival rates. These findings lead to us to speculate that there was a strong element of denial and leaves us wondering how “happy” was

defined. The general course of emotional response has been considered in terms of a "honeymoon" period (associated with relief at receiving life-sustaining treatment), followed by depression and resentment at being dependent on dialysis (Reichsman & Levy 1972). Research in response to this dilemma has tended to focus on depression in the light of incompletely treated uremia (Czaczkes & Kaplin De-Nour 1978), anemia and pharmacological interventions (Hinrichsen et al. 1989), as opposed to psychopathology.

Our observations have suggested that the majority of patients who are described as depressed have dysthymia, a milder form of depression (Baines & Jindal 2000). While chronic depression is more debilitating than dysthymia in the short term, dysthymia can deteriorate into chronic depression if it is undiagnosed and untreated. Discrepancies in classification of depression and/or the tendency of researchers not differentiating between depression and dysthymia make interstudy comparisons difficult (Craven et al. 1987, Levenson & Glocheski 1991).

It has generally been considered that dialysis is dependent upon "partial regression in the service of the ego," as a means of accepting or delegating their "dependence" to dialysis and to the medical staff. There has been some preoccupation with defensiveness and resistance among renal patients, which is generally considered in terms of denial. They consider themselves to be "marginally ill" and "marginally handicapped" in spite of suffering from a chronic illness. Patients were thought to move from denial to reality in a seesaw fashion over the course of their illness. This situation may be due to the fact that these patients go about their daily business do not have any easily recognizable evidence of illness and are treated as "normal."

After transplantation, body image problems have been attributed to introjections of the new organ and from the physical bodily changes arising from side effects of medications. Transplantation has been compared to the promise of "re-birth" by some authors (Abram 1972) with patients having unrealistic expectations as to how well they might become. It was even suggested that dialysis patients avoid contact or communication with transplant patients to maintain a state of denial. It has also been reported that some patients refuse transplantation if they knew of a patient who had a difficult postoperative course or had a failed transplant (Dubovsky & Penn 1980).

## **OBSTACLES TO PSYCHOLOGICAL INTERVENTION**

The paucity of research appears to reflect the spasmodic and intermittent nature of psychosocial intervention among patients with chronic

illness. Obstacles to intervention have centered on the reluctance of mental health professionals to accept referrals from this patient group and some patients are not willing to attend therapy. For their part, psychiatrists have considered emotional disorders a reaction to chronic illness and believe that it would be difficult to bring about a change in mood during this time. This philosophy was based on the fact that if the patient received a transplant then any emotional distress would automatically subside.

The dearth of psychotherapeutic services patients has been attributed to resistance from patients, medical, and psychiatric staff. It has been seen that patients on dialysis demonstrated the same skepticism and reserve toward psychiatrists as the general population: more specifically, displacement toward the psychiatrist of anger that patients were afraid to express toward their attending physicians. However, the practical logistics of time and accessibility of the psychiatrist, given the time already spent engaging in treatment, should be given due consideration. Resistance on the part of the medical and psychiatric staff toward psychological intervention is centered on differences in definition, diagnosis, the professional's expectation, and the patient's response. Primarily, liaison psychiatrists resisted using antidepressant medications, as they felt that depression in these patients was more in keeping with a grief response and that these patients would be better suited to psychotherapy.

Early attempts at psychotherapeutic intervention in patients receiving dialysis and organ transplants were largely negative (Sorensen 1972, Buchanan 1975, Campbell & Sinha 1980, Gerber et al. 1981). Obstacles to insight-orientated therapy were considered for patients having problems in identifying with each other, resulting in a withdrawal of other patients from the group. This deliberate withdrawal or "abrogation" in relationship to fellow dialysis patients has been noted outside of the psychotherapy group situation and has been associated with higher survival rates (Lifton 1967). The survival aspect of such behavior was analyzed in keeping with studies of Hiroshima and concentration camp survivors. The authors suggested that common factors between dialysis patients and concentration camp survivors included an "immersion into death" which in turn left a "death imprint" and guilt over surviving at the expense of others, a phenomena that could be implied to any of the above-mentioned chronic illnesses.

## **PSYCHOTHERAPEUTIC INTERVENTION AND CHRONIC ILLNESS**

There appears to be a general consensus among health professionals as to the need for psychological support for these patients. However,

provision of psychosocial support varies not only between disease classifications but also between one facility and another. The field of oncology has gone as far as to deem psychosocial intervention as a subdivision of oncology, psychooncology. In the main, psychooncology has tended to manifest clinically in the form of Cognitive Behavioral Therapy (CBT) (Edelman & Kidman 1999), supportive group intervention (Spiegel et al. 1981), and a combination of group, relaxation, and exercise therapy (Jereczek-Fossa et al. 2001).

There appears to be a plethora of data concerning women with breast cancer, the reason for which is not entirely clear. Group therapy (supportive-expressive) has been used extensively in women with metastatic breast cancer. A recent multicenter, randomized study (Goodwin et al. 2001) did not find that this form of therapy prolonged survival in women with metastatic breast cancer; however, patients reported improvement in mood and the perception of pain, more so in patients who were initially more distressed. In an accompanying editorial, the results of this form of therapy in patients with breast cancer have been summarized; half the studies reported benefit in terms of survival while others did not.

Edelman et al. (1999) conducted a randomized controlled study among 124 women with metastatic breast cancer. Patients were randomized into two groups: a CBT intervention group consisting of 8 sessions and 3 monthly posttreatment follow-ups, or to a control group that did not receive therapy. Both groups were required to complete both a profile of mood states and the Coopersmith self esteem inventory before, at 3 and 6 months for follow-ups. The group that received CBT demonstrated reduced depression and total mood disturbance and improved self-esteem versus the control group. However, the positive effect of CBT was not evident at the 3- and 6-month follow-ups. The reader should be aware that this might not necessarily mean that CBT was not effective, rather that it needs to be ongoing or run parallel to the course of the illness. In contrast, intervention conducted over a longer period of time (1 year) and in a group setting—which drew upon peer support and which targeted problems specific to terminal illness, including relationships with family, friends, physicians and death issues—has been shown to have more enduringly positive effects.

Diabetologists have also attempted to integrate psychosocial support in health care programs. As in the *Oncology* trials, CBT has featured predominantly in the treatment of psychosocial issues among this patient group. Lustman et al. (1998) studied the relationship of various demographic, diabetic, and depressive characteristics to change in depression



in 42 patients with type 2 diabetes who completed a randomized clinical trial of CBT compared with patients assigned to a control, no-therapy group. The therapy group demonstrated significant improvement in depressive states and improved adherence to treatment regimes over their control-group counterparts.

Counseling input among cardiac patients has tended to be integrated into educational programs aimed at change of lifestyle and subsequent reduction of biological risk factors associated with risk of cardiovascular disease. Steptoe et al. (1999) studied the direct effect of behavioral counseling upon the adoption of a health regime and biological risk factors (smoking, high cholesterol, high body mass) among 883 men and women at risk of cardiovascular disease. Change was measured by the administration of questionnaires at months 4 and 12. The majority of patients demonstrated significant overall improvement, but most consistently regarding dietary fat intake and increase in regular activity. The authors pointed to the need for ongoing counseling support as a means to reinforce change and sustain change over time.

Behavioral therapy has also been utilized with some success among patients before and after heart transplantation. We have seen how these patients not only have to implement a change of lifestyle but also endure the emotional stress of transplantation (Hook et al. 1990). However, while psychological manifestations of such an experience have been recognized among this patient group there has been a tendency to concentrate on pre- and postpsychological assessment as opposed to the development of treatment intervention (Gentelli et al. 1997). This trend has been attributed to scarcity of organs and the need to determine the best psychological and biological outcome, defined in terms of those patients most psychologically able to endure the transplant process (Couples & Steslow 2001). Similarly, authors who have attempted to relay the psychosocial experience have limited themselves to patient experiences that fall within the bounds of classifiable disorders, the typifying of the reaction to hearing the news that a transplant is needed, and the nature of interaction between the donor family and the recipient (Notova 1998).

In contrast, psychosocial support among liver transplant patients appears much more advanced equating such support as a facilitator to the gaining of physical strength (Forsberg et al. 2000). However, intervention is mainly more geared toward psychosocial change, with early indications that supportive psychotherapy can impact upon the depression and anxiety associated with liver disease as well as aid social integration and adjustment after a successful transplant. Nickel et al. (2002) investigated



the ability to cope and recover from depressive and physical symptoms in recipients of liver transplants. Sixty-five members and 20 nonmembers of a self-help group who had received a liver transplant between 6 and 36 months previously completed a postal survey, comprised of the SF-36 (to determine quality of life) and the Freiburg questionnaire (to determine levels of coping with illness). The members of the self-help group demonstrated significantly better coping skills, were less likely to be depressed, and registered better physical and mental quality of life compared to the control group of patients.

## **PSYCHOTHERAPEUTIC INTERVENTION AND RENAL DISEASE**

In keeping with the aforementioned chronic illnesses, the development of individual psychotherapy in renal patients has taken a predominantly psychoanalytical perspective to address the transition from dialysis to transplantation and the subsequent adaptation from illness to normal health (Freedman 1983). CBT has been used to address the same symptoms of stress, anxiety, depression, and psychosocial adjustment to illness of patients needing to adjust to living with an enduring prognosis (Abbey et al. 1990). The findings were analyzed within the context of two intervening variables: interpersonal support, and control over their treatment to determine compliance with the medical regime. The results suggested that CBT had a positive effect on all patients for some of the above issues, in particular for anxiety. However, there was no evidence that CBT had an impact upon compliance with the medical regime. Other studies utilizing CBT among patients receiving dialysis reported slightly more positive results with compliance behavior.

Short-term group psychotherapy among kidney transplant patients and their families has been considered quite positively (Buchanan 1975, Abbey & Farrow 1998). Buchanan (1975) described the primary benefits of group therapy: the opportunity to observe and support coping strategies, mutual support, and encouragement. The authors point to the tendency of patients toward "seclusion" which were actively addressed by the group facilitator as and when they arose. However, the short-term nature of the group and open membership (ongoing or changing membership of the group from week to week) were not conducive to the exploration of relationship difficulties.

Group therapy among multiorgan transplant patients has been integrated into the transplant program at the University of Toronto, Canada, as it was shown to be cost effective in addressing emotional issues before

and after transplantation (Abbey & Farrow 1998). Common recurring themes were infection, rejection, body image changes, and emotional problems such as delirium and depression. However, in our own comparative study of group and individual psychotherapy among posttransplant patients, group therapy did not appear as effective as individual therapy (Baines & Jindal 2001).

“Modified” group therapy has been utilized among patients receiving dialysis (Hollon 1972). The group was initiated following the recognition of the stresses of ongoing dialysis and the need to address such problems if they were not to become an obstacle to transplantation. The author commented on how he had witnessed the progression of dialysis from an experimental to a definitive treatment, which sustained life, but created emotional stresses regarding body image, dependency on dialysis, resentment, and conflict within families. Other studies have attempted to utilize group therapy in dialysis units to combat isolation and psychological denial and as an effective educational tool (Sorenson 1972, Buchanan 1975, Campbell & Sinha 1980, Gerber et al. 1981).

While individual and group therapy are different modalities, they have common goals: to benefit the patient. This is achieved by encouraging the patient to disclose his/her feelings and experiences and, with the rest of the group, to reflect on them and eventually address them. The role of the therapist is to facilitate such an exploration and assist in making sense of them. Patients tend to present their feelings and experiences using a “story” format; every patient has a tale to tell and this is usually related in the group in terms of recalled interactions with their social networks outside of the group and often replayed between members of the group. Each member of the group will bring with them a set of expectations, fears, and hopes of what they might achieve from treatment and how the therapist will facilitate such change. The most difficult dilemma for most patients is that of wanting to change and yet reluctant to relinquish familiar coping mechanisms, ways of thinking, behaving, and their perception of themselves.

Once again we see the emergence of the tendency to avoid specific psychological scenarios as described by patients, or a patient-led approach in favor of classifiable disorders. The response has also been a tendency to favor a structured response or approach to treatment in the form of CBT among renal patients that featured in the overviews of psychosocial issues pertaining to cancer, diabetes, heart disease, and heart and liver transplant. CBT seems to have gained greater acceptance among health care planners and is being promoted as a therapy of choice. However the opposite view also needs to be considered: whether cog-

nitive behavior therapy is ahead in the field because it focuses on the qualitative tradition of research favored by physicians rather than its intrinsic superiority to other therapies.

## **CREATING AN ENVIRONMENT CONDUCTIVE TO PSYCHOTHERAPY IN THE MEDICAL SETTING**

One of the major obstacles to the delivery of psychotherapy in the medical setting has been the difficulty in creating an environment conducive to therapy. The core psychotherapeutic variables have traditionally been considered in terms of physical and relational proximity. Orthodox treatment placed great emphasis on the physical location and arrangement of the consulting room and the contract or framework in which therapy takes place. Traditionally, attention has been given to creating a quiet room, appropriate lighting, temperature, sitting, and reclining facilities, with a minimization of background noise, clutter, and interruptions. In addition, the number of sessions and the venue were planned in advance and in consultation with the patient. All these factors were thought to be essential to produce positive results.

Psychotherapists in ward settings often find themselves standing or crouching by a patient's bedside who may be too ill to move, with the full cacophony of ward life going on in the background. Individual therapists working in the medical setting will need to adapt their approach in an attempt to meet the needs of individual patients. In our experience, the most absurd interaction was that of treating an infamous member of the local Mafioso in renal failure. Our sessions were conducted in an open plan dialysis area with the patient attached to his dialysis machine by one hand and handcuffed to the arm of the chair by the other. The handcuffs were connected to a long chain, which passed under the small screen, which separated us from the prison officer to whom he was attached. I was required to perch on a stool within the confines of the curtain with the patient. This arrangement continued for some weeks until the prison office authorities gave permission for me to enter the prison. We must have appeared quite a farcical trio to fellow dialysis patients, who to their credit maintained an air of disinterest, which only occasionally got the better of them. Meanwhile the patient, whose macho image could not accommodate a consultation with a psychotherapist, informed his fellow dialysis patients that I was a high-flying litigation lawyer come to consult on his case, which was met by a conspiratorial head nodding by fellow patients.

While we are not actively advocating psychotherapy while attached to a dialysis machine, stringent transportation arrangements, and or distances from the dialysis unit can prevent patients attending at other times. Therefore, such facilitation is driven by the need to be available to all patients irrespective of how far they live from the unit or the severity of their problem. This is usually a short-term measure, which is often rectified with cooperation from the transport and medical staff. We have also noted when attending patients on the dialysis machine that not only are fellow patients extremely facilitative of treatment, but also over time, enter into therapy themselves by association.

## PSYCHOTHERAPY SKILLS

Skills form the means by which psychotherapists put their particular theoretical orientation, ideas, and concepts into practice. The basic skills available to the therapist vary little from one theoretical model to another. The foremost skills that are utilized are those of “attending,” “listening,” “reflecting,” “probing,” and being “concrete.” These skills are interdependent and one refines them over time with experience. “Attending” and “listening” appear to be separate entities but one cannot be implemented without the other. Patients need to determine that you are “attending,” or following what they are saying. Much of “attending” is conveyed by body language, such as facing the patient in a one-to-one situation without any distractions, appearing calm, maintaining eye contact, and appropriate facial expressions that reflect an empathetic response not only to the content, but also the emotions portrayed by the patient.

Psychotherapists “listen” to recollections of experiences, behavior, feelings, and thoughts with a highly tuned ear, rather like the physician who monitors blood results with a well-focused eye. As a skill, psychotherapy is differentiated from lay counseling by listening and by being active as opposed to being a passive participant. Therefore, therapists talk of “active” listening, which incorporates “attending,” hearing,” and “understanding” what the patient is saying. This can be a complex skill to master, as the therapist is having an ongoing dialogue with him- or herself as he/she assesses the information within the context of the patient’s disclosures. This is being carried out at the same time as attempting to reconcile this information with a working hypothesis before deciding on specific intervention.

“Reflection” helps the therapist to “listen” and “attend” within an internal frame of reference. This involves the therapist helping the patient

to adopt a broader external perspective by stepping outside of the body and viewing him- or herself within the context of his social networks. Reflective skills manifest clinically as interventions such as restating, paraphrasing, and summarizing what the patient has said. The therapist develops a heightened sensitivity to thought processes and is attuned as to which words or actions are meaningful at any given time. In contrast, probing skills have been referred to as an “external frame of reference” or the therapist’s perspective. Probing skills manifest clinically as open (explorative), closed (encouraging “yes”/“no”) answers or leading questions (a more pointed answer is required by the patient), either/or (restricted answer required by patient), making statement (softer probe), and “why” (searching on part of patient or therapist) questions. On the other hand, being concrete can combine all of the aforementioned skills virtually simultaneously and is aimed at bringing about specific insight and change in patient’s perspective and behavior. This often takes the form of encouraging the patient to give specific examples of behavior or experiences about a specific problem.

## THE PATIENT AND THE PSYCHOTHERAPIST

Traditionally, therapists treat “clients” as opposed to “patients.” Basically, this comes down to “what is in a name,” which is that references to “patients” are thought to encourage dependence references to “clients” promote independence. However, in this book “patients” remain as “patients,” simply because they were “patients” at the point of being referred and will remain renal “patients” for the rest of their life. In our opinion, to introduce the concept of “clients” is to introduce a conflicting identity.

Contrary to popular opinion, therapists are only human and have idiosyncrasies, personality traits, styles, preferences, life experiences, issues, and problems. Training can vary along with level of skill, experience, and talent, all of which colors or influences the relationship that he/she has with patients, just like any other member of the transplant team. The recognition of such potential for vulnerability of both the therapist and patient is a relatively new development and is in contrast to the philosophy of the founding father of psychotherapy, Sigmund Freud. Freud felt that psychotherapists model themselves on the “surgeon” who he suggested “put aside all of his feelings, even his human sympathy, and concentrate his mental forces on the single aim of performing the operation as skillfully as possible.” Freud’s philosophy stemmed from the idea that the countertransference was an unconscious interference that hampered the therapist and the outcome of treatment.

However, most contemporary psychotherapists consider therapeutic processes to consist of two potentially vulnerable individuals who affect and influence each other. Albeit, each participant has different roles, but they are bound by mutual interest toward the goal of recovery. Indeed, psychotherapy brings about a heightened sense of insight and awareness of humanity, or better defined, as the therapist and patient are "more human than otherwise." It is now commonly thought that such disconnection does not facilitate personal development in either the therapist or the patient; self-disclosure is only advised with caution.

Psychotherapy has been referred to as a "perilous calling" by virtue of the emotionally challenging nature of the profession. The therapist is trained to believe that patients need to experience you as a person, who is not afraid to let the patient take them by the hand (metaphorically speaking) and take them into their world, with is often multifaceted, convoluted, imperfect, frightening, and uncertain. The therapist attempts to emulate flexibility, tact, empathy, indulgence, warmth, candor, responsiveness, and a holding or active storage environment for their problems, in an egalitarian as opposed to the authoritarian environment of the transplant team. However, excessive familiarity is discouraged; the therapist should not become a replica of the patient who needs you to be strong and able to hold their feelings and move them on.

The role of the psychotherapist, particularly in medical settings is complex without a clear framework or guidelines. Therefore, ongoing supervision with an experienced outside therapist who practices within a similar theoretical framework and has no role in evaluating the patient is advocated by regulating bodies. External supervision provides a safe environment in which to learn and develop skills, explore countertransference reactions, deal with emotive situations and ensure that therapists' own prejudices do not influence their work with patients. This practice is a necessary prerequisite to establishing a productive working relationship with patients. This is particularly true in the light of a growing body of evidence which suggests that one of the most influential variables regarding the outcome of psychotherapy is the quality of the relationship between therapist and patient (Frank 1979, Hynan 1981).

## **AIMS OF PSYCHOTHERAPY**

The fundamental aims of treatment are to ameliorate the disruptive or most worrying symptoms, to establish some level of emotional equilibrium, promotion of the understanding of the patient's symptoms along with better coping techniques for the future. Patients usually start treat-

ment with an idea of a predetermined outcome or symptoms they would like relieved and relational or situational problems that they would like to solve. However, the solidity and flexibility of such symptoms and issues are often dependent upon the course of their illness. As mentioned previously, patients undergoing dialysis live in an unpredictable world, which is focused very much in the present and upon their immediate survival. Major changes are very often not an option and the goals of therapy are very much about maintaining some sort of ongoing emotional, social, and relational equilibrium within the bounds of their reality, as determined by their experience of their illness. The goals for treatment are often determined in an orthodox setting as patients need to come to terms with time lost to chronic illness and are building a future under the constant shadow of possible rejection of the transplanted organ. Much of psychotherapy in this context is concerned with easing patients out from under this shadow toward optimism and confidence in their ability to create (a working present and realize their aspirations for the future) and endure the unpredictability of their illness.

## **THE PSYCHOTHERAPEUTIC ALLIANCE**

A precise definition of the psychotherapeutic alliance remains illusive, but suffice to say it is constructed of the relationship between the therapist and the patient, requires cooperation, and is the vehicle or main agent of change. In turn, the main aim of the alliance is that it should have direct psychotherapeutic benefit to the patient through the implementation of effective intervention, interpretation, and exploration of material brought to the session by the patient. The psychotherapeutic alliance is subjected to transference and countertransference reactions and can at times become extremely volatile. Transference reactions refer to the transference of feelings held by the patient onto the psychotherapist when these feelings are not in keeping, or unjustified, within the context of the patient-therapist relationship. Countertransference feelings are unconscious feelings that arise in the therapist as a result of his/her interaction with the patient and are subsequently transferred onto the patient. Therapists take great care to avoid such a scenario; this makes it necessary for the psychotherapist to be in ongoing personal supervision. The very nature of the relationship in terms of the appropriateness of self-disclosure (on the part of the therapist) and the formation and addressing of the transference and countertransference (on the part of the therapist and the patient) are the most debated aspects of the relationship. These include objective characteristics, such as age, ethnicity,



gender, professional background, and therapeutic styles, and intervention and subjective characteristics, such as social influence attributes, expectations, therapeutic philosophy, personality and coping patterns, emotional well-being, values, attitudes, and beliefs.

Increasingly, research has suggested that the psychotherapeutic alliance is a powerful predictor of change. Therefore, the need to measure and identify alliance ratings and structure has increasingly been integrated into the measurement of treatment prediction and outcome, using confirmatory factor analysis and correlation. Therefore, unlike medical studies, outcome of therapy is much harder to classify; it is becoming increasingly difficult to pinpoint a single effective outcome variable.

## REFERRALS AND ASSESSMENTS

Patients are made aware of psychotherapy service upon admission to the ward and referrals are made from ward staff, the primary-care team, and patients themselves. It is understood that if a staff member wishes to make a referral, then that member should ask the patient's permission. The initial assessment can take up to ninety minutes—it is not different from any assessment that a member of the transplant team might undertake—and is concerned with the identification of the problems. Unlike a psychiatrist, the psychotherapist is not concerned with matching signs and symptoms of the patient with a known classifiable disorder. Some of our patients have already seen a psychiatrist and have received a diagnosis and pharmacological intervention. In these cases, the therapist will liaise with the other mental health professionals involved to determine the best way of complementing existing intervention in the most effective means possible. Also, if a patient presents with a collection of symptoms that might warrant psychiatric intervention, an appropriate referral needs to be made. However, the reader should be aware that some psychotherapists will not work with patients who are taking psychotropic medication, on the basis that such intervention causes the patient to present with an altered or artificially enhanced persona, thereby masking the extent of the problem. Some therapists do not accept the concept of diagnosis on the basis that it labels patients. However, in our practice we do not adhere to either of these philosophies. If a patient has a diagnosis of chronic anxiety and depression following the onset of renal disease, these symptoms might be preventing him or her from complying with the dialysis treatment. Therefore, if psychotropic medications can lift the mood to the point whereby the therapist can interact with the



patient, intervene and help the patient come to terms with what has happened, before slowly decreasing the medication, then so be it.

However, many of our patients do not necessarily have classifiable disorders but relational or emotional issues that they want to explore and that have often been brought to the fore by ongoing dialysis or transplantation. A sense of this will be apparent by listening to the patient during the initial assessment and focusing on the characteristics of an individual and how these have contributed to the problem and how they might be utilized to bring about change. The individual is regarded holistically, which includes individual strengths and weaknesses as well as resources and wider social systems. This is often a very complex business as patients are often deeply rooted in family and work along with financial, peer, and cultural systems. These systems could also hamper or enhance the patient's progress in therapy. The outcome of therapy can very much depend upon how negotiable the relational dynamics of the patient and how flexible the role of the patient is within these systems. The presenting problem might not be the primary problem at all and there might be multiple interpretations and outcomes, which require intervention and contemplation over time at multiple levels. At the end of assessment, feedback is offered to include analysis and summary of presenting problems and an indication of the potential for intervention. If the patient wants to proceed, then the frequency and venue is set with a date for a review. This usually takes the form of once-weekly sessions of 1-hour duration for any number of sessions from a single meeting to an ongoing situation. However, on average most patients attend for twelve once-weekly sessions initially, followed by a review and a graded discharge. The content of sessions remains confidential and is not routinely disclosed to members of staff without the patient's consent. However, patients are made aware that their consultant will be informed that they are attending. Brief details of sessions are kept as process notes under a pseudonym and stored in a locked cabinet for up to a year. The service is funded by a local charity and there is no charge to the patients.

### **Case Illustration**

Recently, I was asked by the nursing staff to speak to an adult son of an elderly female patient (receiving hemodialysis) who had taken to approaching nursing staff every day when visiting, each time in a more agitated and distressed state. The patient had had multiple admissions recently as a result of various medical complications that it was felt she had contributed to by ongoing noncompliance behavior. The son de-

scribed a pattern of events quite eloquently whereby his mother was admitted to hospital, and how her 8 children and their various spouses and offspring would begin visiting the hospital on a daily basis. As the son was talking, I was both listening to him and matching what he was saying with my own observations of this patient. The family presented (to the outside observer at least) as very attentive. They could easily be spotted at visiting time advancing up the ward with an assortment of lavish offerings. She could barely be seen as she was surrounded by balloons, teddy bears, and flowers. In this context, it was obvious that she was very much the contented matriarch of the family.

Accordingly, the son explained how not only was such behavior very worrying for the family, but also that it was very difficult for him to continue to visit the hospital on a daily basis. I was told that she was not coping very well with household chores and cooking and that his mother and father did not get along. They lived in a remote rural area with few visits from family and friends. All formal offers of help with meals and self-care had been refused by the couple. I was instantly struck by the contrast between the busy attentive scene in the hospital and the stark reality of home life. Both the patient's son and I readily agreed that the patient enjoyed attention, a position achieved in hospital, but not at home. This led us on to the next stage, which was voiced silently by me, but vocalized by the son when he said that he just did not have the time to visit their house every day, with his present work and his family commitments.

I wondered aloud about the potential of a scheduling system for visiting spread out among the eight siblings. This intervention might make the mother feel more supported, less isolated, and more inclined to comply with treatment and hence less likely to be readmitted to hospital. However, the son was not optimistic as he had tried this before but his other siblings had proved unreliable—in any case he was the *favorite* and it was really he that she wanted to see every day. The real dilemma for this son was that he felt unable to *stand up* to his mother who had been *manipulating* him all of his life. It became apparent that this had also caused problems in his marriage when he had felt divided loyalty between his wife and mother. He knew that he had to speak to his mother but felt *ill at the thought of it* and that he had inadvertently been *badgering* the nurses to *stand up* to his mother on his behalf. I suggested that he would need to find a way to communicate with his mother and reach some mutually agreeable time and frequency of visits that was compatible with his home life and work commitments. It also seemed to me that the other siblings were reconciled to his favored status and indeed

were making little effort to support their mother when she was at home. We both agreed that he might encourage other siblings to take on a more supportive role building on the point of his centrality in the family. In other words, he would take a coordinating role while other siblings if willing or able would act as directed by him. This would reassure the mother of his ongoing involvement and support, but would create an illusion of a greater deal of involvement than he was actually able to give. If the mother had been younger with a better prognosis this may well have been the time to set boundaries in the mother-son relationship. However, the mother was frail and on dialysis with a not-particularly good prognosis and we were looking for a working alliance within which every one had done their best and there would be no regrets. The reader might see how the presenting problem appeared to be that of the mother's apparent inability to manage with dialysis at home and subsequent non-compliance. The son presented to ward staff each day with the expectation that they would *talk some sense* into his mother on his behalf. However, the primary problem was his inability to stand up to his mother, which was also causing problems in his relationship with his wife.

## **MAINSTREAM PSYCHOTHERAPEUTIC APPROACHES**

There are many different therapeutic approaches, however, the most commonly utilized are those of behavioral therapy, psychoanalysis, and non-Freudian psychoanalysis. Many therapists do not work within one model of therapy and tend to integrate one aspect of a particular model with another. Systemic Integrative Psychotherapy utilized in this book represents a formal systematic model of integration. However, it is lesser known in mainstream psychotherapy but our experience suggests that it is the best-placed therapy to reflect the experience of renal patients, who live with an uncertain prognosis. This therapy will be discussed in greater detail later.

## **COGNITIVE BEHAVIORAL THERAPY**

Cognitive behavior therapy is based upon the premise that emotional problems arise from maladaptive learning, which can be corrected by a process of relearning (Holmes 2002). This process of relearning occurs by the utilization of classic and operant conditioning. The best example of classical conditioning is the work of Pavlov and his work with dogs

and other animals. Pavlov's theory was based on the concept that dogs salivate when food is placed into their mouths, what he termed an unconditioned or unlearned reflex. This scenario is considered in terms of the unconditioned stimulus of the food in the mouth and the unconditioned response of salivation. Pavlov demonstrated that it was possible to train a dog to salivate to a neutral stimulus such as a tone or training stimulus. The training stimulus was produced just before presenting the food in the beginning of the experiment. After this had been repeated a few times he presented the tone, but no food and found that the dogs still salivated, a conditioned reflex. However, the conditioned reflex did not endure after the food had not materialized for a few times, he called this experimental extinction. Behavioral therapy is based upon the hypothesis that classical conditioning is largely responsible for the manifestation of emotional disorders in humans. It has been most successfully and commonly used in patients suffering from phobias. Marks (1969) showed an example of a patient who fell down a flight of stairs and then developed a phobia of all heights (stimulus generalization). From the patient's perspective, all high places became conditioned stimuli that led to a conditioned fear response. It is thought that fears and phobia develop as a result of classical conditioning in which the patient associates a neutral stimulus with a painful experience. The behavioral approach utilizes techniques of flooding (placing the patient in an extreme example of a fear-provoking situation, until the fear has subsided), systematic desensitization (the patient is exposed to an increasingly hierarchical level of difficult situations until the fear is overcome) or aversion therapy (patients are exposed to situations under controlled conditions that have a negative impact upon their life). The main criticisms levied at behavioral therapy is that it assumes that behavior identified among animals can be applied to human beings. Also it is questionable whether the intensity of fear and phobic response experienced by patients in the contrived therapy situations is an accurate representation of that experienced by the patient in everyday life. This then brings into question whether any reduction in fear during treatment is translated into a reduction of fear in the daily lives of the patients. The above-mentioned techniques are discussed in greater detail in later chapters.

## PSYCHOANALYSIS

Freud, the grandfather of psychoanalysis, based his theory upon the repression of painful or undesirable thoughts and memories from the conscious to the unconscious level of thought. Repression maintains

these thoughts in the unconscious, thereby, serving to prevent the manifestation of anxiety in the conscious. The suppressed material chiefly relates to experiences during childhood, conflicts between the instinctive (sexual) motives of the child, and the curbs placed upon their behavior by parents. Freud believed that children passed through the following 5 stages of psychosexual development: the oral, anal, phallic, latency and genital stage. Focus on the mouth during the oral stage soon shifts to the anus (anal stage) during toilet training. This is followed by attention upon their own genitals (phallic stage) and then the genital stage, whereby pleasure is obtained from another person as well as oneself. Any conflict at any of these stages results in a delay at any one stage (fixation). Likewise, as adults do when emotional problems emerge, patients will present with regression in relationship to the psychosexual stage of development at which they had been previously fixed. Treatment was conducted with the patient lying on a couch facing away from the therapist. This positioning was thought to make the patient less inhibited and prevent the patient being influenced by the therapist's nonverbal behavior. Treatment was aimed at curing neurosis by facilitating the patient's access to the repressed ideas and conflicts from the fixated stage. This was followed by the confrontation of any repressed emotions that emerge from the unconscious. Freud suggested that the therapist and patient should also concentrate on the feelings that accompanied the repressed material. The patient is thought to transfer powerful emotional reactions upon the therapist that were historically directed at the parents, family, or peers. In addition to transference, psychoanalysis utilizes the techniques of dream analysis, hypnosis, free association, and interpretation. Freud referred to the analysis of dreams as the access point of the unconscious, as conscious awareness is thought to be much more accessible during sleep than waking thought. Dream analysis is thought to provide insight into patient's aspirations and wishes as they are heightened during dreams. Hypnosis was utilized by Freud in his treatment of patients with paralysis and nervous coughs. Hypnosis is thought to uncover repressed memories as a result of the reduction in cautious thought during the process, including, however, a number of imagined or manufactured memories as well as those that have been repressed. Therefore, hypnosis is not always wholly reliable as an indicator of repressed emotions or future aspirations of patients. Free association involves patients saying the first and subsequent thoughts as they come into their mind. The goal is that those specific repressed memories will come to the fore in the process. However, patients are liable to distort, resist, or become

hesitant to divulge thoughts in an unedited format. Resistance is thought to manifest during treatment in the form of prolonged silences that are often an indicator that the patient is verging on or contemplating something. The therapist's quality and accuracy of the interpretation of the material presented by the patient is central to the technique of psychoanalysis and determines the course of treatment. However, interpretation is not a one-sided affair, as the patient's response to any interpretation will often determine the accuracy, poignancy, and unrecognized complexity of the patient's presentation. Outright denial of the therapist's interpretation by the patient is often seen as denial. One of the most common criticisms of psychoanalysis is that it has not been subjected to scientific research, while the main obstacle to quantifying psychoanalysis is that it would need to involve the stimulus of neurotic states in patients. Also, the convoluted and historic nature of the material produced during psychoanalysis can be complex and difficult for patients to apply to their daily lives in the present and may appear disjointed as it is dependent upon the accuracy of past memories.

## NON-FREUDIAN PSYCHOANALYSIS

Many of Freud's followers became concerned at his sole focus upon sexuality and his lack of consideration of the role of social factors as being at the root of emotional distress (Adler 1928, Horney 1932). Emphasis remained upon social problems as the main causative factor of neurosis even when the patient presented with sexual dysfunction. Therefore, non-Freudian psychoanalysts placed much more importance upon social factors, particularly what they saw as the repression of women and conflicts arising from interpersonal relationships. In contrast to Freud who attributed great importance to sexuality, neo-Freudians preferred to consider neurosis from the point of culture. In short, it was thought that one's emotional state in adulthood could be understood in terms of the culture in which he or she was raised. Therefore, the causative factors of emotional disorders might vary from one culture to the next. The effect of culture on the manifestation of emotional disorders is discussed in greater detail in chapter ten. However, the goals of treatment, the identification of repressed unconscious feelings and experiences, and facilitating the patient's emotional insight into these problems remain the same as in psychoanalysis. In contrast to Freudian psychoanalysis, patients are not required to lie on a couch, but in what is considered to be a more natural interactive positioning, face to face in an armchair.

## SYSTEMIC INTEGRATIVE PSYCHOTHERAPY

The experience of ongoing chronic illness and major surgery causes these patients to consider their own existential reality somewhat prematurely. It also creates a heightened sense of awareness of time—in terms of time lost to chronic illness, present time focused upon survival, and future time remaining to them with or without a transplant. Systemic Integrated Psychotherapy (Clarkson & Lapworth 1992) compiled to be sensitive to “the evolution of time” appears well suited to this client group. Further, it is capable of reaching across time, by virtue of its integration of existential (present), psychoanalytical (past) and transpersonal (future) perspectives, essential to emotional stability and personal development after transplant. The ability of this model to incorporate such an expanse of time offers continuity throughout the transplant process. The emphasis is upon “framework” as opposed to “theory” or “model,” to allow the therapist to accommodate patient needs. We have found that this form of therapy best accommodates the needs of patients and reflects their heightened sensitivity to time. Patients view their life through three time zones: the past (time lost to chronic illness), present (based upon daily survival), and the future (time remaining to them). During dialysis, the focus is very much on the present, which manifests during therapy as doing what they need to do to survive; there is little personal development during this time and they barely glance back (past) or forward (future). After transplantation, patients are concerned about reconciling the past lost to chronic illness. There is often much talk of “getting back to normal” after transplantation. However, “normal” is defined in time past and is often not a realistic baseline after transplantation, as time has moved on. Ordinarily, individuals develop, or change over time (defined in terms of attitude, behavior and perspective), a phenomenon, which is often reflected in their interaction and the nature of their relationships with others. However, for patients receiving dialysis, time and personal development often stagnate, while family and friends continue to make progress in their lives. Therefore, after transplantation, patients often find themselves in a sort of “developmental limbo” in which they can flounder. Much of the therapist’s work after transplantation involves helping the patient to redefine “normality” based on their present physical ability and emotional availability and gently contemplate the future. Normality might be determined differently after transplantation but that doesn’t necessarily mean that it was inferior or any less worthy before. We often suggest to patients that life might be *different* after transplantation, but not necessarily any less meaningful than their premorbid life.



The theoretical integration or "theory mashing" of different theoretical orientations and techniques of psychotherapy came about in the hope that collectively they would be more effective than the individual theories. Systemic Integrative Psychotherapy integrates psychoanalysis (past), existential (present), and transpersonal (future) theoretical models. In other words, it is based upon the need to consider needs over a time span, which includes past, present, and future perspectives. These are recalled during therapy sessions and give continuity over the transplant process over an undetermined, or uncertain period of time. This specific form of therapy places great emphasis upon the concept of "time," and more specifically, movement through time, a common concern among kidney transplant patients. Time is described as spanning "back" (downwards) to the past, "through" the present, and "upwards" to the future. The time spent in therapy is considered to be a mere moment on the scale and the counseling relationship relates to a point in "time" of the client's life. It has been suggested that it exists existentially in the present as a working psychotherapeutic alliance in order to accommodate current life experiences within the family, friendships, and practicalities which make up daily experiences and which are often complicated by feelings of loss, conflict, and confusion. In turn, the relationship is likely to regress to the past as the patient recalls early childhood and experiences of chronic illness which have led to current feelings of conflict, confusion, and loss. In considering the past, counseling relationship is liable to psychoanalytical concepts of the transference and countertransference. As the past is left behind, it is thought that the future comes to be contemplated as a more realistic option with emphasis upon the transpersonal or aspirational time of the future. This is largely uncharted territory for most patients, but among transplant patients, this concept is particularly difficult to contemplate and complicated by fear of rejection of their organ. However, it is important that this aspect of uncertainty is overcome so that the patient can begin to contemplate the future and the direction in which treatment is heading.

The transpersonal is the spiritual arm of the approach and introduces a personal and interpersonal element into a therapist's work with patients. In short, these include aspects of the patient's life (experiences, aspirations, behavior, and relationships) that have not been realized or acknowledged in some cases. Among psychotherapists generally, the transpersonal has become associated with the realization of a spiritual path and can encompass a number of elements including, psychosynthesis, Jungian approach, meditation, Buddhism, dream work, and imagery.



## CASE STUDY OF INDIVIDUAL PSYCHOTHERAPY

Marion is a 45-year-old married woman with sons of twelve and seventeen years. She was diagnosed with diabetes at 18 years of age; initially the disease had not impacted adversely upon her life. She had progressed in her publishing career to a senior editorial position. However, in keeping with the progressive nature of the disease, her eyesight began to deteriorate to the point whereby her vision was blurred, her mobility became restricted, and her kidneys had failed 5 years previously. She underwent hospital-based hemodialysis three times a week and became a chronic noncomplier with fluids. Although transplantation was her goal and the main motivating factor in life, she was frequently suspended from the transplant list due to medical complications. Marion attended psychotherapy once weekly before her dialysis session. This often became quite a culinary affair as our session invariably coincided with her lunchtime. Marion is a real devotee of food and was not prepared to reschedule her meal times. We would sit in my small office with a cantilever table between us upon which she would ritualistically unpack various containers and lay out a feast fit for a queen before avidly devouring everything.

### Presenting Problem

Marion considered that her high intake of fluid, coupled with insomnia, were detrimental to health and were constantly *getting her into trouble* with the physicians and nurses. Excessive fluid retention curbed her mobility, making her more dependent upon others for her personal needs, while the ongoing insomnia made her anxious and exhausted. She often referred to her *bigger problem*, namely, the deterioratory effects of her illness. A common retort at the beginning of treatment was, *look at the state of my hair*, alternated by *this (hemodialysis) takes up so much of my life*. Further, the abrupt end to her career was a great source of frustration and disappointment to her, which was often expressed indirectly or in a misplaced fashion by her intolerance of those she considered to be her intellectual inferiors.

### Initial Assessment

Marion arrived at the initial assessment slumped in a wheel chair, unable to walk. She informed me that her increased body weight was as a result of excess fluid, her hair was falling over her face, to the point

where it was almost obscured, she wore no makeup and her clothes appeared too small and not to match. The impression was that of a lady who looked and felt tired and disheveled. Much of the initial session was taken up with her relaying her medical history and her experiences of medical staff.

It is not uncommon for patients with chronic illness to define themselves in terms of their illness. The psychotherapist needs to tease out or find a way to differentiate the patient from their illness during the initial session. This differentiation needs to feature in the therapist's summing up at the end of the initial assessment as a means to sustain the patient through the seemingly unending routine of dialysis and as a method of tentatively pointing to the future. The individual patient's point of differentiation from his or her illness might manifest as a personal ambition to attend college, marry, or adopt a pet. These personal ambitions are often tentative and so precious that they are rarely referred to directly during the course of therapy and I suspect not mentioned at all outside of our sessions together. However, I often spend a little time with patients once they have arrived back from operating room following transplant. It is at this time, still woozy from anesthetic and amid the hustle and bustle of lines going in and machines being set that they start to refer directly to these ambitions and how they might actualize them into the practicalities of their daily lives.

Marion was very angry at what she saw as other people's overly sympathetic attitude toward her. Prompted by me she went on to describe how family and friends focused on her symptoms, as opposed to treating her as the intelligent lady that she was. The reader should note the disparity between her internal (how she felt) and external (how she presented to others, or how they perceived her) frame of reference. At this point, I wondered aloud, gazing slightly away from the client (as if contemplating to myself, to lessen the impact and to prevent her recoiling behind her hair again), whether she felt that others were quite literally unable to *see* who she really was, apart from her illness. In other words, as she could not *see* others very well, how well could they *see* her, if at all? Marion indicated that she certainly felt *invisible* at times, particularly since she had been in her wheelchair primarily as a result of excess fluid, except when in the dialysis room with the nurses bemoaning her excess fluid. I realized that noncompliance with fluids served to keep Marion *visible* (as opposed in *invisible*), albeit, not in the manner that she might necessarily wish to be viewed, but nevertheless *visible*.

The working hypothesis at this point in treatment was that noncompliance with fluids served to ensure that the medical staff did not forget

the patient. However, fluid overload served to debilitate her and reinforce the perception of her as disabled. Therefore, in reality, she might be more entrenched in the chronic illness role than she admitted (to me anyway). One of the goals of therapy would be the need to separate her from a position whereby she drew attention to herself from a point of negativity to a position of positivity.

When these issues were discussed, Marion chose not to respond directly (this did not necessarily mean that intervention did not resonate with her), but went on to express the hope that therapy might help her to cope a bit better with her illness. In turn, I suggested that in “time” (defined in terms of the sessions—a moment in time, and developmentally) she might find a way to express her individuality more comfortably within the bounds of her illness. At the end of the initial assessment it was agreed that we would meet once weekly for one hour over the course of three months. The situation would be reviewed at this juncture and had the potential to be extended for three-month periods if necessary. In this particular case, sessions were reviewed and extended three times.

### **The Development of Therapy—Pattern, Plan, and Intervention**

Marion attended every session with the exception of prearranged holidays and two absences due to illness. She never arrived in a disheveled state again. Whenever we met, she was always in full makeup, which included bright orange luminous (beacon-like) lipstick, coordinated clothing, and natty accessories. Indeed, from then on she would regularly delve into her voluminous handbag from which she would extract a compact and begin preening and primping (just to let me know that she had her eye on the ball).

During the first 3 months or so of our sessions, Marion would talk incessantly. Long convoluted stories of her immediate family were described in great detail. She seemed unable, or perhaps unwilling (too much risk of personal exposure and subsequent vulnerability) to describe her feelings in a straightforward manner. It became difficult to make any sort of intervention, or bring the session to a close in a face of what felt like a stone wall of words. Initially, I viewed this presentation as a reflection of how the patient was feeling. In terms of intervention, I tried to identify the themes, similarities and contradictions between her experiences. In keeping with most dialysis patients, Marion rarely drew upon past (defined in terms of premorbid) time; neither did she appear to have any idea as to how to resolve her current issues. However, I

needed a point of comparison or a base line to understand how these conflicting relationships had arisen and therefore started to probe using open and closed questions as to the origins of the various strands of discord between members of her family. Once again, Marion did not respond positively to this more direct approach and appeared not to hear.

One of the most discerning patterns of our interaction was, that very often, Marion did not appear to hear or did not acknowledge meaningful or poignant intervention from me at the time that the intervention was made. However, she would often refer to these as her own (as if it had never been uttered previously) during later sessions. One possibility for such behavior might be seen as a means to hold my attention, but more likely this was her way of controlling the pace of the sessions and access to her own thoughts.

### Key Content Issues

The main content issues centered around her relationship with her husband and two sons, which was strained and compromised. Like many other patients on dialysis, Marion would often recall friendships that had not endured her illness, partly as a result of the unpredictability of her illness from day to day, which made it difficult to plan and keep social engagements. However, she also felt that many people did not have the ability to make the extra effort needed to maintain a friendship with a chronically ill person.

Marion experienced the transplant team as unsympathetic to her needs. She felt that they ignored her at times, which made her even more anxious. From the detailed account of interactions and exchanges that Marion brought to the sessions, I felt that she was becoming quite aggressive in her demands of the nurses. In response, the nurses seemed to retreat from her. I waited for her recollection of the next encounter with the nurses and quietly reflected that she sounded quite *aggressive* when she recalled this incidence. We hypothesized whether she might also sound *aggressive* to the nurses and pondered the difference between appearing *aggressive* as opposed to being *assertive*. We refer to assertiveness here more as a means to communicate competently; "competence" defined in terms of receiving the required response (intervention from the nurses). The remainder of the session was given over to refining the art of assertive and concise interaction with others, taking in voice tone and body language, particularly facial expression. A bemused nurse involved in dialysis room later recalled how Marion had played out this session as she had sat thronelike on her chair, attached to the machine in full ther-

apy mode and with acquired accent and mannerism not dissimilar from mine. Marion also started “coaching” her equally bemused fellow dialysis patients on how to be *assertive* but *concise*. I have always believed that psychotherapists should never take themselves too seriously and maintain the potential for humor and this is a case in point. However, this also confirmed a suspicion I had for sometime, that Marion needed to be different from other patients, whether this was from a point of negativity (noncompliance) or positivity (possessing superior knowledge). Being in therapy itself may well have served to differentiate her from fellow patients. The concept of individual difference is discussed in greater detail in relationship to noncompliance in chapter two.

Marion worried that if her health continued to deteriorate she might not live long enough to see her sons move into adulthood. More specifically, she retained an ongoing concern regarding her son’s memory of her which manifested two-dimensionally, first that he would only remember her as disabled (unable to walk and without much energy) and more worryingly that he might not remember her at all. These are common concerns that we have seen not only among renal patients with young children and grandchildren and have been well documented by our colleagues in other areas of chronic illness. We want better for our children than we had for ourselves, but we also want to be alive to see it. In an attempt to develop the session in a reassuring and productive way, I recalled how Marion had become dismayed during a previous session when recalling an event she had suddenly stopped and exclaimed *I sound just like my mother*. Parents are recalled and kept alive by virtue of being able to recollect their parent’s physical appearance, talents and interests, mannerisms, feelings, sensations, figures of speech, the passing on of family rituals, all of which create a familiar aura and generational connection. A patient whose parent died when the child was quite young (usually under four years of age) often becomes quite distressed when unable to recall (as an adult) the face of a parent. The rest of the session was spent exploring ways in which she could leave an emotional and physical legacy for her sons. This could be through the reinforcement of mutual talent, interests, rituals, and quality time together which reinforced by the bequeathing of a photo album and compilation of her drawings.

The matter of Marion’s marriage was a slightly more ominous affair with which she became increasingly preoccupied. It was complicated further by her staunch defense of her husband’s bullying behavior toward her and their children. I was also becoming worried at the negative effect that their obviously deteriorating relationship was having on her health

and was keen to try and find some working solution to calm things down in the interim while a longer-term solution was contemplated. The general pattern of our interaction during the first few months took the form of Marion proclaiming her unhappiness at her husband's latest misdemeanor. I soon learned not to pursue or probe into these proclamations but just utilized the silence that followed them to ramify whatever thoughts that were running through her mind. Free from my intervention, Marion began to fill the silence by articulating her thoughts and recollections. She recalled how bad-tempered he was when arriving home from work. Further, in common with a lot of women with renal disease with whom we have worked, she appeared to withhold the extent of her medical condition from him. *I didn't tell him about the infection, there's nothing he can do . . . I can't expect him to put his life on hold because of me.* Whether it was therapy, a combination of therapy and life experience, or completely unrelated to therapy, there had been a shift in her expectation of her marriage. In Marion's view her husband was *hopeless with money* and *uneducated* and had only married her because she was *good with money*, indeed, *actually had some money* and was educated. In her opinion, the combination of her money and education had elevated him professionally from the janitor to the owner of an apartment block. It seemed that before the onset of renal disease, this arrangement had worked out well. However, the onset of renal disease had rendered her a *shadow of her former self* and she felt that she let him down and that he was disappointed and *looking to another woman to prop him up*.

Acute periods of antagonism and discord between her husband and herself could be directly related to noncompliant behavior and melancholic episodes. However, she remained compliant with our sessions. During such episodes, we would often spend long periods of silence only broken by her own contributions with interventions when appropriate by me. At no time did I attempt to break the silence, as I did not wish to create the expectation that she needed to speak or interrupt her thought process. It was during these long silences that I recalled a comment from a previous supervisor and psychoanalyst in New York: *you know, this (psychotherapy) is a funny old business. It's not just about what the patient tells you (the therapist) but what they tell themselves.* In other words, the patient was using our sessions as a sanctuary to reflect on whatever it was that was troubling her.

I was never entirely sure of the intricacies of these events and I am not sure that I really needed to. However, it should be remembered that dialysis (as with other chronic illness) often compromises a woman's femininity, defined in terms of her ability to end and initiate new rela-

tionships. This keeps them focusing on the present, powerless to change either the past or the future in their present predicament. Low self-esteem, physical disfigurement, and financial considerations often cause patients (mainly women) to remain in relationships, which no longer work for them (chapter seven). However, it was important that my behavior contrasted with that of the nursing and medical staff who would be berating her about excessive fluid intake. I understand that this was quite difficult for the rest of the team but one more voice to the chorus would probably have made little difference. I do not mean to imply that the nursing and medical staff behaved incorrectly; indeed they would have been failing the patient not to point to the danger of noncompliance. It is just that we each expressed our concern in different ways in keeping with the ethos of our respective professions; the cumulative effect was to encourage the patient back to a position of compliance.

I attempted to support the nurses in their management of this very volatile patient making practical suggestions and acting as a vent for their frustration. Physicians can be very hard on themselves when patients do not comply with treatment. I try to support them in the knowledge that they would have offered counseling and done their best to facilitate compliance. However, given the dramatic shift in compliance behavior that was synonymous with the beginning of therapy, it became important that we maintained a dialogue (even a mute one) and did not ostracize the patient. Marion redefined her own self worth in terms of the value that her sons obviously placed on her and the ability to feel worthy of herself. This would ensure that she had multifaceted ways of defining her self worth and would make her less vulnerable to her husband's *whims* and *moods* and which would lead to improved compliance.

Marion received a cadaver transplant after 6 years of dialysis. The transcript below is an extract from our first session after the transplant.

### *Session ninety-three (5 days after transplant)*

Marion enters room on sticks (as opposed to a wheelchair) and smiles as she sits down.

**Marion:** *See, I am on sticks and I am standing up.*

**Psychotherapist:** (Big smile) *Yes, I can see Marion. How does it feel?*

**Psychotherapist's thoughts:** Given the patients previous preoccupation with being *seen* by others, the psychotherapist attempts to reassure her that indeed she can *see* her, but she tries to broaden her perception of herself to how the patient might be *feeling*.



**Marion:** *I can hardly believe it, although I knew that it (transplant) would happen one day.*

**Psychotherapist's thoughts:** I can hardly believe it either, you have been off the transplant list so much due to illness that I was not sure that you would get a transplant.

**Marion:** *My head's racing. I still can't sleep. Other patients told me that the sleep gets better after transplant but it hasn't.*

**Psychotherapist:** *Mmmh.*

**Psychotherapist's thoughts:** I am not intervening, as I do not want to interrupt her freely flowing thoughts just staying with her physically in the form of my ongoing presence in the session in an attempt to determine what exactly is *racing* through the patient's mind.

**Marion:** *Every time I close my eyes I can see them, you know.*

**Psychotherapist:** *Can you tell me what it is that you can "see?"*

**Psychotherapist's thoughts:** Who does she mean by "them?"

**Marion:** *Those other patients I dialyzed with, those who didn't make it. (Marion assumes a far-off look, stares at nothing in particular, appears to be at another place). There was a young girl, Susan, she took a turn one day on the machine, right in front of us all. There were lots of nurses and doctors trying to bring her round in front of us all, no curtains, nothing. I didn't know where to look; none of us were looking at each other; it was like we were avoiding each other's eyes, like it wasn't really happening. They never did bring her round and nobody ever mentioned it again. Some of the patients in my room deteriorated so badly that they virtually took up residence in the hospital. They would get wheeled in on their beds and we would all greet them, all smiles and cheer, but we knew.*

**Psychotherapist:** *It sounds as though there was some obligation to be "cheery" for each other. But I was wondering how it felt for you.*

**Psychotherapist's thoughts:** This is the first time during any of our sessions that Marion has attempted to recall or reconcile events in the past, a notable shift from preoccupation from the present (before transplant) to the past (after transplant), a general trend that we have observed among these patients. In keeping with the concepts of Systemic Integrative Psychotherapy, intervention becomes more analytical. There were a number of interventions that could be made by us at this point. She could explore what it was that they (patients) all *knew*. Presumably, this was a reference to each of the patient's own mortality but if the therapist was to pursue this avenue in a one-to-one situation, then we would inevitably be faced with the matter of our own mortality. I tried to personalize the experience, by moving the patient from her own use of the plural (*we*) to the singular (*you*). Also by focusing on how it *felt* as opposed to what she *knew* of dialysis and watching fellow patients deteriorate and die literally in front of her eyes.

After a few minutes, Marion focused again on me and somewhat dramatically heaved herself into an upright position as if bracing herself for something.



**Marion:** (Patient personalizes her feelings) *I still cannot believe that I* (possibly as opposed to fellow patients who did not) *got a transplant.* (The next sentence was uttered with hands and eyes tightly shut in a determined fashion.) *I always knew that I had to hold on in there* (as opposed to those patients who did not), *I am exhausted.*

**Psychotherapist:** *“Holding on in there” feels like a difficult and unpredictable place to be.*

**Psychotherapist’s thoughts:** Marion appeared to have followed my lead and chose to personalize her experience but has not done so in a way that explores the issue of her own mortality. However, given her tendency to reintroduce difficult issues at a later date this subject may feature in either an overt or covert manner in the future. From previous sessions, it had become apparent that she had not been at all sure that she would receive a transplant and during her long hours on dialysis may well have had plenty of time to contemplate and prepare for her own death. This was presented initially as a concern that her son might not remember her.

**Marion:** *Mmmh, it was I can tell you, if I could just get some sleep.*

**Psychotherapist:** *In order to sleep you would need to relax, quite the opposite of the more tense experience of having to “hold on in there.”*

**Marion:** *Yes, all the time I felt tense, just staying focused, just staying alive.*

**Psychotherapist:** *“Felt” or feel tense?*

**Psychotherapist’s thoughts:** Is this state ongoing in the present as opposed to the past and how might it be related to the prevailing insomnia?

**Marion:** *Well, now you come to mention it, I still feel tense.*

**Psychotherapist:** *I am wondering whether sleep continues to allude you, because it entails the opposite of “holding on,” rather letting go. Sleep is an unknown and uncontrollable quantity not unlike (death), the unknown quantity that has been your reality since the onset of renal disease.*

**Marion:** *I don’t feel that I can let go just yet, results are good, but you never know.*

**Psychotherapist:** *Maybe, given the good results, you could relinquish your grasp just a little.*

**Marion:** *Do you think that I should start playing my relaxation tapes again?*

**Psychotherapist:** *Sounds like a good place to start.*

**Psychotherapist’s thoughts:** Ordinarily, therapists avoid leading the patient. However, patients who have suffered chronic illness for some time often emerge into remission with a certain amount of institutionalization and very often need a few prompts and reassurance as they take the first few hesitant steps toward independence.

Three days later, I was walking through the noisy outpatient department and spotted Marion, fast asleep balanced precariously on a standard hospital waiting room chair oblivious to the full chorus that generally accompanies the waiting area outside consulting rooms.

## THE PSYCHOTHERAPIST AND CRISIS INTERVENTION

Emotional and relational crisis intervention is by no means the sole prerogative of the therapist. Social workers, occupational therapists, nurses, and health professionals who place an emphasis of the social well-being of patients are equally well equipped by virtue of their professional training to intervene. However, in such situations each professional will converge his or her particular skills and quite possibly a few acquired along the way aimed at sustaining the patient through the crisis and restoring some kind of equilibrium in the patient's life. As we have mentioned, patients with an ongoing chronic illness are compromised socially, relationally, and emotionally as they go about their daily life. Therefore, when called upon to attend to patients in relational and emotional crisis, professionals often find themselves working in a more focused manner determined by the urgency of the situation. These interventions are more than likely to be conducted in unorthodox situations and with patients whom they might not otherwise have come into contact with. Crisis intervention has been discussed in greater detail elsewhere (Dattilio & Freeman 2000). We present a short case example to illustrate this point.

### CASE STUDY OF CRISIS INTERVENTION

David is a 72-year-old gentleman, married for the second time, but with two adult children from his first marriage. He had been attending our hemodialysis center for six years and was not considered suitable for transplantation due to poor cardiac reserve. He was referred to me by a nephrologist who had become increasingly concerned about his behavior. His gradual transformation over the few months leading up to the referral was from a *hardy, forthright character* to withdrawn and emotionally labile which had seemed a dramatic change to the patient whom staff had come to know. On the day of the referral, he had entered the dialysis room in an agitated state and had delivered a torrent of verbal abuse to the nurse who had attempted to put him on the machine. The nurses had subsequently placed the patient in a side storeroom and called the physician, who subsequently called me. When I arrived approximately thirty minutes after the incident, the patient was sitting in an armchair surrounded by boxes, his head in his hands. On hearing me approach, he looked up and adopted a suitably contrite expression. Introductions were exchanged and the door of the dingy store room was

closed behind me by some member of staff. As I looked around the room for somewhere to sit (it was the end of a long day and in any case I needed to be at the same level as the patient during our interaction) it seemed that a coffee table was my only option. So this was “us,” the stage was set, one contrite patient in a battered old armchair and the therapist perched on a coffee table surrounded by a stack of ominous brown boxes. However, the patient did not seem to be aware of the absurdity of this state of affairs so who was I to complain?, I thought, this is the National Health Service, a government-run free service, in all its glory.

**Psychotherapist:** *I was wondering if you could tell me what you think might have caused you to become so upset today?*

**Psychotherapist's thoughts:** Yes, he needs to apologize to the nurse, but I need to try and move him on for now to try and bring some clarity to whatever is bothering him.

**David:** *Can't really think of anything in particular.*

Further questions were met with profuse head shaking (I could detect a hint of a sheepish self-indulgent smile), that he was a *stupid old bugger, fed up with coming here* (dialysis) and *he should do everyone a favor and just curl up in a corner and die*. After this repartee had been repeated a few times to no avail, I decided to take a more indirect route so as to prevent backing the patient into a corner and to try and identify some clues as to what might be bothering him. I was aware that the sheepish self-indulgent smile was in some ways quite playful almost as though he knew that he had caused offense, or not behaved in a wholly fair manner to either himself or some significant other person in his life. It could be that the self-derogatory prose had served as a means to balance that in the eyes of the psychotherapist and possibly himself. Direct inquiry as to his working life and family revealed that he had spent much of his working life as a taxi driver in the neighborhood in which he had lived since a child. He had two adult children (a son and a daughter) from his first marriage to an alcoholic, but it had ended after ten years. He described this time in his life as *chaotic*—he did not consider his first wife to be a very *good housewife*. Contact with his children following his divorce had been intermittent, in particular he found his daughter difficult to interact with. However, he had maintained regular contact with his son, meeting at some halfway point between both houses for a meal every week until his son's job had necessitated a move to another part of the country. Since that time, his son had not returned to Scotland and the patient had not heard from him very often. The patient's second

marriage had by his own admission not been very *happy*—while she had been a *good housewife*, the *kindly girl* he had met and married had effectively *ignored him* for the past ten years of their marriage. David said that he had contemplated leaving the house a few times but did not have anywhere to go. In addition, his illness had made him feel tired and he did not have the energy to play golf anymore. His golfing buddies had also lost interest and stopped calling on him. David added that his mother and sister had died quite suddenly about five years ago. I contemplated silently that there had been quite a lot of loss in the patient's life over the past five years, namely the loss of a mother, sister, and various golfing friends, quite apart from the fact that his ongoing renal disease had created a loss less easy to conceptualize, a loss of the way of life as he had known it as a result of lethargy and lost time spent on dialysis. However, these losses had happened gradually over a period of time. Furthermore, David was presenting the larger picture of his life as a means to conceal or to more slowly come to terms with what had caused his current upset. While the loss of any of these relationships could be upsetting, it was the relationship with his son that had been most traumatic. Also, if the cumulative effect of the various losses had served to make the patient feel lonely and isolated, the relationship with the son appeared to be the only one that could potentially be re-established. I was just about to explore the circumstances of this separation a little further when the patient intervened:

**David:** Delivered in a slightly impatient tone but with the same slightly sheepish grin as used previously. *The thing is, I seem to have fallen out with my son.* David looked at me expectantly, almost as if to say, get a move on we need to go a little faster here.

**Psychotherapist:** Responding almost immediately and with a hint of exaggerated enquiry. *Seem to have fallen out with your son?*

**David:** A little too defensive as if to say we don't need to move that quickly. *I don't know what I have done. I have hardly heard from him since he went away.*

**Psychotherapist:** Delivered with a deliberate air. *Mmmh. Tell me about your son?*

David began moving his head from side-to-side as if contemplating whether or not to tell me something. He continued in this vein for a minute or so before leaning toward me in a conspiratorial manner. Then he started whispering (although there were only the two of us in the room) in a tone that seemed to imply that he was talking to someone with severe learning difficulties (almost like I should have known all along).

**David:** *Well my son is g-a-y, of course.* Then he leaned back in his chair, folded his arms and looked at me as if to say, “so what are you going to do about it?”

**Psychotherapist’s thoughts:** Ah!

**David:** *So what do you have to say about that, doctor; you tell me.*

**Psychotherapist:** *At this point in time I am wondering what you have said about it, or more specifically what you have said about it to your son.*

**Psychotherapist’s thoughts:** We are getting there, or not as the case may be.

**David:** Looking decidedly shifty and unable to make eye contact with me. *I have not said anything, never mentioned it.*

**Psychotherapist’s thoughts:** I am not entirely sure that David is telling the truth but the homosexuality of his son may be the key to the distrust and lack of contact between father and son.

In crisis situations when patients are not forthcoming, it is often possible to pattern-match the situation to the common cultural drift and hypothesize aloud in an apparently abstract manner and await a response. In this case, I was well aware that Glaswegian culture was not particularly conducive to homosexuality, particularly among David’s generation. I suspected that given my observations of the patient and his interaction to date, that not only would he have difficulty coming to terms with a homosexual son, but that it had also been a source of tension between them or even an argument. I adopted this scenario as a working hypothesis and decided a direct confrontation from me would cause him to retreat and would not advance the session in any way. I suspected that David was one of a growing number of men of his age group who missed the generational connection to the sexual shifts in perspective. They present with attitudes and opinions that are a variant on the prevailing social environment, apparently untouched by the forces of cultural change. This usually pertains to the social role of women, attitudes toward race, and homosexuality. Therefore, they end up disconnected from their children and grandchildren and the support and companionship that they need to endure chronic illness. That is not to say that they are oblivious to such cultural trends, rather that such trends to too much of a variant on their own early socialization process prove irreconcilable or they face the fact that they do not have the skills to bring about a reconciliation. In David’s case, he was aware that his negative views regarding homosexuality were out of step with current social trends and had brought about a rift between his son and himself. He was also aware that he did not have the skills to single handily bring about the reconciliation needed with his son. The ongoing conspiratorial nature of our interaction, the pragmatic

emphasis that he placed upon resolution, and dogged way that he carried out my suggestions tended to suggest that he sought skill and insight from me to bridge the gap between his son and himself. I retained a certain amount of admiration for David, not only for recognizing that he needed help and sought it out, but that he teamed up with a therapist (possibly another product of the social revolution that he managed to miss) and a female one at that.

**Psychotherapist:** *I wonder though if your son might anticipate that you might find his homosexuality difficult, shall we say? I looked directly at the patient, paused for effect (to let the David know that I was going with his version of events and that he need not get defensive), then he might not only try to conceal his sexuality from you, but put some distance between you. Possibly unable to carry the ongoing burden of concealing who he really is.*

**David:** Leapt up in the air jabbing his finger at me. *Yes, that's definitely it, you've got it, spot on. So what do we do doctor?*

**Psychotherapist:** Keen to convert the plural "we" to the singular as a means to revert the responsibility for change onto the patient. *What would you like to do?*

**David:** *I miss my son, I am not really up for this homosexuality business but I don't want to loose contact with him. He has done well for himself; he is a senior engineer now, you know.*

This mixture of pride and disdain often characterize rifts between parents and adult children never fails to amuse me. However, it is also a good factor to build upon in trying to bring about reconciliation between patients and their estranged family and friends.

**Psychotherapist:** Aware that I was taking the lead but mindful that this impromptu session had lasted an hour and that I had a scheduled patient waiting. *I was wondering how you used to maintain contact with each other?*

**David:** *Oh, he would call me.*

**Psychotherapist:** *How would you feel about calling him?*

**David:** *Yes, I suppose I could.*

David telephoned his son, although to this day I am not sure what was said between father and son. However, in a follow-up session David informed me that he had visited his son and was planning on buying a weekend caravan in the same town. He informed me the caravan was to be a bachelor pad and the illusive *somewhere to go* from his second marriage. Shortly after our session, David reverted to his artful and forthright self, a larger-than-life figure in the dialysis room. However, he remained a big fan of the counseling service and I suspect that he was behind a

flurry of referrals from other patients in the dialysis room. His reconciliation became more poignant as David did not make it to transplant and died a year later of stomach cancer.

The above case illustration not only serves to recall one of many crisis sessions staff are called upon to diffuse, but that psychotherapy can prompt a change in perspective or behavior in patients without the therapist really being fully aware of all the details of the patient's experience. Further, it shows that emotional problems experienced by renal patients are not always directly attributable to their illness. Rather, the ongoing experience of chronic illness compounds their everyday dilemmas and erodes their confidence, tolerance, and emotional stamina to resolve them alone.

## **GROUP PSYCHOTHERAPY**

Individual and group psychotherapy both aim to benefit the patient emotionally, socially, and relationally as defined above as a means to promoting a patient's understanding of him- or herself. Meanwhile, the therapist aims to facilitate such personal growth through interpretation, intervention, and reflection in response to the stories, thoughts, hopes, ambitions, fears, and recollection that patients bring to sessions. In both contexts, a satisfactory psychotherapeutic alliance is a prerequisite to effective outcome. However, in a group situation they will be expected to interact with other group members, including the psychotherapist.

In the group situation, as opposed to individual psychotherapy, the therapist needs to attend individual and group interaction. It is through group and individual interaction that themes emerge which in turn facilitate the progress of the group. However, too much or indeed too little intervention on the part of the psychotherapist can hinder or totally suppress the process of the group. During individual therapy, the therapist will be concerned to contrast, invite comparison, or pattern-match stories and recollections in keeping with the patients' past or present experiences and hopes for the future. In the group situation, he or she might use one patient's experience to encourage other group members to contribute similar happenings or as an opportunity to compare or contrast experiences between group members. Similarly, if members ignore, deviate, act in a dismissive manner, fail to give proper consideration, or avoid particular themes, he or she will need to decide whether to draw this to the group's attention immediately, in the future or at all. It is the depth of understanding and ability to make decisions as to what is happening in the group that differentiates the lay from the professional therapist.



## The Evolution of the Group

As the group evolves, the therapists will need to be aware of the characteristics and properties of group life. These have been summed up for the pragmatic clinician who needs to know how to intervene with a particular patient at a particular point in time and identify benchmarks in treatment, and how to facilitate and indeed recognize change. In considering change, the therapist is alert to shared beliefs of group members, the agenda and hidden agenda, moods, atmospheres and emotional contagion, cohesiveness, development, and change. We have spoken previously about the goals of individual psychotherapy; however in this context there are often two sets of goals, those of the group and those of the individual group member.

## Goals of the Group

The majority of group members will enter into group therapy with common goals, or what is often referred to as a “mission statement.” Common goals generally refer to what the patient hopes to achieve by attending the group. In case of renal patients, this is often articulated as the need for support and the exchange of shared experiences among fellow renal patients. A posttransplant patient who was having difficulty coming to terms with the time spent on dialysis and the inability of family and friends (however hard they might try) to come understand his experience suggested that *there should be a place where transplant patients can go*. In other words, a *place* were patients are living with the same past (heightened sense of own mortality on dialysis and waiting for a kidney transplant) and the same tentative future (uncertainty as to how long the transplanted kidney would last). When this statement is explored further, the *place* would ideally have been a different planet, but in the interim, a group would do.

There will also be unarticulated individual goals and motivation for attending the group, which will often remain unsaid and manifest as an undercurrent. Much of patient’s satisfaction with the group will depend upon the therapist’s ability to recognize, explore, and confront these issues. This is achieved through listening to experiences of others, by articulating their problems, and receiving supportive intervention either from the therapist, fellow group members, or both. Group members might also have predetermined ideas as to how the group will be managed concerning issues such as conflict, the formation of subgroups, volatility, and outbursts of emotion. The ability of the therapist to manage



or facilitate the group and the quality of his/her appropriateness and intervention will have a direct effect on patient's confidence in the group and willingness to share and explore meaningful issues.

### **Norms and Shared Beliefs**

Norms or expectations as to what constitutes acceptable and nonacceptable behavior among group members might differ. The manner in which many group members will behave will largely be reflected by their cultural or family background. One of the most apparent norms can relate to individual modes of expression, for example, the use of sarcasm or ridicule, which might be acceptable to some patients, but not to others. Furthermore, there is always a danger in socioeconomically mixed groups that the better educated and more articulate patients might articulate their thoughts, while the less educated either feel intimidated or inadequate. There is also a tendency among the better educated to intellectualize issues which in a group situation can lead to a "debating style" being adopted.

However, some members who might remain silent for the most part in one group might be much more articulate in another group, where they feel either intellectually or socially superior or equal to other group members. However, such individual trends tend to emerge over time and are apparent during group interactions. The psychotherapist will become aware of repeated patterns of interactions or silences, which will alert him/her to alliances, allegiances, and exclusion between group members. One way for a therapist faced with a fragmented group is to introduce some cohesion to the group through the "shared beliefs" or views, opinions, attitudes, and shared reality of group members.

### **Themes, Agendas, and Apparently Hidden Agendas**

A theme usually constitutes a single or a number of issues or concerns, that usually recur over the life of the group in an overt or covert (hidden agenda) manner. Covert agendas can be the most difficult for the therapist to address as they often manifest in a distorted and misplaced context. These agendas always have a content or underlying message, which is not necessarily apparent to group members and have the potential to influence the course of the group if left unresolved. In one posttransplant group, protracted ruminations about late hospital transport (often a valid theme but not justifiable as the main group theme), alerted the psychotherapist to the existence of a hidden agenda. These ruminations were

characterized by competitive thoughts, antagonism, anger, and rivalry. The same feelings associated with the inadequacies of hospital transport were later expressed in the context of the potential for the entire hospital system to work efficiently and more specifically in direct response to their needs in the event of a medical emergency.

### **Moods, Atmospheres, and Emotional Contagion**

Any particular mood or atmosphere can be triggered by one group member and gain momentum throughout the group manifesting as a permanent, or transient aspect, and does not necessarily apply to every group member. Prevailing moods might include feelings of anger, rebellion, apathy, or stress to name but a few and manifest as both verbal and nonverbal behavior.

The use of the metaphor "contagion" is often used to alert therapists to the manner in which prevailing group moods, atmospheres, and emotions can emerge from apparently nowhere and spread without warning. Group "contagion" has been discussed more systematically elsewhere and is thought to develop in the presence of two variables: initiators and imitators. These roles are assumed in the face of areas of unresolved or unrecognized conflict on the part of the imitators who experience a strong impulse to express the conflict, but even stronger pressure from ego or superego to suppress them.

### **Change and Development**

Therapists have been keen to differentiate between change and development over the life of the group. We study both change in group membership and in the mood, perspective, course of the personal, social, relational, and medical status of individual members. Most groups change (alternate or drift from one state to another without any prevailing direction) over time, a phenomena largely attributable to the aforementioned influences. However, not all groups develop satisfactorily (alternate, or shift from one state to another) in a directional manner, with any reversals in direction being temporary. It should be remembered that both change and development might not always be positive or a shift toward the goals of the group, thereby adding to the growth of the group. Rather, it might be negative and moving away from the goals of the group and have a deterioratory effect on the individual group members.

The concepts discussed above are not easily observable phenomena to the untrained eye. Further, group development can also be complicated

by the fact that while we have discussed the concepts separately in order to advance understanding of the multifaceted and complex nature of group work, they do not necessarily present in a singular fashion. Any number of concepts could be present and/or interacting with each other at any one time in any one group.

## CASE STUDY OF GROUP THERAPY

A 62-year-old retired university-store man called George repeatedly flounced out of the group after 10 minutes or so complaining that he was *bored*. However, not before he had dominated the group with a monologue account of the course of his illness and his opinions of the hospital administration. The doggedness of his tone and the logical reasoned response to his illness caused me to suspect that he wished to change the dynamics of the group to a more structured, predictable, and hence controllable format. This ensured that he did not have to confront his inability to tolerate any unstructured inward reflection necessary for individual change. By a process of intellectualization (a tactic that had served him well in keeping others in his life at an emotional distance), he was able to defend against this for the first ten minutes of the group, after which he flounced out of the room.

This seasoned performance left other group members with feelings alternating between ambivalence, sympathy, concern, and anger. Instead of expressing their anger directly at George, they attributed it to their families' and friends' neglect or lack of understanding of their feelings following transplant. As such outbursts always immediately followed one of George's dramatic exits, I attempted to address this issue by asking whether it was an *unreasonable expectation* of the group that he should remain with them for the duration. While group members did not give a definitive *yes* or *no* answer, this intervention prompted others to reveal that they had also found it difficult to remain in the group. Much of this difficulty was as a result of fear that they might not understand what was happening in the group (mainly the less-educated members) and fear that someone might *go places they just couldn't go at the moment* (fear of rejection, thoughts of the cadaver donor).

Further exploration revealed that many patients found that their family's expectations after a successful transplant were too high. With the sort of insight and tolerance for others that is often synonymous with those who have suffered a chronic illness or had to come to terms with their own mortality somewhat prematurely, they were keen to make the group more user-friendly or bearable for George. In the following ses-

sion, a fellow group member addressed this issue with him at the beginning of the discussion. Indeed, the group member intervened to gently but firmly (with the skill a seasoned therapist would be pleased to possess) suggest that he had trouble being in the group because of the very real fear that might be required to *go places that he just couldn't go at the moment*. In response to George's initial denial, and watched intently by other group members, he ignored his denial and reiterated his point in a more contrite manner taking on my mannerisms, to which the group roared with laughter. This served to break the deadlock and George described how he felt that the potential for exploration of his experience of renal disease meant that the situation (group) might get out of control, as if he started to explore this he did not know where it might end. I did not see any ridicule or nastiness in the group members adoption of my mannerisms, rather that the group member might have had a crisis of confidence and felt the need to adopt an arguably more authoritarian persona in order to make his point.

I felt the need (rightly or wrongly) to reassure the confronting group member that this behavior was fine in this particular context. Therefore, I began my next intervention by adopting a similarly light-hearted tone and suggesting that his mannerisms need to be worked upon. Also, that it might be helpful to others (generalizing the absence out in an effort to take out the intensity of the impact upon George), if he was able to stay physically with the group for the duration and contribute what he felt able on a group-by-group basis. As a point of interest, psychotherapists know that their patients have turned a corner in treatment when they are able to counsel themselves, or each other. In other words, when they know how to think independently of themselves (prevailing thoughts, prejudices, attitudes) and move themselves from one point to another metaphorically speaking. It does not happen with every patient but when it does occur, it proves a very pleasant surprise that makes me puff with pride.

## GROUP THEORY

Support groups might be differentiated from psychotherapy groups in so far as the latter make sense of the complex happenings in the group in terms of a theoretical model. Therefore, when a situation deteriorates, such as a negative mood or failure to bring about development, the therapist is able to analyze in concepts described above and his/her theoretical orientation. This repertoire will at best bring some clarity and at worst some working hypothesis to the situation and will subsequently

influence the next therapeutic intervention. It is a combination of the therapist's understanding of group interaction, the goals of the group, the need for development, and his/her assumptions about the likely reaction of the group or outcome that will determine the choice of intervention. These situations and the need for intervention can develop over time (in which case one has the luxury of retrospective contemplation), or instantaneously (requiring immediate intervention). However, in the latter situation, therapists like most professionals, often function on automatic pilot, or use a taught procedural or graded intervention to an adverse situation.

## **INTEGRATIVE GROUP PSYCHOTHERAPY**

We will describe a working framework that we have modified over time and that continues to evolve and could be further modified and examined to suit patients in group therapy. Our various research projects have suggested that transplant and dialysis patients start therapy very much in the context of present time. Therefore, the group should be able to accommodate the present, or here-and-now time frame virtually instantaneously so as to give feedback and build confidence in the group. The patient's perception of the present then forms a baseline for delving into the past (psychoanalysis) considered in terms of how the past manifests in the present and potentially the future. The future is considered in terms of the transpersonal or the higher or spiritual aspirations of the patient. While we have described the past, present, and future as separate entities, they often manifest clinically as coexisting or interdispersed aspects of a patient's life and require maximum creativity and intuitiveness on the part of both the patient and the therapist. In our experience, the adoption of such a model, capable of encapsulating past, present, and future aspects of patient's lives, encompasses a holistic perspective of a patient's experience before, during, and after transplantation. Therefore, we may be better able to help patients deal with presenting issues in their lives and work toward a constructive future.

The need to develop a group from the point of existential theory as a means to meet the needs of our patients was no mean feat, as existential group psychotherapy has yet to be defined into a systematic clinical format. The foremost obstacle to existential group psychotherapy has been the difficulty of determining the psychotherapeutic position of the patient within the group regarding individuality and primary relatedness. In short, does the group recognize the concept of individuality in the group? The work of traditional existential theorists tends to suggest that

the recognition of individuality in the group would always be problematic as existential phenomena was based upon the concept of a "intersubjective field" (Merleau-Ponty 1962). Along with primary relatedness, this is a world in which the world is always one which "I share with others" (Heidegger 1962). Therefore, the concept of an individual existing in isolation or without interaction to others is inconceivable.

In our research project described below, we compared the efficacy of group and individual psychotherapy as a means to treat emotional problems after kidney transplants. We worked on the basis that far from individuality and intersubjectivity being polar opposites, both concepts could coexist. That is to say, that individuality and intersubjectivity can coexist at different levels of prominence and/or priority in the group, within the bounds of what we termed an existential "presence." We observed a semipermeable boundary on the periphery of the group, which appeared to be composed of an amalgamation of individual members' "ontological" (that which is given, or inescapable) and "ontic" (individual ways in which we respond to the "ontological") experiences. However, when Heidegger spoke of the concept of "being-in-the-world" or means of belonging, he did not do so in direct reference to a psychotherapeutic group. Rather, he spoke in broader terms of one "entity" existing within another as follows: "Both water and glass, garment and cupboard, are 'in' space and 'at' a location, and both in the same way" (Heidegger 1962). Within the context of our group, the individual was "in" the group, the group was held "at" the hospital and the hospital was "in" the community where group members lived. While this might appear somewhat simplistic, we did not contemplate such concepts purely from a point of containment, but as interpermeable. It has already been suggested that we should not just focus on what happens "within" the group to the exclusion of the happenings "outside" of the group, and that "outside" may well permeate the "inside" (Foulkes 1948). In our groups, we will see how such an analogy provided a relational base from which to consider more complex intercontextual issues that arose both "inside" and "outside" of the group.

Given the above proposals, "intersubjectivity" needs to be an integral component of the existential psychotherapy group. Therefore, it would be helpful for both therapist and group members to identify it clinically as a baseline for group experiences and interactions. Within this format, we used recollections and reenactment of their individual "ontic" and "ontological" positions and experiences which they brought to the group to form a "temporal" or time-sensitive (past, present, future) group psychotherapy. At the beginning of every group, we used the patient's physi-

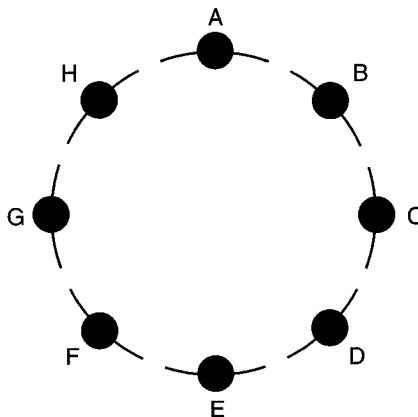
cal presence and the “ontic” and “ontological” experiences, which we called an intersubjective “presence.” The intersubjective “presence” compiled to form a psychotherapeutic baseline from which the group could draw upon emotionally and experientially. This is best located visually within the circle in which patients sit during group psychotherapy as shown in Figure 1.1

An intersubjective “presence” was always ongoing and composed of expressed and unexpressed physical, social, and psychological components of group member’s daily lives. An intersubjective “presence” was always a conscious phenomenon and served as an ongoing identification to the group. Also, it had a permeable quality, which could be likened to a semipermeable membrane (represented as a broken line, Figure 1.1). Patient’s everyday experiences permeated into the group and group experiences permeated into the lives of the patients outside of the group. However, our observations suggest that patients appeared to consciously contemplate or filter what to share with group members and what to retain. We described previously the concepts influencing this decision along with the clinical manifestation and consequences for both the group and the individual. However, little is known about the individual determinants of this process, except that it seemed to be specific to each individual, and influenced by their individual “ontic” and “ontological” experiences.

Patient’s individuality within the group was further expressed when the intersubjective “presence” was activated or became fluid, as group

**Figure 1.1**

**An Intersubjective “Presence” during Group Psychotherapy. Group members are represented as nodes and the group intersubjective “presence” as broken lines.**





members communicated and interacted with each other and the remaining group members recalled their own common or contrasting experiences. In turn, through interaction and observation, these experiences were refined, reenacted, and resolved within the bounds of their primary relatedness to the group. This came about as group members either verbally or nonverbally associated (making them more prominent in the group) or dissociated (becoming less prominent to the group) with themes and topics as they arose. Foulkes (1948) referred to a "common pool" of meaning when describing his philosophy of the group's network of communication, with each individual interpreting communications at different levels of meaning, or "that which is most meaningful to him personally." He called this process "resonance" which, he in turn, considered in terms of an individual's stage of development.

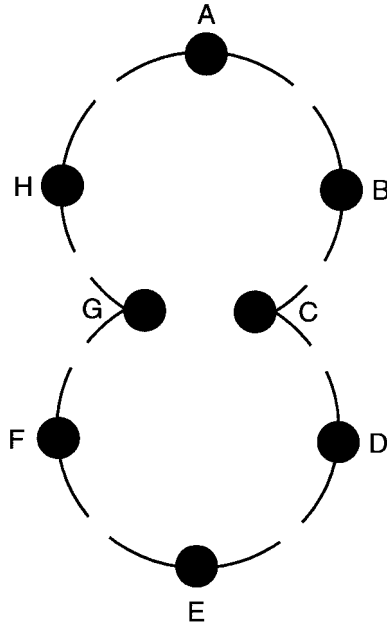
Within the group, patients' expressed interest was considered in terms of group prominence, which increased or decreased as their intersubjective "presence" kept pace with them. Prominent group members were considered to be consciously expressing their individuality from or within the group as they currently perceived it, and therefore came to form the focal point of the group for that point in time and with which other group members identified to a greater or lesser extent. Focal interactions could be composed of any number of individuals at any one time but always within the boundary of the existential "presence." Therefore, the "presence" had the potential to exist at multiple levels of individual figure ground prominence at any one time as shown in Figure 1.2.

These experiences manifested in the group as recurring patient-specific emotional states and configurations, which were enacted over the life span of the group. The concept of recurring interactional states has been described in greater depth later in the chapter on femininity and renal disease. Horowitz (1987) developed the concept of configurational analysis in which identification of recurring patterns of interaction produced by patients was used to chart individual change and development over time. He believed that each individual developed unique ways of responding to certain events. Similarly, in the context of the existential therapy group, recurring states and patterns of interaction among patients were identified by the therapist on an individual basis. The concept has the potential to be extended by the therapist, through interpretations to the point whereby common configurations between members were utilized to link one interaction to another and one session to the next. The therapist's role was to recognize these repetitive patterns and generalize them throughout the group and into the social "entities" and contexts of



**Figure 1.2**

**Intersubjective “Presence” as a Dynamic Concept.** As members G and C interact they become the focus/prominent members of the group illustrated pictorially in the diagram by a move to the center of the group.



individual group member's lives. The group is therefore a serial dynamic concept, the focus of which changes over time.

## GROUP FORMAT

The groups were member-led, while I remained “with” the group aiming to systematically identify, understand, refine, and develop individual experiences through to generalized group themes. Group members were encouraged to raise whatever issues they wished. In turn, we aimed to be responsive, interactive and emotionally supportive to facilitate individual and group treatment goals. The primary problems associated with ongoing chronic illness such as low self-esteem, uncertainty regarding future, loss of time to chronic illness, and redefining normality were incorporated into the goals of the group. It soon became apparent that individual attempts to define normality in terms of the premorbid past (as opposed to the present and in some cases not having a working definition of normality at all) meant that they had difficulty constructing a daily routine. Through the sharing of common experiences it was hoped

to address interpersonal issues, which might be obstructing the formation of a more satisfying existence.

## EXAMPLE OF GROUP THERAPY TRANSCRIPT

The extract below is from the sixth session of the post-transplant group that ran for twelve weeks. Cynthia is a 38-year-old married woman with no children who received a kidney transplant 3 months previously after being on hemodialysis for 6 years. Cynthia appeared to be having difficulty returning to a daily routine and experiencing life free from dialysis. She had previously worked as a secretary, but had been forced to leave this position soon after starting dialysis. It seemed that her employers had been unwilling to accommodate her on half-time status. During previous group sessions, Cynthia had been very critical of herself as she felt that she had *held out* for a transplant for so long that now that it had happened she was not sure what she wanted for the future. There had been a lot of support among other group members at this reflection. I had suggested that it might be easier for group members to think about what they *did not want* and work from there. All patients, including Cynthia, were quite clear on what they did not want; the common theme was a return to a previous career, but to do something different. She also said that she *did want* a change in her relationship with her husband, a relationship that appeared to have regressed during her illness and did not improve after the transplant. Other group members had previously indicated that they had similar experiences, which they were keen to share.

**Cynthia:** Head in hands, body bent double and arms and legs crossed and twisted. *It is difficult to describe how I am feeling.*

**Psychotherapist's thoughts:** Patient is thinking in terms of the present, which tends to indicate that something has developed at home since we last met. The rest of the group appeared to acknowledge Cynthia's statement either by a slight shift of the body, or by glancing toward her with nonverbal expressions, as if sensing that there was more to come and not wanting to interrupt her momentum. She has made herself prominent in the group, while the rest of the group remained on the periphery.

**Psychotherapist:** *Just try to describe how you are feeling as best you can.*

**Cynthia:** *My head is whirling and my body is tied up in knots.*

**Psychotherapist:** Adopting a kindly but not patronizing tone. *Are you aware that you are sitting with your body in a knotted position?*

Jean and Irene, two females of approximately the same age, mutter their agreement and in so doing show the sympathy and support required for Cynthia to feel safe enough in the group to continue.

**Cynthia:** *Oh, I am always like this these days.*

**Psychotherapist's thoughts:** Emphasis upon the last three words alerts me to Cynthia's ongoing emphasis upon the present. However, the implication that things might have been better in the past needs further exploration and might hold an indication as to how to bring about change in the present. I ponder how to address this apparent conflict between past and present feelings. I decide to replay these two words back again to Cynthia to prompt her to recall her dilemma.

**Psychotherapist:** *These days?*

**Cynthia:** *I do not want to go back to work. I have done all that and don't need the hassle. But I want to be in charge of the house again. You know; I have got my appetite back again now and want to start doing the shopping again. I need some new sheets and want to get out to the shops. I just let my husband do all that while I was dialyzing, I didn't feel well half the time and couldn't be bothered. He did everything like that, but now I cannot get back in what am I to be? A vegetable waiting for my kidney to fail? The bed linen he brought scratches me like crazy I did not worry before because I was either flat out on the couch, throwing up, having a dizzy turn, or at dialysis (amused laughter from periphery of group). I am starting to notice things now and want to get out a bit, but I find that I am not insured on the car any more and cannot face the bus. Some one has got to speak to him (looking at me) he is in his element, a control freak, he always was, and now he is in his element.*

**Psychotherapist's thoughts:** There appeared to be a need for Cynthia to redefine her role in the present after the successful transplant and also deal with gender issue, which the male members of the group were quick to point out.

**Male group member:** Delivered in an angry tone while heaving his body forward into the center of the group and thereby leaving the periphery of the group both physically and emotionally. *Well, he is probably just trying to help, so that you don't have to worry. Anyway, what a way to talk about your poor husband, you just cannot win.*

**Psychotherapist's thoughts:** Something Cynthia said has accurately reflected (mirrored even) his own situation. I began to wonder how the patient's own role as a husband had fared during his ten-year experience of dialysis and probably more pressing was how he was experiencing his posttransplant marital role in the present.

**Female group member:** Looking at a male member. *Just ignore him, that's what I do when my husband starts bossing me about, just do what you got to do and tell him to get lost.* This intervention was followed by a howl from Cynthia.

The reader will see from the above extract how a number of themes and agendas over a course of a few minutes can be playing out in a group at any one time. I had to decide whether to address Cynthia or the male member or whether to pull together the common themes presented by both her and male members, the difficulty adjusting to a de-

sired role after transplant and the tendency to define normality in terms of the premorbid past. This case also points to the relational aspect of therapy (family, friendships, and groups pertaining to the client and counselor) as they manifest both inside and outside of the group. These relationships are commonly referred to as systems and have been described in terms of component parts on both a small (subsystems) and a larger scale (suprasystems) that are considered to be interdependent or to exist in relationship to each other. In turn, these component parts come to form a hierarchical-based complex whole, or larger view of a patient's life. In short, Systemic Integrative Psychotherapy is considered as a process of integration within a systemic, holistic framework. It features not only the concept of sub (micro) and supra (macro) systems but also the attention to relationships which sociologists would consider further, most notably in terms of class, race, disability, gender, and religious belief often referred to in psychotherapy as the "cultural drift."

In considering our life in terms of materialistic and social achievements in isolation, our performance may seem fine. However, in considering life in comparison to the position of others (friends, co-workers), our perceived success may seem deficient. While individuals differ in terms of what they value, we generally define our "success" in life by comparison. This is known as the theory of social comparison, which is often expressed by clients during counseling in a more generalized fashion. Patients may compare their plight favorably to others whom they consider to be in a more difficult position than themselves. Alternatively, they may use the achievements of others as a marker for underachievement and as a goal for future change.

## **EVIDENCE-BASED PSYCHOTHERAPY**

There has been a growing realization that the traditional clinical trial, or control study, has serious limitations, in so much as the identification of the subtle nuances described above have been lost in the crude data that such studies produce. Consequently, such studies may have served to seriously undermine psychotherapy research for the clinician who needs to know how to proceed with a particular patient at a specific point in time. Therefore, psychotherapists have taken the view that quantitative research is not the only way to evaluate the outcome of treatment. However, more explorative or qualitative research has been slow to gain moment, a trend that might be attributed to an unconscious desire among therapists to emulate the quantitative style favored by the medical profession.

Certainly, it is not easy to create a randomized control group in psychotherapy, as social circumstances and individual patient experiences and perspective may shift over time. Coupled with influence of interactive personality traits and the dynamic social environment in which they live, such a group is far from sterile and has the potential to become out of control. The internet has increased knowledge, access, and expectations, regarding treatment of any specialty, whether it be traditional or complementary. While some social scientists have argued against the use of control groups fearing that they cluster together individuals into homogenous groups to which they administered a predetermined treatment without regard for the kind of intervention the patient would prefer or for individual need, personality traits, or social variables. Waiting list controls have been considered as the middle ground, however, the validity and ethics of this methodology are questionable, in that to place a patient on a waiting list instills hope by virtue of anticipation. Therefore, it could be classified as a minimum treatment condition and is not comparable to receiving no intervention.

In order to produce holistic research, we combined the quantitative and qualitative approaches, in other words, a mixed-method approach. This can manifest both clinically and academically as follows: a quantitative research framework that is analyzed both quantitatively and qualitatively as in our project designed below; the qualitative analysis of quantitative research; the drawing of qualitative hypothesis that can be tested quantitatively. In our experience, such a multifaceted and inclusive research design ensures that the findings reflect the multidisciplinary composition of the transplant team, produce a holistic picture of the patient's experience of chronic illness and indicators for future research.

Evaluating the efficacy of psychotherapy is far from an easy matter and certainly not for the faint of heart. Within the context of this book, we have pointed to findings arising from various research projects initiated and conducted in our service. We have also presented our observations and hypotheses derived from these projects that either challenged or brought into question our original research hypothesis, in an evidenced-based manner. However, despite efforts to present our work in a systematic and evidenced-based fashion, it can not be said that we are excluded from the quandary that the profession faces in the need to determine not only the immediate success of psychotherapy, but its efficacy in the long term. There are five main issues that need more clarity: individual variations between therapists, definition of recovery, quality of life, control groups, and comparison between different types of theoretical approaches (Rowland 2000).

## **INDIVIDUAL VARIATIONS BETWEEN THERAPISTS**

There are two main factors that determine individual variations between therapists, namely, individual personality traits, and the extent to which the therapist and patient have shared outcome goals. Therapists are trained to view their patients objectively and with unconditional positive regard, however, they are after all human and individually different. They will therefore inevitably bring different skill-based and personality strengths to the treatment environment, which will affect their analysis and delivery of treatment, even when working within the same theoretical framework. Therefore, success or recovery rates may vary from one therapist to another. Generally, therapists who are perceived as empathetic and warm by their patients are usually associated with a good outcome. The extent to which patients and therapists share the same treatment goals will determine nature of the relationship and subsequent efficacy of treatment. It is for this purpose—to determine treatment goals that are mutually acceptable to both patient and therapist—that the initial assessment is utilized. Many therapists also use the initial interview to explain the process, nature, and tools of therapy. This ensures that patients are not caught unaware and are more forthcoming when they are asked if they could elaborate on dreams or the manifestation and onset of specific emotions in particular social and environmental contexts.

## **DEFINITION OF RECOVERY**

The reader will already have begun to realize that the pathway to recovery for many patients is often long, tedious, painful, and convoluted, yet the end goal for both patients and therapists is recovery. However, within the psychotherapy profession, there is no standardization as to what is constituted by recovery. This dilemma has come about primarily as a result of psychotherapists leaving the classification of patient's disorders to psychiatrists and psychologists. Within the remit of classification, one might define recovery from a particular disorder when the patient is no longer classifiable at any given point in time. Primarily left to their own devices, many therapists will work with the patient to determine recovery on an ongoing basis, within the individual patient goals determined at the outset of treatment. This type of qualitative evaluation is much-favored by therapists on the basis that it is much more humane than assigning a classification upon a patient, to which they may or may not be able to relate. However, the adoption of such a patient-

specific definition of recovery leaves both therapists and patients open to the criticism of bias. In other words, both patients and therapists may have a vested financial and emotional interest in claiming the efficacy of the treatment, in which they have vested considerable time and money. One way to render oneself less liable to such criticism is by adopting a combined-outcome measurement, as we have done in a number of our research projects. Therapists working within a medical setting might consider adopting a combined methodology (quantitative and qualitative), thereby ensuring multiple measures of outcome or recovery. Meanwhile those therapists who work in more generic settings could utilize multiple social variables (relationships, employment, behavioral, and emotional states), which can be documented in an evidenced-based manner.

However, the above findings should be interpreted with caution. Not only is it difficult to determine the effectiveness of therapeutic intervention, it is also quite problematic to compare the efficacy of various models of therapeutic intervention. We described previously the main schools of therapeutic intervention that health professionals and patients are likely to encounter, namely, behavior therapy, operant conditioning, psychoanalysis, non-Freudian psychoanalysis, and cognitive therapy. However, while providing an overview of each was relatively straightforward, attempts to determine whether one model is more effective than another have been inconclusive. Therefore, in evaluating one therapy with another attention has turned once again to patient-specific and social variables, which are thought to render one treatment more appropriate than another. These include age, social class, motivation of patient and therapist toward treatment, the nature of the patient-therapist relationship and differences in the severity of the emotional states. It might therefore be concluded that different models of therapy might be better indicated for specific groups of patients (e.g., the elderly), there are no official guidelines for therapists working in the field.

### **A COMPARISON OF GROUP VERSUS INDIVIDUAL SYSTEMIC INTEGRATIVE PSYCHOTHERAPY**

The prevalence and clinical manifestation of emotional, psychological, and psychiatric liability among transplant patients has been referred to above and is described in greater detail throughout the book. However, the precise effectiveness of specific delivery and modality of treatment whether it be group or individual treatment has not been determined in the context of renal transplantation. Therefore, we have implemented a

comparison study using an inclusive methodology encompassing a qualitative and quantitative design to determine the efficacy of group versus individual psychotherapy in terms of patient outcome.

In contrast to controlled studies, comparison studies assume some benefit to the patient from both treatments and are much more definitive, in that they seek to determine which treatment is associated with the better outcome. The comparative design is dependent on the two treatments being similar in format and credibility (theoretical orientation, patient groups, number of sessions) in order that the treatments are more similar than the treatment/no treatment design. This design also takes into consideration any nonspecific effects, which are common features of psychotherapy as being similar and thereby controlling the threat to validity.

We recruited patients who were within three months of transplant surgery and were able to give an informed consent. The local ethics committee approved the study. Patients were randomized using computer-generated numbers with attention to age and gender bias to receive a twelve-week course of group or individual psychotherapy. Patients were treated using the same psychotherapist and theoretical model (Systemic Integrative Psychotherapy) in both the groups. The study was based on the need for at least 80% statistical power to determine the difference between the two success rates. Recipients of live transplants and those patients who received more than one transplant were excluded and emotional issues are different as discussed in later chapters. All patients were Caucasians as the population in the West of Scotland is 98% Caucasian.

Recipients of first cadaver renal transplantation were randomized (using computer-generated numbers to ensure even gender and age distribution) into two groups, to receive a 12-week course of Systemic Integrative group or individual psychotherapy. We decided against a control group (no therapy group), as to deny patients such intervention was deemed unethical, particularly given that the demand for psychotherapy services was high. The BDI (Beck and Steer 1987) was utilized as a measure of change in emotional state, pre-therapy, at 3, 6, 9 and 12 months. A higher score on BDI was suggestive of psychological dysfunction. All recipients during the recruitment period were offered the opportunity of participation in the study.

In the first instance, data was analyzed within a quantitative framework, by virtue of the Beck Depression Inventory (BDI). This is a psychological measurement tool that renders a precise and ongoing indication of emotional distress before therapy (baseline) and as a means to determine change at termination of therapy and at 3-, 6-, 9-, and 12-



month follow-ups. The BDI consists of 21 groups of graded statements (the higher the score the more negatively intense the feeling) relating to mood as follows:

### **Question One**

- 0 I do not feel sad.
- 1 I feel sad.
- 2 I am sad all the time and can't snap out of it.
- 3 I am so sad and unhappy that I can't stand it.

### **Question Two**

- 0 I am not particularly encouraged about the future.
- 1 I feel discouraged about the future.
- 2 I feel that I have nothing to look forward to.
- 3 I feel that the future is hopeless and that things cannot improve.

The questionnaire is of a self-report design and required the patient to read the statement and circle whichever statement most accurately represented feelings at the point of assessment (before therapy began, at termination, and 3, 6, 9, 12 months later).

In the second instance, this data was then analyzed in keeping with individual patient characteristics, the course of their transplant, and moods, themes and interventions during psychotherapy sessions. The study is ongoing but for this analysis, we took the end point at a follow-up of 1 year. The data are expressed as mean  $\pm$  standard deviation. The comparisons of the means of the scores at various time periods between the individual and group-therapy groups were made by the use of Mann-Whitney U test and one-way ANOVA test as appropriate. The significance of the impact of therapy within each treatment arm was assessed by Wilcoxon rank sum test. The individual parameters were assessed for their effect on the final result with the help of multivariate analysis. All the significance was calculated as two tailed and is measured at a level of  $\leq 0.05$ . A statistical software package was used for the computations (SPSS 9, SPSS Inc., Chicago).

Eighty-nine patients who had a first cadaver kidney transplant were recruited for the study. They were randomly allocated into the two study groups, 49 for individual therapy and 40 for group therapy. Of these, 82 patients have completed 12 weeks of therapy (45 patients from the individual treatment arm and 37 from the group-therapy arm). Fifty-five patients have so far completed one-year followup (33 in individual ther-

apy and 32 in the group therapy). The demographics of the study population are shown in Table 1.1.

In both groups, there was a significant improvement in the scores following therapy. The mean score was  $26.3 \pm 17.9$  before and  $20.5 \pm 8.8$  after therapy in the individual group ( $p = 0.001$ ). The mean score was  $29.8 \pm 3.9$  before and  $27.1 \pm 3.9$  after in the group therapy population ( $p = 0.01$ ). The improvement appears to be more significant in the individual therapy session compared to group therapy session ( $p = 0.01$ ). This change is graphically demonstrated in Figure 1.3. Another important observation is that at longer followup (3, 6, 9 and 12 months following therapy) the lowering of the scores remained sustained (Table 1.2). This is present in both treatment arms. The change from before the treatment was statistically significant ( $p = 0.01$ ).

A higher percentage of patients who had been on more than three years of dialysis was seen to have been allocated for group therapy. Apart from this, there was no significant difference between the characteristics of the study groups in the two arms. Table 1.2 shows the mean BDI scores in the two groups before treatment and at various time points after the treatment. In both groups, there was significant improvement in the scores following therapy.

Multivariate analysis of the possible factors that can have an influence on the final results was performed (Table 1.3). These factors included

**Table 1.1**  
**Patient Demographics**

		Individual Therapy	Group Therapy	p-value
Age (years) Mean $\pm$ SD		36.2 ( $\pm 8.9$ )	39.1 ( $\pm 11.1$ )	0.19
Gender	Female	27 (55%)	17 (42%)	0.29
	Male	22 (45%)	23 (58%)	
Dialysis status	Less than 3 years	35 (71%)	18 (45%)	0.01
	More than 3 years	14 (29%)	22 (55%)	
Number who had previous treatment		7 (14%)	7 (18%)	0.45
Employment status	Employed	9 (18%)	7 (17%)	0.57
	Unemployed	40 (82%)	33 (83%)	

Figure 1.3  
Box Plot Showing the Effect of Therapy on BDI Scores

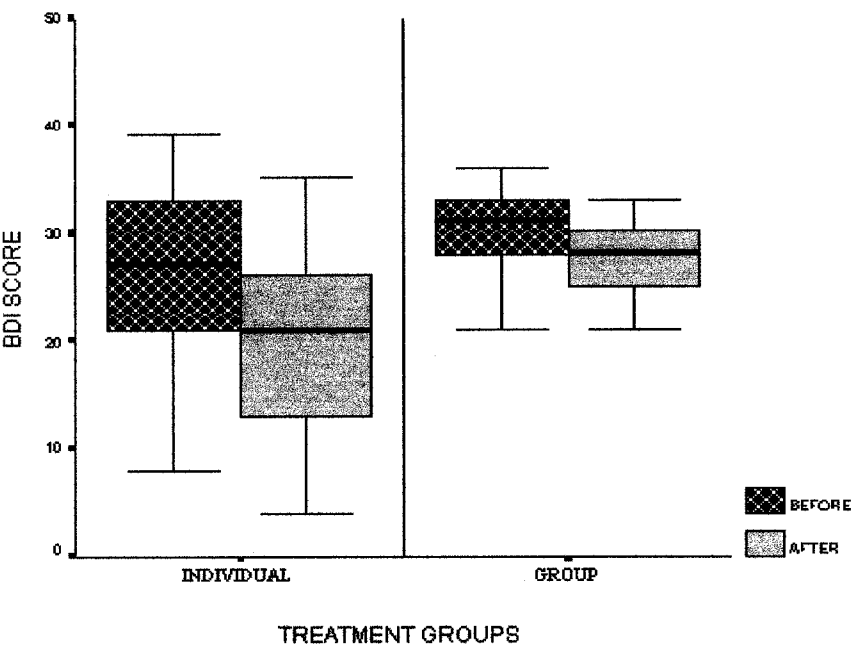


Table 1.2  
Mean Scores of BDI Index at Various Time Points (SD is given in brackets)

		Individual Therapy (n=33)		Group Therapy (n=32)	
		Mean score	Mean rank	Mean score	Mean rank
Before therapy		26.6 (7.9)	5.9	30.2 (3.8)	5.7
After therapy	12 weeks	20.6 (8.8)	4.0	27.4 (3.9)	4.0
	3 months	19.8 (8.9)	3.5	27.2 (4.1)	3.6
	6 months	19.6 (9.1)	3.1	26.8 (3.9)	3.1
	9 months	19.2 (8.8)	2.5	26.5 (4.0)	2.6
	12 months	18.9 (9.0)	2.0	26.0 (4.2)	1.8
p-value #		0.001		0.01	

#: one-way ANOVA

**Table 1.3****Multivariate Analysis of Possible Factors of Influence on Final Results: *p*-values**

	Individual therapy	Group therapy
Age	0.55	0.57
Gender	0.58	0.84
Employment status	0.13	0.38
Previous psycho therapy	0.30	0.84
Duration of dialysis	0.39	0.84

age of the population, gender, employment status, duration of dialysis (if in dialysis for more than three years), and psychotherapy given before transplantation. The results indicate that none of the parameters significantly affected the results of the treatment.

Our overall impression of the patients was that they tended to be from the lower socioeconomic groups, with less advanced, formal education (in the form of postgraduate degrees), a situation caused or compounded by chronic illness. However, they tended to have good insight into their own problems and were extremely perceptive as to the idiosyncrasies of other patients, staff, and the therapist. They were also doggedly compliant with psychotherapy defined in terms of attendance, often despite having to travel long distances and being dependent upon the notoriously late hospital transport. Generalizing across the two groups, pretherapy scores were indicative of significant but not necessarily debilitate (given that patients were mobile and willing to attend the hospital for treatment and able to interact with the therapist) emotional disturbance. Our observations were that patients presented more in keeping with the DSM IV classification of dysthymia as opposed to the chronic depression described previously among dialysis patients. In keeping with dysthymia, common symptoms among patients included moderate low mood, ac-

accompanied by feelings of low self-esteem, loneliness (irrespective of marital status and unworthiness), insomnia and fatigue. These symptoms faded over time and were less severe (as indicated by pre- and posttreatment BDI scores) but are more likely to recur (not in keeping with BDI scores). If left untreated, dysthymia can deteriorate to chronic depression and may account for the common theme among second time transplant patients who felt that they had not achieved any of their life goals following their first transplant.

Of concern, both groups of patients showed significant feelings of failure and discouragement regarding the future despite having endured a chronic illness and received a kidney transplant. It would seem that patients do not view transplantation as a panacea for all their problems. However, interestingly, both groups of patients had significantly improved scores after treatment, which were not only maintained but also improved during the course of therapy.

The patient's primary reason for entering psychotherapy was centered upon the need to "return to normal," with "normal" often defined in time past, before the onset of renal disease. The primary problem is that we cannot recapture the past, and even if we could, the lack of personal growth and the experience of chronic illness often changes personal attributes and perspectives. Therefore, much of the work during treatment sessions was given over to redefining normality within the context of present time. Inability to make such a redefinition led to feelings of ongoing frustration, feelings of failure and decreased mood. Improved mood states were associated with individual psychotherapy, which seemed better able to facilitate this highly personal process.

The BDI has generally been considered as a crude measurement that does not do justice to the idiosyncrasies of the treatment process, the patient, or therapist for that matter. However, we wanted to produce objective data, which could encourage other centers to embark on similar projects using the BDI or other instruments, or even devise a specific instrument for this purpose.

In order to produce holistic research, we combined the quantitative and qualitative approaches, in other words, a mixed-method approach. This can manifest both clinically and academically as follows: a quantitative research framework that is analyzed both quantitatively and qualitatively as in our project designed below; the qualitative analysis of quantitative research; the drawing of qualitative hypothesis that can be tested quantitatively. In our experience, such a multifaceted and inclusive research design ensures that the findings reflect the multidisciplinary composition of the transplant team, produces a holistic picture of the

patient's experience of chronic illness, and encourages further research. We conclude that both individual and group psychotherapy were beneficial to our patients, however, individual therapy was found to result in lower BDI scores versus group therapy at the end of the treatment period.

## CONCLUSION

We have seen how patient's psychosocial perspective fluctuates over time with the course of their illness and consequently is dynamic, as opposed to a static phenomenon. Therefore, any treatment model needs to be responsive to changing reality and be flexible in order that it can accommodate and reflect the experience of living with a chronic illness. The unpredictability associated with psychosocial issues means that it is often difficult to standardize treatment protocols. We have pointed to the manner in which control groups and overly rigid assessment tools can hinder and provide a limited view of research findings. We have therefore advocated a combined qualitative-and-quantitative methodology that places emphasis upon enhancing quantitative findings through qualitative enquiry. Qualitative methods include the systematic documentation of recurring themes as described by the patient and the identification of the skills used by the therapist to facilitate emotional stability. This ensures that meaningful research is produced that gives the clinician guidelines in interpreting symptoms and how to proceed. Patients tend to articulate their feelings with past, present, and future time zones. In my experience Systemic Integrative Psychotherapy seems to represent the heightened sensitivity to time (past, present, and future) as experienced by renal patients and is more congruent with their view of life.

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## **Chapter 2**

# **MEDICAL NONCOMPLIANCE: A PSYCHOSOCIAL PERSPECTIVE**

Compliance among patients undergoing dialysis and after transplantation has become an important issue as noncompliance with the primary treatment regime leads to complications and even death. The problem of noncompliance is thought to be particularly acute among the lower socioeconomic groups (Bame et al. 1993, Leggat Jr. 1998), in patients between 20–30 years of age, females (Leggat Jr. 1998) and in patients of minority race such as African-Americans in the United States (Alexander & Sehgal 1998). Furthermore, patients who do not adequately comply with dialysis are less likely to be placed on the waiting list for kidney transplants. This is particularly true for black women and women in lower socioeconomic groups who are more likely not to complete the transplant selection process, and therefore, have higher rates of morbidity than those patients who do comply and receive a kidney transplant (Alexander & Sehgal 1998). It has also been shown that patients identified as noncompliant with dialysis who did receive a kidney transplant were more likely to lose their graft or die after transplant (Alexander & Sehgal 1998).

However, despite the pivotal importance of compliance behavior among this patient group, a concise definition and standardized measurement of the concept remains illusive and effective intervention is not well defined. This situation is worrying as considerable attention has been given to measuring and predicting compliance, despite a lack of

consensus between various centers as to what is being measured and predicted.

Traditionally, compliance behavior has been considered in terms of the physician's ability to influence the patient and the patient's willingness to respond. However, in an attempt to move away from connotations of the "all powerful" physician and the powerless patient, there was a move to replace the term "compliance" with that of "adherence" and more recently with "concordance." "Adherence" and "concordance" play to the contemporary espousal of a more empowered patient and a more egalitarian physician. However, legislation that translates into purchasing power and subsequently patient's ability to choose their physician and facility at which they are treated—in short, real world empowering of patients—has been lacking for the majority of patients in the United Kingdom and may be the primary reason why the term "compliance" has prevailed. Therefore, we will use the term "compliance" throughout the book.

Patients who do not comply with the medical regimen and lose their grafts may be denied a second transplant, an area of considerable controversy and debate. Furthermore, health-care financing is assuming a central role in our society. Patients who lose their transplants due to noncompliance will result in significant drain on finances as these patients are placed back on dialysis, a modality of treatment more expensive than a functioning transplant. Medical noncompliance is also important as it is estimated that more than 25% of patients who enter into clinical trials of antirejection drugs may be noncompliant and hence influence the results of these trials.

A number of authors have studied various factors that affect medical compliance after kidney transplantation. These include demographics, social and educational status, mental and behavioral patterns, pre- and posttransplant symptoms and beliefs, and the characteristics of the transplanted recipient. A variety of validated instruments has been described to assess and in some cases predict noncompliance after a kidney transplant. These methods include pill counts, clinic attendance, drug levels and self-administered questionnaires. Each of these methods has pitfalls and may not be equally applicable to all patients.

Indeed, it would seem that transplant patients tend to be divided into those who comply with the treatment regime and those who do not. Noncompliance with dialysis is not necessarily an accurate predictor of posttransplant compliance and should not always be used as a means to exclude patients from the transplant program. However, patients with a history of noncompliance with dialysis are liable to feelings of fear of a

recurrence of noncompliance behavior which might jeopardize their transplant, but over which they feel they have no control. They may have symptoms of anxiety, insomnia, and guilt at having received a kidney from a cadaver source and hesitancy regarding the future, accompanied in some cases by low mood. These mood states can be effectively treated using short-term psychotherapy aimed at increased understanding of past noncompliant behavior. In turn, such insight creates a more stable and productive mood state and facilitates actualization of a better quality of life in the future (Auer 1983).

Relentless striving for incremental improvement can make progress. This can be achieved in designing better and improved cars, saving money, or losing weight. We believe this principle of incremental improvement can be applied to increase medical compliance with medications and the transplant process itself. The treatment of noncompliance in this setting has been fragmented and nonuniform. Ultimately, the transplant community needs an inclusive model capable of detecting and treating the noncompliance before it proves fatal. In our own transplant unit, we have been working toward such a multifaceted approach using psychotherapeutic principles as a means to detect, understand, and treat noncompliance among dialysis and transplant patients. This work is based upon our understanding of the patient's experience of renal disease and organ transplantation as recalled during therapy.

Skotzko et al. (2001) carried out a survey to determine the views of the transplant community on psychosocial issues. They found that there was overwhelming support for providing psychosocial support both pre- and posttransplant to increase compliance and rehabilitation of patients. There was also a broad support for substance-abuse treatment programs for recipients of organ transplants; most respondents also acknowledged the impact of psychosocial factors on compliance, quality of life, and survival. Respondents to this survey also pointed to the need for formal studies of psychosocial intervention on cost and resource utilization, which will convince health service planners to adequately fund such programs. We agree with these authors that standard practice guidelines need to be formulated for psychosocial intervention, in particular, for training of health care providers working with recipients of organ transplants.

In this chapter, we have reviewed available information on noncompliance in patients receiving dialysis and after a successful kidney transplant. We also consider and question the validity of scales and assessments as a means to predict compliance behavior after transplantation. We draw upon case illustrations and vignettes to describe how

our work with patients receiving dialysis and kidney transplants has enabled us to develop a method of psychosocial profiling that enhances the understanding of this behavior. This, we believe is a significant advance, given that there is little understanding of the social, emotional, and psychological components of noncompliance.

## **NONCOMPLIANCE AMONG PATIENTS WITH CHRONIC ILLNESS**

Despite awareness of the fatal consequences of noncompliance and the increased likelihood of reduced quality of life, noncompliance is an ongoing problem in chronic illnesses. This is seen among patients suffering from cancer, diabetes, cardiovascular disease, or those who undergo cardiac, liver or kidney transplant. Much of the research in the area of noncompliance has been concerned to identify groups of patients that are at risk of noncompliance based upon socio-economic, demographic and psychosocial variables.

In an attempt to identify risk factors with women's compliance to mammography screening among the general population, Carney et al. (2002) utilized a population-based mammography registry to recruit 625 women in the age group of 50 years and above and divided them into 2 groups: those who had a history of compliance with mammography screening and those who did not. The results suggested that noncompliance with mammography screening could not be linked to any predetermined psychological profile. However, compliance was determined by previous mammography experience, specifically the nature of the interaction between the female patient and the technician conducting the screening. Compliance was associated with technicians who talked the patient through and provided educational input during the screening process. Therefore, previous negative mammography experiences was thought to be the single most determining factor to future compliance.

Among patients who are diagnosed with cancer, there has been a recent increase in treatment involving the use of oral anticancer agents, which rely upon patient self-administration, in contrast to intravenous treatments that are administered by health care professionals. In turn, it is anticipated that this new development in treatment might give rise to new concerns about the ability of patients to compliance with treatment. In a comprehensive review of the literature on compliance with oral anticancer agents, Partridge et al. (2002) estimated that incidence of noncompliance in region of 20%–100% of high-risk population, particularly among adolescents. Reasons for noncompliance were thought to rage

from unpleasant side effects to the inconvenience of frequent oral ingestion of medications.

The study of compliance behavior among diabetics has been considered in direct relationship to quality of life and the implementation of psychosocial therapies. Delamater et al. (2001) reviewed literature pertaining to quality of life, psychosocial issues, and compliance with the diabetes treatment regime in an attempt to identify key areas of concern and future research. Their analysis suggested that psychosocial factors were one of the most influential variables in determining compliance with the treatment regime. Furthermore, early indications suggested that the provision of psychosocially orientated treatment could not only help address psychosocial problems but could positively impact upon glycemic control and quality of life. Hanestad and Albrektsen (1991) investigated self-assessed quality of life in diabetic patients to determine the nature of the relationship between quality of life and poor blood glucose control. Two hundred and forty-seven patients with type 1 diabetes who attended a diabetes clinic were asked to assess their quality of life in relationship to their adherence behavior at any given point in time. The findings suggested that higher quality of life was associated with better compliance behavior. Smoking, exercise, and control of weight regimens were identified as the most difficult areas for these patients to maintain compliance.

There appear to be a number of obstacles to compliance, defined in terms of attendance and adequate participation in rehabilitation programs among cardiovascular patients, despite significant evidence that such regimes can enhance recovery and prevent mortality. Daly et al. (2002) defined compliance in terms of attendance and participation. A comprehensive review of the literature suggested that compliance associated with attendance could be influenced by lack of physician referral, associated illnesses, perceived benefit/outcome, geographical distance from the clinic, provision of adequate transport arrangements, self-concept, self-motivation, family composition, social support, self-esteem, and occupation. Compliance with the treatment regime itself was associated with age (older patients were less likely to comply), female gender, less formal education, perceived benefits of participation in rehabilitation, a diagnosis of angina, and an inactive life style. While the authors criticized many of the studies for methodological shortcomings, including differences in design and definition, it was clear that a combination of medical and psychosocial factors could interact to determine compliance behavior. Evenson and Fleury (2000) considered obstacles to compliance among patients with cardiovascular diseases in keeping with a series of



“barriers.” The “barriers” included those cited by Daly et al. (2002) but they also referred to financial problems, such as the cost of traveling to and from the clinic and loss of income through taking time off work.

Lewin et al. (2002) in a randomized controlled trial of newly diagnosed patients with angina took a more active or intervention-orientated approach to improving compliance. Having equated psychosocial issues, poor quality of life, and compliance behavior, they compiled an Angina Plan consisting of support Cognitive Behavioral Program. One hundred and forty-two patients were recruited from primary-care practices to receive the Angina Plan or regular nurse-led secondary prevention educational session. The results suggested that while there were no differences in baseline measures; at 6-month follow-up, patients in the Angina Plan demonstrated significantly greater reduction in anxiety and depression and in the frequency of angina episodes. They were also more likely to report self-motivated initiatives toward an improvement in diet and exercise regimes. It would seem that the Angina Plan not only impacted directly upon compliance behavior but also caused patients to become enthusiastic in other areas of the program.

Among patients who receive heart transplants, compliance with immunosuppressive therapy is a matter for increasing concern. Grady et al. (1998) and De Geest et al. (2001) carried out a study to understand why patients who have received a much-wanted, and often times long-awaited heart transplant, do not comply with posttransplant treatment and render themselves liable to graft rejection and certain death and predict patient groups at risk of noncompliance. De Geest et al. (2001) assessed 101 noncompliant heart transplant patients between 1 and 6 years post-transplant, using electronic event monitoring and patient self-report measures. The authors were especially concerned with determining the influence of a combination of medical and physical (depression, self-efficacy, knowledge, perceived health, symptom frequency, distress, social support) upon compliance behavior defined in terms of attendance at outpatient appointments and intake of medications. The authors suggested that medication noncompliance appeared to be linked to depression in 5 out of 9 patients who experienced rejection episodes. Furthermore, the compilation of profiles on individual patients served to highlight patients who were most at risk.

For many patients who present for a liver transplant for alcoholic cirrhosis, compliance takes on a new dimension, namely abstinence from alcohol before and after a successful transplant. While alcoholic cirrhosis is increasingly becoming accepted as an indication for liver transplant; psychosocial, legal, and economic problems that accompany an ongoing

alcohol problem mean that patients are particularly vulnerable to stress and poor coping mechanisms (Stilley et al. 1999). For this reason, liver transplantation among this patient group remains somewhat controversial. However, despite having painted such a cautionary picture, recent studies have suggested that relapse to alcohol among this patient group is relatively low (Stilley et al. 1999) and other aspects of compliance are relatively high (Berlakovich et al. 2000). Nevertheless, the experience of liver disease and, more specifically, transplantation would appear to be different for alcoholic and nonalcoholic patients. Weinrieb et al. (2001) compared 30 alcoholic with 30 nonalcoholic patients, and found that the alcoholic group had a greater lifetime consumption of alcohol, were likely to suffer from alcohol cravings, and showed little motivation to enter into alcohol-treatment programs. However, despite the reluctance of alcoholics to enter into treatment, the authors suggested that treatment intervention should be devised to accommodate both their medical condition and support continued abstinence.

It is becoming clear that compliance, psychosocial issues, and quality of life do not exist as independent entities but interact with each other and the medical course to determine a patient's experience of chronic illness. While every patient's experience will be somewhat different than the next one's, we have seen common themes that should enable us to identify patients who are particularly vulnerable and who in turn might benefit from psychosocial intervention. We have also seen how the patient's perception of his or her relationship with health professionals can also alter the course of the illness. Physicians might benefit from adopting some of the psychotherapy skills detailed in chapter one as a means to understand vulnerable patients.

## **QUALITY OF LIFE AFTER TRANSPLANTATION**

The reader would have observed that both psychosocial issues and compliance are increasingly discussed in relationship to quality of life (QOL). Therefore, the subject warrants some additional clarification and discussion. There is an increasing amount of data on QOL among most chronic illnesses, particularly, it would seem after solid organ transplantation; some of the instruments used are generic, but recently there is a tendency to use disease-specific instruments. However, there is still a great deal of confusion and skepticism on the precise utility and interpretation of these data. For example, should the information obtained by QOL studies be used for research purposes or be integrated into economic outcomes to evaluate the performance of individual centers?

The definition of QOL is patient-centered as opposed to physiological measurements, and as we have seen previously, may encompass clinical, socioeconomic or even spiritual nuances. Whiting (2001) has succinctly defined QOL as measurement and quantification of the patient's subjective perspective of various health-related concepts. Schipper et al. (1996) have arbitrarily divided QOL into four components: physical and occupational function, physiologic state, social interaction, and somatic sensation. Each component can be measured by standard verifiable instruments, an area particularly familiar to sociologists but increasingly demanded of physicians and surgeons by health-care-funding agencies. Whiting (2001) has described three basic elements of QOL instruments: health preferences, health values, and utilities; however, in practice these are grouped under the term "utility measure." The eventual goal of these measurements is to perform a cost-utility analysis; the value of 0 is attached to death and 1 to perfect health. For example, life on dialysis is valued at 0.45 to 0.60, while life with a functioning kidney transplant is valued between 0.65 and 0.85.

The concept of quality adjusted life years (QALY) is also gaining acceptance among health economists. The figure is obtained by multiplying the utility value between 0 and 1 with the actual life years gained by an intervention.

There are a variety of instruments to measure health status—a fact that may have caused confusion among investigators. The most widely used generic questionnaires are the sickness impact profile, Nottingham health profile, and the SF-36, the latter instrument has been condensed to SF-12—a measure validated in numerous disease states and in many countries (Ware et al. 1995, 1996). The disease-specific questionnaires in transplantation, which have been validated are the Kidney Transplant Questionnaire (Laupacis et al. 1993) and the NIDDK Liver Transplant Questionnaire, while the Liver Transplant Disability Scale has been validated for pediatric transplant recipients (Midgley et al. 2000).

The widespread use of QOL in recipients of organ transplants will increase accountability of service providers and eventually increase patient satisfaction, as these instruments are patient-reported. Unfortunately, most studies in this area are small with short-term follow-up. Dew et al. (1997) reported that despite these shortcomings, in a meta-analysis of 14,750 patients, there was clear evidence that QOL improved after transplantation; however, QOL of transplant recipients did not generally improve to the level of matched healthy population.

More recently, it has been proposed that QOL questionnaires may be able to differentiate between various immunosuppressive regimens. Shield

et al. (1997) evaluated QOL in recipients of kidney transplants who participated in the phase III trial of cyclosporine versus a new drug, tacrolimus. They recruited 303 patients and used a variety of instruments administered at week 6 and months 3, 6, and 12. They found that the baseline scores were similar between the groups, the mean scores for patients with rejection were lower versus patients not experiencing rejection; overall scores in the two study arms were similar. In another smaller study, Hilbrands et al. (1995) administered QOL instruments to patients who were on standard immunosuppressive therapy (cyclosporine and prednisone) and then at 3 months allocated to either withdrawal of prednisone or conversion of cyclosporine to azathioprine. They found that in both groups of patients, scores improved progressively after transplantation reaching levels of general population in Netherlands, acute or chronic rejection had a negative effect on scores, while patients who were on cyclosporine monotherapy had the best outcomes in terms of psychosocial functioning. This positive effect was thought to be due to the withdrawal of prednisone, a drug that has many harmful side effects.

For the widespread incorporation of QOL in transplant related studies, there is a pressing need for larger studies with longer follow up in prospective multicenter trials, using disease-specific questionnaires. This will enable transplant centers to compare their outcomes with other programs and to monitor quality and institute suitable changes, justifying the added administrative cost of this exercise. It remains to be seen is whether QOL should be made compulsory and part of the accreditation for all transplant centers.

## **NONCOMPLIANCE AMONG PATIENTS RECEIVING DIALYSIS**

The techniques of measuring noncompliance have generally been analyzed in terms of apparently tangible constructs. These include a single or combination of measures at either one point in time or over a specified period as follows:

### **Transport Records and Interviews**

Noncompliance measured in terms of shortening and researchers at the Vanderbilt Dialysis Clinic, Nashville, Tennessee, investigated missing dialysis visits. They used a series of interviews and transport records, which they related to doses of hemodialysis received (as determined by hospital records), to assess whether or not this group of patients was

compliant. They found that a significant number of shortened treatments were due to delays in hospital transportation, but missing treatment visits were thought to be related to other undefined variables. The authors used their findings to stress the need for ongoing educational programs to encourage compliance (Latham 1998).

### **Fluid Volume Excess**

Fluid volume excess has frequently been used as a means to measure noncompliance with hemodialysis. Fluid volume excess is measured by weight gain, peripheral edema, and abnormal pulmonary findings taken before each hemodialysis treatment. Subsequent measurements were used as a means to determine ineffective management by patients of their hemodialysis treatment (Sciarini and Dungan 1996). This technique remains one of the commonest measures of noncompliance in patients receiving hemodialysis.

### **Biochemical Data**

Investigators measured the midmonth blood urea nitrogen, serum potassium, and phosphate values of 54 maintenance hemodialysis patients at regular intervals over the course of a 6-month period to determine compliance with hemodialysis (Arici et al. 1998). Their analysis revealed deviation in compliance of a significant number of patients. The authors suggested that the monitoring of biochemical indicators was a reliable means to determine compliance with hemodialysis.

### **Supply Inventories**

The use of materials required for home peritoneal dialysis during nursing home visits patients has been utilized at the University of Pittsburgh, USA, to compare compliant versus noncompliant patients. Forty-nine patients were investigated during home visits at three monthly intervals. Compliance was determined by percentages, and based upon the number of exchanges performed (based on inventory and deliveries), divided by the number of exchanges prescribed. The resultant percentage scored was considered in relationship to the following variables: staff evaluations, patient attitudes to compliance, demographics, hospitalizations, dialysis adequacy, "Derogatis Affects Balance Sheet" (a validated tool of affects balance), and outcomes. Thirty-five percent of patients were found to be

noncompliant with prescribed exchanges based upon the supply inventory. Age, race, gender, peritoneal dialysis time, and number of comorbid conditions or incidence of diabetes could not differentiate compliant and noncompliant patients. This method of evaluating compliance was found to be predictive of noncompliant behavior. Twenty-nine percent of non-compliant patients were changed to hemodialysis versus only 6% in case of compliant patients. The authors concluded that approximately one-third of the patients at their center did not comply with treatment, which in turn resulted in inadequate dialysis treatment and poor outcome (Bernardini & Piraino 1998).

### **Self-Assessment**

Self-assessment forms were used by researchers in Cleveland, Ohio, to determine patient's baseline functional health status in relationship to their clinical outcomes. The SF-36 score rating was used to assess baseline functional health status. The MOS SF-36 (Medical Outcome Study Short Form) is an adaptation of the full-length MOS, a 36-question generic instrument without specific reference to chronic renal failure. The questions address the patient's ability to perform vigorous activity, daily activities, and to participate in social, family and occupational activity. This scale is used to assess the patient's mood, current and past health and judges their energy and susceptibility to illness. The scales are scored on a 0 to 100 range; the higher number is a more favorable rating. The component summary scores combine the physical and mental of the eight scales into a physical and mental component summary score. One thousand patients were studied across three outpatient dialysis centers. The authors found that patients with physical component scores below the median were twice as likely to die and 1.5 times more likely to be hospitalized as patients with scores at or above the median score. In turn, patients who missed more than two treatments per month often had higher physical component score than patients who did not miss treatments (DeOreo 1997). In a recent study from Belgium, researchers tested a dialysis diet and fluid nonadherence questionnaire (DDFQ) in patients on hospital-based hemodialysis. Measuring weight gain, potassium and phosphate levels and serum albumin in patients who had noncompliant behaviors confirmed the validity of the questionnaire. They found that noncompliance with diet and fluid guidelines was very common, particularly in men and smokers. Younger age was also negatively correlated with nonadherence (Vlaminck et al. 2001).

### **Individual Psychotherapeutic Assessment**

Psychologists at the University of Iowa, USA, hypothesized that there was a relationship between individual attention style and compliance with medical regimen (Christensen et al. 1997). The authors focused on two attention styles in 51 patients with chronic renal disease in response to a “health related threat.” Patients who were alert (high monitors) and those who were ambivalent (low monitors) to harmful health related factors. These researchers used the Miller Behavioral Styles Scale (MBSS), which assesses or “monitors” individual attention styles in relationship to the patient’s environment. Patients were asked to reconstruct in their mind 4 anxiety provoking scenarios, which was followed by questions as to how the patient would cope with such situations. In this study, patients considered to be high monitors were more likely to be active and alert to harmful health related factors versus patients considered as low monitors.

### **SOCIO-DEMOGRAPHIC CHARACTERISTICS OF NONCOMPLIANT PATIENTS ON DIALYSIS**

Socio-demographic characteristics such as race, age, and length of time on hemodialysis of patients have been utilized in an attempt to predict compliance in hemodialysis patients (Leggat Jr. et al. 1998). In a study conducted in Ann Arbor, Michigan, race, age, staff observations were used to predict noncompliance. They identified 6,251 patients who were on hemodialysis for more than one year. Noncompliance was defined in terms of missing one or more hemodialysis sessions in a month, shortening by 10 or more minutes one or more sessions a month, an interdialytic dry weight gain of more than 5.7%, and serum phosphorus levels of greater than 7.5 mg/L. Overall 8.5% of patients missed hemodialysis sessions, 20% shortened their dialysis sessions (7% three or more times), 10% had more than 5.7% interdialytic dry weight gain, or serum phosphate of greater than 7.5 mg/L. Using the Cox proportional hazards models adjusted to incorporate the sociodemographic variables above, they found a significant correlation between noncompliance among blacks, patients between 20–39 years, and smokers. Among those who skipped one or more treatments a month, there was a 25% higher incidence of mortality; patients with greater than 5.7% interdialytic weight gain had a 35% higher incidence of mortality.

In a comparative study of male and female “coping strategies” in two hemodialysis centers in the United States, 15 males and 15 females were



surveyed retrospectively. The "Jalowiec Coping Scale" was used to determine differences in coping strategies across the genders. This scale included 60 coping strategies and eight subscales and used a 4-point rating scale with zero indicating "never used" and 3 indicating "often used." The eight coping styles in this scale are as follows: confrontative, evasive, optimistic, fatalistic, emotive, palliative, supportive, and self-reliant. Findings suggested that both male and female patients tended to use emotionally focused coping strategies (Blake & Courts 1996). The only significant variable to coping styles was determined by the number of years on hemodialysis, age, and degree of formal education. Patients on hemodialysis less than 8 years, between the ages of 50–60 years, who had only undergone the mandatory formal education, were more likely to use emotion-focused coping strategies.

In a later descriptive study from the United Kingdom, coping strategies of men receiving hemodialysis were once again examined. However, in this instance the authors attempted to conceptualize these strategies in relationship to a number of other social variables namely: their social networks, patient perceived social support, and conflict and reciprocity in their personal relationships. Thirty participants were studied using the "Ways of Coping Questionnaire" and the "Interpersonal Relationship Inventory." The findings suggested that although both problem-focused and emotion-focused coping strategies were used, patients tended to use problem-focused coping, especially the seeking of social support. Overall, patients perceived high levels of social support and moderate to high levels of reciprocity with members of their social networks, and only moderate levels of conflict in their interpersonal relationships (Cormier-Daigle & Stewart 1997).

## **PSYCHOSOCIAL FACTORS INVOLVED IN NONCOMPLIANT PATIENTS ON DIALYSIS**

Psychosocial factors have been considered in terms of noncompliant behavior and mortality in hemodialysis patients by a number of authors. In a prospective study at George Washington University Medical Center, in Washington, D.C., researchers attempted to determine the effects of psychosocial variables upon compliance with hemodialysis. Baseline or initial psychosocial variables of well-being in relationship to the effects of their illness and satisfaction with life were measured using the "Beck Depression Inventory," serum albumin concentration, Kt/V and protein catabolic rate. Behavioral compliance was measured in terms of shortening of sessions and attendance. In addition, the type of hemodialyser



was noted for each patient. Over a 26-month period it was found that lower levels of social support, decreased behavioral compliance with hemodialysis, and a negative perspective of the illness were associated with a significant increased risk of mortality (Sensky et al. 1996). This study served to emphasize the relationship between psychosocial well being and compliance with hemodialysis. It emphasized the need for a positive perception of the illness and the need for social support in accepting the consequences of chronic illness.

Cognitive factors have also been combined with psychosocial variables to increase our understanding of compliance in patients receiving dialysis (Furr 1998). At the Charing Cross and Westminster Medical School, London, psychosocial and cognitive variables including gender, age, duration of time on hemodialysis, affective disturbance, past psychiatric history, health locus of control, social adjustments and social support of 45 patients in a single hemodialysis unit were measured using multiple regression analysis. Compliance was determined by adherence to diet (measured by prehemodialysis serum potassium), and to fluid restriction (inter-dialysis weight gain). The findings suggested that compliance was not significantly influenced by any one variable but by a complex interaction of all the above variables, thereby confirming the multifactorial nature of non-compliance.

At the University of Iowa, health beliefs and personality traits of individual hemodialysis patients were studied in relationship to compliance with the medical regime. The authors based their study on the hypothesis that the identification of premorbid conscientious-type personality traits and beliefs would facilitate and ensure accurate prediction of patients' compliance with the medical regime. They used the "health beliefs model" and the "hierarchical regression analysis" on 70 patients on hemodialysis. They found that even those patients who were assessed to be conscientious and had appropriate health beliefs were found to be noncompliant with the hemodialysis regime. In this study, noncompliance was measured by interdialysis weight gain and serum phosphorous levels (Wiebe et al. 1997). These findings tend to suggest that the anxiety and stress of ongoing hemodialysis overrides premorbid conscientious-type traits, making the prediction of compliance difficult.

Fatigue is a common side effect found among hemodialysis patients and a recurring factor in those who do not comply adequately with treatment. In one study, 110 hemodialysis patients suffering from fatigue were studied to determine the relationship between fatigue, depressive mood, provision of social support, and biochemical data. Using a combination of fatigue scale, "Beck Depression Inventory" and biochemical

laboratory data, they found that although fatigue was relatively mild, there was a definitive correlation with depression (Chiang and Chung 1997).

## **NONCOMPLIANCE AMONG RECIPIENTS OF KIDNEY TRANSPLANTS**

We carried out a systematic literature search to include the key words “compliance,” “noncompliance,” “medical compliance and kidney transplants,” “organ transplantation and medical compliance/noncompliance.” Additional reports were identified from the reference lists of key manuscripts and review articles in the English language only. For the analysis of data, only peer-reviewed articles in English-language journals were considered. Only manuscripts in the cyclosporine era and adult recipients of kidney transplants were included.

### **The papers identified were as below:**

- Collins, D.C., Wicks, M.N., Hathaway, D.K. *Transplant Proc* 1999; 31 [Suppl. 4A]:16S-7.
- De Geest, S., Borgermans, L., Gemoets, H., Abraham, I., Vlaminck, H., Evers, G., Vanrenterghem, Y. *Transplantation* 1995; 59:340-7.
- Didlake, R.H., Dreyfus, K., Kerman, R.H., Van Buren, C.T., Kahan, B.D. *Transplant Proc* 1988; 20 [Suppl 3]:63-9.
- Douglas, S., Blixen, C., Bartucci, M.R. *J Transplant Coordination* 1996; 6:53-8.
- Dunn, J., Golden, D., Van Buren, C.T., Lewis, R.M., Lawen, J., Kahan, B.D. *Transplantation* 1990; 49:349-53.
- Frazier, P.A., Davis-Ali, S.H., Dahl, K.E. *Clin Transplant* 1994; 8:550-7.
- Greenstein, S., Siegal, B. *Transplantation* 1998; 66:1718-26.
- Greenstein, S., Siegal, B. *Transplant Proc* 1999; 31:280-1.
- Greenstein, S.M., Siegal, B., and the Compliance Study Group. *Transplant Proc* 1997; 29:3741-2.
- Hilbrands, L.B., Hoitsma, A.J., Koene, R.A.P. *Transplantation* 1995; 60:914-20.
- Isaacs, R.B., Connors, Jr. A., Nock S, Spencer C, Lobo P. *Transplant Proc* 1999; 31[Suppl 4A]: 19S-20S.
- Kalil, R.S.N., Heim-Duthoy, K.L., Kasiske, B.L. *Am J Kid Dis* 1992; 20:63-9.
- Kiley, D.J., Lam, C.S., Pollak, R. *Transplantation* 1993; 55:51-6.
- Raiz, L.R., Kilty, K.M., Henry, M.L., Ferguson, R.M. *Transplantation* 1999; 68:51-5.

- Rodriguez, A., Diaz, M., Colon, A., Santiago-Delpin, E.A. *Transplant Proc* 1991; 23:1807–9.
- Rovelli, M., Palmeri, D., Vossler, E., Bartus, S., Hull, D., Schweizer, R. *Transplant Proc* 1989; 21:3979–81.
- Rovelli, M., Palmeri, D., Vossler, E., Bartus, S., Schweizer, R. *Transplant Proc* 1989; 21:833–4.
- Santiago-Delpin, E.A., Gonzalez, Z., Morales-Otero, L.A., et al. *Transplant Proc* 1989; 21:3958–60.
- Schweizer, R.T., Rovelli, M., Palmeri, D., Vossler, E., Hull, D., Bartus, S. *Transplantation* 1990; 49:374–7.
- Siegal, B.R. *Transplant Proc* 1993; 25:2502.
- Siegal, B., Greenstein S. *J Transplant Coordination* 1999; 9:104–8.
- Siegal, B.R., Greenstein, S.M. *Adv Renal Replacement Ther* 1997; 4: 46–54.
- Siegal, B., Greenstein, S.M. *Transplant Proc* 1998; 30:1310–11.
- Sketris, I., Waite, N., Grobler, K., West, M., Gerus, S. *Transplant Proc* 1994; 26:2538–41.
- Subach, R.N., Abul-Ezz, S.R. *Renal Failure* 1999; 21:223–6.
- Troppmann, C., Benedetti, E., Gruessner, R.W.G., et al. *Transplantation* 1995; 59:467–71.

## Data Extraction

This was carried out by two authors and checked for accuracy by a third author. Tables of the collected data were prepared for statistical analysis.

## Validity Assessment

None of the papers reported a randomized trial; the majority of the studies were of a descriptive nature. The selected papers were prospective in which questionnaires were given to recipients who already had a functioning kidney transplants.

Of the 26 papers identified, manuscripts (Siegal & Greenstein 1999, Raiz et al. 1999, De Geest et al. 1995, Frazier et al. 1994, Kiley et al. 1993, Schweizer et al. 1990, Didlake et al. 1988) were considered to be suitable for further analysis. To analyze the different factors affecting medical noncompliance after kidney transplantation, we selected the manuscript by Frazier et al. (1994) as a template against which other studies were analyzed. These factors were age, race, gender, marital status, income, employment, number of transplants, and mental issues

(anxiety, hostility, depression, distress, stress, chance, pain, and coping). Other variables analyzed were infection, type of transplant (cadaver or living), time since transplant, birth country, education, diabetes, number of rejection episodes, dose of steroids, tremor, clinic attendance, distance, dialysis compliance, and treated rejection episodes. We also took into account the self-care agency score, self-efficacy score, and situational operational knowledge.

### **Manuscripts Selected for Detailed Analysis**

Siegal and Greenstein (1999) prospectively sent questionnaires to 2,500 patients in U.S. transplant centers of which 1,402 returned, of which 22.4% reported some level of noncompliance with their medications after renal transplant. These patients were over 18 years of age and were on cyclosporine therapy and had a functioning transplant. In their study, noncompliance was scaled from one (never forgot) to eight (forgot every day). For each variable, they calculated the frequency, means, percentages, and standard deviations and then logistic regression analyses were used to identify predictors of noncompliance. Cluster analysis was used to identify groups of noncompliant patients based on similarities with respect to variables identified by logistic regression. Raiz et al. (1999) did a postal survey of 712 patients from the Ohio State University Medical Center who were 18 years old and had a primary renal transplant for at least 12 months. They used the Dillman's method for mailed surveys using dependent and independent variables for analysis by multiple regression method. Usable data was obtained from 50% of the patients. De Geest et al. (1995) performed a descriptive cross-sectional study from the Catholic University of Leuven, Belgium, on 150 recipients of kidney transplants who were at least 18 years old and one year after transplant. All but two patients were recruited and they were subjected to interviews and psychometric tests. These authors used a variety of statistical tests, which included Wilcoxon on rank sum test and Student's *t* test for independent variables. Logistic regression analysis was applied to model with variables or combinations of variables best predicted whether a patient belonged to the compliant or noncompliant group. Frazier et al. (1994) sent detailed questionnaires to 500 recipients of renal transplants at the University of Minnesota, of which 49% were returned. Using a variety of standardized instruments such as the Beck depression inventory, brief symptom inventory, inventory of social supportive behaviors, and multidimensional health locus of control, investigators used multiple regression analyses and measured the alpha score for each item. Schweizer et

al. (1990) performed a combination of retrospective and prospective analysis of patients receiving kidney, liver and heart transplants at the Hartford Transplant Center, Hartford, Connecticut. Their study was divided into a retrospective chart review of 260 patients between 1971 and 1984 and a prospective study of 196 patients between 1984 and 1987. The study authors excluded patients who lost their transplants in the first three months. The results were analyzed descriptively. Didlake et al. (1988) from the University of Texas Medical School at Houston, Texas, performed a mail survey of 295 patients who had received a kidney transplant between 1980 and 1986 and were compared with 70 patients who had a functioning transplant for at least 18 months. They defined noncompliance when two members of the transplant team interviewed the patients presented with rejection episodes, and the blood levels of cyclosporine were subtherapeutic. They used the mean values of population parameters by the independent t-test.

Patients who were older, married, male gender, and had a higher income were significantly more compliant with posttransplant medications (Didlake et al. 1988). The numbers were too small for analysis in Kiley et al. (1993) while in a paper by Siegal and Geenstein (1999), younger patients and white collar employment status were significant factors leading to noncompliance. In the study by Raiz et al. 1999, Caucasians were more compliant while Didlake et al. (1988) found that race (Caucasians) and older age were associated with greater compliance. Schweizer (1990) found that blacks and younger recipients of kidney transplants were more noncompliant, while De Geest et al. (1995) found that single or divorced patients were significantly more noncompliant versus married patients.

Recipients with a history of previous transplant were less compliant and those who had been transplanted a longer time ago were less compliant with following a regimen than were recipients who were more recently transplanted (Frazier et al. 1994). In a study by Siegal & Greenstein (1999), recipients who received a living transplant had received a transplant a long time ago, had no history of diabetes, had a history of infection, and were born outside the United States were more noncompliant. In the study by Raiz et al. (1999), transplant type and other transplant-related characteristics were not important. In the Schweizer et al. (1990) paper, transplant characteristics were also not important. Didlake et al. (1988) saw no difference in the type of transplant, duration of pretransplant dialysis, primary or retransplant but the important differences in the noncompliant group were greater than one rejection episode, prednisone dose, presence of tremor, greater distance from the clinic, dialysis compliance and greater rejection episodes.

Noncompliant patients were associated with greater emotional distress, higher transplant-related stress, and the belief that health outcomes were due to chance and the use of avoidance-coping strategies. In Raiz et al. (1988), noncompliant patients had greater anxiety. In De Geest et al. (1995), compliant patients had a higher level of self-care agency, perceived self-efficacy of long-term medication and higher situational-operational knowledge. Results are summarized in Table 2.1.

The half-life of transplants has increased steadily: cadaver kidney

**Table 2.1**  
Summarizes the Results of Noncompliance Studies

	Frazier	Kiley	Siegal	Raiz	Didlake	Schweizer	Geest
		Too small					
Age	+		+	+	+	+	
Race	0				+	+	
Gender	+				+		
Marital Status	+						+
Income	+						
Employment	0		+				
# of transplants	+						
Anxiety	+			+			
Hostility	+						
Depression	+						
Distress	+						
Stress	+						
HLOC (chance)	+			+			
Coping (avoidance)	+						
Pain							
(others)							

Notes: \* = also significant in multivariate analysis

\*\* = only reported for multivariate analysis

\*\*\* = only those with noncompliance leading to rejection Vs complaints

*Siegal et al.*

*Didlake et al.*

*De Geest et al.*

Infection\*

>1 rejection episodes,

Self-care agency score

Living related donor\*

Prednisone dose

Self-efficacy score

Time since transplant\*

Tremor

Situational-operational know

Clinic compliance

Education

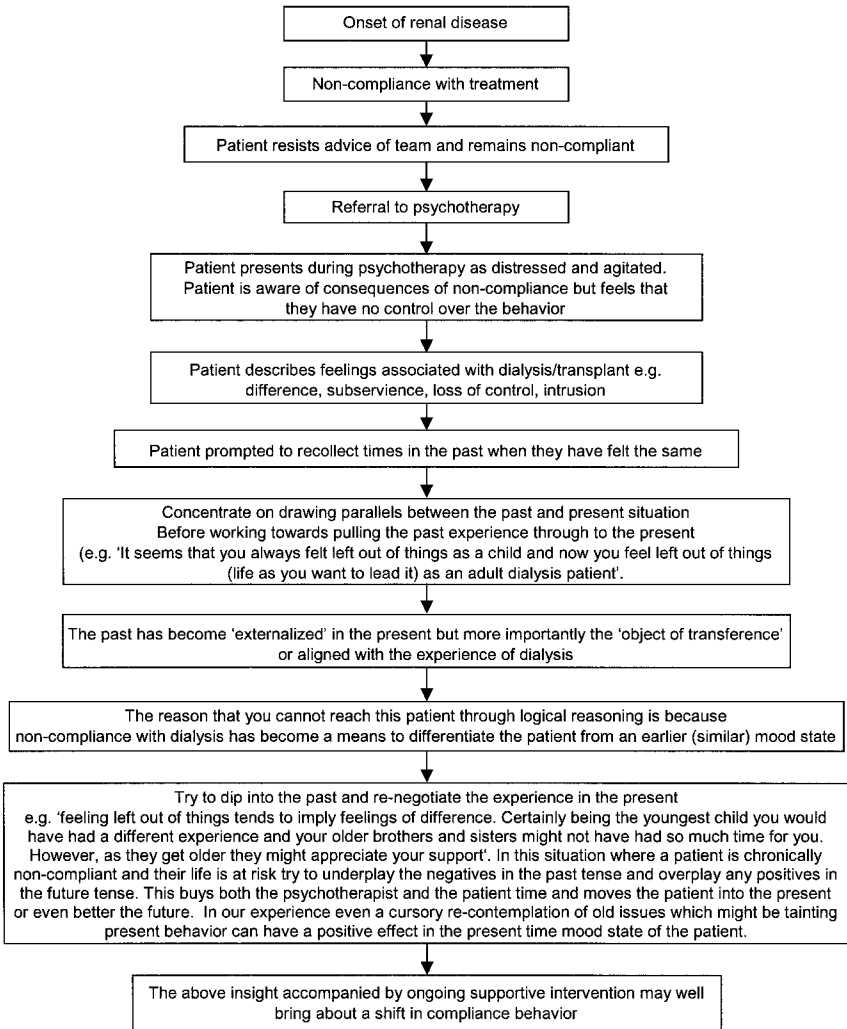
US-born,

Treated rejection episodes

Distance and Diabetes\*

Dialysis compliance

**Figure 2.1**  
**Psychosocial Profiling and Noncompliance**



transplants are at 9–11 years and living transplants are at 15–17 years. This has meant that each center is following larger numbers of transplants; in Glasgow we follow approximately 1,700 recipients of kidney transplants. Current restrictions of health-care financing do not allow each patient to be seen by a qualified therapist to address psychosocial concerns, and some of these unresolved concerns may lead to noncompliant with medications. It is estimated that 25% of this cohort of pa-

tients may be noncompliant with medications; one-to-one therapy with a qualified therapist would be prohibitively expensive. In this scenario, we suggest that special attention be given to specific groups, such as younger, female, unmarried, and non-Caucasians, to increase the level of compliance. Other specific patients groups who may require special attention, are recipients of living transplants, and were transplanted longer time ago with a history of previous transplant are also at risk of non-compliance. In addition, patients displaying emotional problems such as anxiety, hostility, depression, distress, lack of coping, and avoidance behaviors may also be targeted for special attention by qualified therapists to increase medical compliance.

Pretransplant screening should include psychosocial assessment using one or more of the standardized instruments to identify patients at risk of noncompliance after transplant. Although desirable, it is impossible to provide long-term counseling to all recipients of organ transplants. From this review, we conclude that patients who are at a higher risk of noncompliance after kidney transplants were younger, female, unmarried and non-Caucasians. Patients who were recipients of living transplants and were transplanted a longer time ago with a history of previous transplants were also at risk of noncompliance. In general, all patients displaying emotional problems such as anxiety, hostility, depression, distress, lack of coping and avoidance behaviors were also at risk of noncompliance after kidney transplantation. A focused approach directed toward patients at high risk of noncompliance would be more cost effective. This strategy may decrease the number of kidney transplants lost due to noncompliance with resultant economic benefit to the society.

## **INSTRUMENTS TO PREDICT POSTTRANSPLANT COMPLIANCE**

Kahan (2000) recently summarized the selection criteria for transplantation as follows: "accepted notion of benefit" (medical need, life remaining, and posttransplant quality of life); "patient's rights" (based upon the right of every patient to transplantation if they so wish; "cost effectiveness" (on the basis of best economic outcome); and "scientific progress" (whether the patient's treatment will advance the medical science). These concepts are designed to assist the physician in allocating scarce resource of organs among an increasing number of patients. In general, psychosocial assessments have centered upon compliance, family support, and the existence of any psychiatric disorders. Primary psychiatric contra-indications generally include history of substance abuse,



psychosis, suicide attempts, dementia, and borderline personality, while “soft”—or what we feel should be more accurately quoted as subjective criteria—include obesity, mood disorder and family support. In the absence of a formalized assessment procedure, the transplant team is likely to rely upon the collective “gut” instincts. “Gut” instincts, however, are wholly inaccurate and unreliable and are unfair on both the patient and the staff. Such feelings can fluctuate from day to day with stress and personal circumstances and the society’s prevailing norms, which are likely to be biased against the minority population and less-educated members of the society.

The principal assessment tools include the Psychosocial Assessment of Candidates for Transplantation (PACT), the Psychosocial Levels System (PLS), and the Transplant Evaluating Rating Scale (TERS). The Beck Depression Inventory and Minnesota Multiphase Personality Inventory (MMPI) have also featured in a number of psychosocial studies among renal patients. PACT focuses upon psychological variables such as substance abuse, compliance, social support, psychopathology, lifestyle, and knowledge of the transplant process. However, PACT does not predict transplant outcomes as such but rather highlights the correlation between decisions to accept or exclude the view of different assessors between recipients.

The PLS evaluates the correlation of decisions to include or exclude patients, based upon past coping skills, psychiatric history, affect, mental health status, support and susceptibility to anxiety. Patients are subsequently classified into three levels of suitability for transplantation. Level one patients are characterized by not having any psychiatric history, appropriate social responses, and good social support. Level two patients are likely to have a history of depression, agitation, or dysphoria and only satisfactory levels of social support at diagnosis. Patients classified at level three are liable to have a significant psychiatric history of substance abuse or major depression and/or suicidal ideation.

The TERS evaluates ten psychosocial aspects of a patient’s functioning and is an expansion of the PLS. In addition to the above-mentioned TERS, PLS level one candidates may display cluster C traits (avoidant, dependent or obsessive-compulsive personality disorders). Level two patients may have cluster C traits or a combination of symptoms from clusters A (paranoid, schizoid, schizotypal personality disorders) and clusters B (anti-social, borderline, histrionic, narcissistic personality disorder). Level three candidates have cluster A and B diagnosis. The use of the aforementioned assessments has been aimed at the development of a single or multiple measure of psychosocial suitability for transplan-

tation, the underlining criteria being whether or not the patient would be likely or capable of complying with the posttransplant regime. However, despite the use of rating tools, there is little consensus about the most effective method of predicting outcome. Other disparities center around the emphasis placed on any number of psychosocial factors and the validity of predicting posttransplant behavior based on past performance. Despite studies that have suggested that it is becoming increasingly difficult to predict patient outcome, there remains a dogged reliance upon such scales and assessments that utilize psychiatric classifications. Therefore, one might argue that the ability to predict compliance behavior is only as good as the initial diagnosis. Therefore, in our view, we feel that they tend not to offer any further insight into a patient's psychosocial or transpersonal worlds; patients are typified or classified at the time of assessment, not allowing for any future shift in position.

We are particularly concerned that chronic illness might exaggerate or underplay particular traits (consistent behavior) or states (two or more traits) and the subsequent psychological profile (two or more states). This would make an accurate assessment difficult and may make judging how a person might behave if relatively well (after a transplant) as opposed to relatively unwell (before a transplant) near impossible. It may well determine how a patient is functioning on the day of the test, but not over time, leading to an inaccurate test result. Upon reflection, such assessments are incongruent with contemporary psychotherapeutic input, which considers patient experience in terms of a dynamic and interactive "process" of change and personal development. Any assessment should take into account the effect upon the individual-self, defined in terms of autonomy, identity, individuality, liberty, choice, and fulfillment of ongoing chronic illness. There is also the authenticity of the patient's presentation to consider, that while interacting with a staff member they may feel hesitant and nervous. Therefore, they might present with the best-case scenario usually accompanied by a tendency toward politeness and reservation. Therefore, a "one off" scale might not have the accuracy and insight of a psychotherapeutic profile, which is built up over a number of sessions when patients might be more at ease with themselves.

Generally speaking, patients receiving dialysis or kidney transplants often present in our clinic as in the form of a "challenged" self, whereby their fundamental guiding emotional resources and identity, which have served them premorbidly, have shifted in keeping with the course of their illness. Transplant patients are at a disadvantage when being assessed by the instruments, which have as their baseline a sense of individual equilibrium or normality. Everyday normality or reality for renal patients is

different from that of nonrenal patients. "Renal patients live in a world which is unpredictable, uncertain and where daily living is geared toward their survival" or a dynamic, responsive process as opposed to the static existence depicted in assessment tools. We consider the former to be much more apt in a psychosocial research environment where increasingly, human development is compared to a human cell, with surrounding membrane to determine the "edge" where the individual ends and the external environment begins, commonly referred to as emotional boundaries. The role of emotional boundaries and well being are discussed in greater depth in chapter 4.

We have often wondered whether clearly known noncompliant and supposedly demanding patients act as an antithesis to maintain compliance among their fellow patients. Our line of thinking is based upon the belief that all patients contemplate noncompliance, but for the majority of the time comply with the treatment regime. Overtly, these patients are very critical of their fellow noncompliant patients. However, during therapy, compliant patients will often relate to a specific noncompliant patient with great compassion, concern for their well-being and relief that someone was not so *accepting of our predicament*. It is as though compliant patients can maintain their position, safe in the knowledge that someone else is articulating their own frustration, fear and anxiety so they do not have to do so. In brief, they are mindful that their feelings are being represented, albeit by proxy.

A case in point was that of a high profile noncompliant hemodialysis patient. I worked with Timothy for more than a year while he was attached to a hemodialysis machine in a communal unit. My main role was to support him through the various physical and emotional complications and setbacks that seem to characterize his time on hemodialysis. Inevitably, I was called in to mediate between the nursing staff and Timothy after his latest tantrum, which he euphemistically described as an *exchange of views* and which was overtly condemned by his fellow patients. Also, when Timothy received a transplant, I was inundated with enquiry about his well-being and asked to relay messages of congratulations. It soon became very clear that Timothy's departure from the dialysis room had left a great physical and emotional void. Interestingly, once he had recovered from the surgery, he returned regularly to the dialysis unit offering encouragement and support to the very same patients.

We often find themselves in the role of witness and ally (as patients relive their experiences), in whose presence they can speak the unspeakable and think the unthinkable. This work is not for the faint of heart,

as he/she will need to utilize any flair for the “transliterate prose” referred to in the previous chapter as a means to build bridges between the patients and staff. In the face of barely veiled antagonism from other members of the transplant team, it will be the therapist’s confidence and clinical judgment that will sustain them through treatment sessions. In the name of good practice, and to ensure that others understand our work, we have developed a systematic model of psychotherapeutic profiling in place of standardized instruments in a move toward inclusion, as opposed to exclusion from the transplant process. This ensures that a holistic picture of the patient is presented at various points in their lives and allows staff to better understand their presentation and enables us to intervene in times of crisis in a more informed manner.

When administering scales and assessments with a goal of screening patients for suitability for transplantation, mental health professionals need to convey to the patient the nature of their primary role. This is particularly important not only for the patient but for the mental health professional as there is potential for abuse of our professional expertise. Mental health professionals might want to consider whether they want to be perceived by patients as assessing their emotional well-being with an eye to supporting and working toward the resolution of their problems or as a means to gain information for the purpose of excluding them from the transplant process. If mental health professionals do not declare their empathy, they may be considered by patients as underhand and as a profession to be feared and engaged with in a cautious manner. We have often come across this attitude among patients when we have approached them to make them aware of the psychotherapy service after they have received their yearly medical assessment for the purpose of staying on the transplant list while on dialysis. Consequently, it is often difficult to determine the severity of the emotional suffering among these patients and any potential for support and intervention.

Given the traditional role of mental health professionals (psychiatrists and psychologists in particular), it is hardly surprising that patient skepticism is one of the major obstacles to treatment. One can hardly expect a patient to share his or her intimate thoughts and concerns with us if he or she is uncertain as to how we might utilize this information. It is our belief that mental health professionals working with transplant patients or any other field of chronic illness should not be regarded merely as gatekeepers, but rather as a part of a team that believes in a holistic model of care.

We are encouraged by the recent guidelines by the American Society of Transplantation (Kasiske et al. 2001) that psychosocial evaluation of

transplant candidates should be done by a professional who understands that bias may be a factor in patients denied a chance to go on the waiting list. To avoid bias, the potential recipient should have adequate cognitive ability to understand the risk/benefit of transplantation, long-term antirejection therapy, and the need for lifelong compliance. It is also clear that medical conditions, which can impair mentation such as thyroid dysfunction, uremia, liver failure, acidosis, and vitamin deficiency, should be corrected and these factors should be taken into account when deciding the suitability of patients going on the waiting list for transplantation.

### **PSYCHOTHERAPEUTIC PERSPECTIVE OF NONCOMPLIANCE**

As the reader would have deduced from the chapter so far, studies of compliance behavior have been founded upon demographic and psychological variables aimed at predicting compliance or to include, exclude, or “select” patients from the transplant list. However, such psychological and demographic variables are not only conflicting, but serve to maneuver groups of patients into homogenous, high-risk or “vulnerable” classifications without consideration of their individual social, emotional, or environmental circumstances. Further, if implemented rigidly in assessment clinics, whole sections of the community are likely to be excluded from transplant programs. For example, patients who unwittingly fall into a high-risk categorization (e.g., black females from low socioeconomic groups) are at best likely to be viewed with some skepticism. Therefore, it is probably fair to conclude that such research is of little clinical relevance to the practicing physician in the transplant clinic.

Latterly, there has been an increasing trend among studies toward the contemplation of noncompliance as a less tangible, conscious phenomenon (Cramer 1995 & 1999, Baines & Jindal 2001). Most notably, noncompliance manifests as missed clinic appointments and drug “holidays.” We have interpreted these actions as a more independent behavioral pattern as they move away from the perception of themselves as ill. When contemplating such noncompliance retrospectively (after graft loss), patients often view such manifestations in terms of personal development or progression (away from their perception of themselves as being ill) as opposed to regression or being noncompliant with the posttransplant regime. In contrast, the conscious acknowledgement of the ongoing need for compliance with immunosuppressive medication is synonymous with the realization that all patients retain the potential for relapse, despite

having received a successful transplant. Traditionally, the patient's perspective of noncompliance has been considered in terms of the extent of the "denial" of their illness and failure to adjust to the stringency of the medical regime, alone with the "intrinsic strength" and their ability to "cope." Also, they are often penalized for being unemployed despite research which has showed that patients on dialysis have difficulty in maintaining paid work, due to feelings of lethargy, prejudice of employers, and the impingement of dialysis their work place.

## **PSYCHOTHERAPEUTIC PROFILING OF NONCOMPLIANT PATIENTS**

The above-mentioned scales and instruments are often known in the business as *psychological* profiling, a collection of data pertaining to an individual or group from a formal test. This data is then utilized as means to predict behavior and/or typify an individual's personality. Mental health professionals have utilized this to classify patients into traits. Employers and investigative agencies use this data to predict how a person may behave or perform in particular situations. However, patients presenting for transplantation are for the most part neither career mental health patients, potential employees, or dangerous criminals; they are human beings who have to confront with their own existential reality or mortality somewhat prematurely. Rather than considering patients in terms of traits, we prefer to consider them in terms of multifaceted personas that may or may not respond to experiences and situations in a predictable manner. While transplantation is not the panacea for all their health problems and in itself carries medical risk, it is for these patients their only chance. Renal patients have a different "ontic" and "ontological" reality to nondialysis/transplant patients; their baseline of normality and reality is different to their contemporaries. Therefore, we have set about giving our patients the best chance of inclusion through personal development and ongoing support.

*Psychotherapeutic* profiling as defined by us is collected over a period of time (up to 12 sessions) and resists classifying patients into traits or typifying personality types. Rather, we prefer to consider them from a more plural perspective or series of subpersonalities that in different circumstances and presented with different dilemmas will interact with each other to produce a different self. Furthermore, psychotherapeutic profiling is not considered purely the domain of the therapist but is formed in collaboration with the patient. The ensuing insight will enable the patient to better understand his/her behavior and change it; the ther-

apist will be best placed to assist the patient to implement change. Our work is based upon the belief that noncompliant patients have the potential to produce a shift in their behavior if they have more insight into it and feel supported and understood. Also unlike psychological profiling, psychotherapeutic profiling in this context is not a static, intrusive, and conclusive tool, but a dynamic collaborative means with potential for intervention. In addition, it can be used insightfully to plan other supportive services and medical treatment regimes so that they best serve the needs of the patients.

### **Developing Psychotherapeutic Profiling**

The protocol for psychotherapeutic profiling was initially formulated, refined, and developed in our work with 25 posttransplant patients (11 women, 14 men) who were noncompliant with dialysis and subsequently received a kidney transplant. These patients went on to comply with the posttransplant regime. Subsequently, these principles and pattern of intervention have been applied to all such patients who have come through our program. The first 25 patients were referred to psychotherapy within three months of receiving a kidney transplant. While each individual experience was different, common presenting symptoms were feelings of guilt after receiving a kidney from a cadaver source, fear and confusion about a patient's own potential for noncompliance, low mood, anxiety, and hesitancy regarding the future. All 25 patients underwent a 12-week course of time-sensitive individual Systemic Integrative Psychotherapy (Baines & Jindal 2000), as described in the chapter one.

Patients in this study complied (measured in terms of keeping clinic appointments, attendance at psychotherapy sessions and taking of medications) with the posttransplant regime, despite being noncompliant with hemodialysis. This cohort of patients was characterized by nonremarkable psychological histories prior to hemodialysis and had maintained some social contact with friends or family throughout dialysis.

Dialysis was found to trigger a mood state of negative feelings, defensive and motivational behavior, and self-concepts that could be directly traced through therapy to an "internalization" of a premorbid relationship, most notably, the loss of a parent during childhood or a childhood experience of being different, that became "externalized" in the present. Therefore, dialysis became the object of transference that was subsequently "internalized" along with the self. Noncompliance was seen as a means to differentiate oneself from the earlier premorbid state. The role of the therapist was to identify the premorbid mood and con-



textualize it in the present, as a means to facilitate patient insight into noncompliant behavior. Patient insight regarding earlier noncompliant behavior was accompanied by a reduction in fear as to their future potential toward noncompliance with the posttransplant regime. All patients reported a decrease in mood, guilt, anxiety and insomnia after completion of the full course of therapy. However, long-term follow-ups will be necessary to see if these patients maintain their emotional well-being and medical compliance.

## **PSYCHOSOCIAL PROFILING AND NON-COMPLIANCE**

### **Case Study One**

Thomas is a 52-year-old divorced man, one of six siblings. He has one son and what he quaintly described as an ongoing attachment with a lady friend. He attributed his divorce to his 20-year career as a drug addict, however he is currently abstinent (we had no evidence to the contrary) for the past five years and is an active member of a local support group for ex-addicts. During his 5-year abstinence he had rekindled the relationship with his son and formed new friendships. Thomas had suffered renal failure two years ago thought to have been triggered by a 20-year addiction to drugs and had been receiving hospital-based hemodialysis. He was considered by many of the staff to be a difficult patient. Thomas moved into adulthood as a nervous and somewhat isolated young man and as soon as he was able, he had distanced himself from his primary family unit and relocated to a different part of the country. Throughout his rehabilitation for addiction he had come to realize that he used drugs to suppress the low-grade anxiety that had prevailed despite having changed his geographical and family environment. Although he had complied with hemodialysis in terms of attendance and adhering to fluid restrictions, he was prone to aggressive verbal outbursts and was considered antagonistic, patronizing, and aloof in his interactions with staff and patients. Much of this behavior had been aligned by staff with personality traits that might be associated with patients with a history of addiction. Inevitably this led to a questioning of his claim to ongoing abstinence despite there being no evidence to the contrary. He was not accepted on the cadaver transplant list, and therefore, his brother came forward as a live donor. This move was received with great skepticism on the part of the transplant team who felt that he would not comply with the posttransplant process. Their skepticism was dismissed



by the brother and patient and therefore the assessment team set about putting the family through a series of delaying tactics and presenting the live donation work up process as a series of virtually insurmountable obstacles.

Thomas's prevailing memory of his earlier life was that of growing up with a verbally and physically aggressive father, who appears to have been an alcoholic. Poverty, aggression, and uncertainty had characterized the early family life. As is often the case such an environment causes each sibling to impose emotional and geographical distance and boundaries around themselves. However, although his primary family social network could be defined in terms of isolation and boundaries, there remained an alliance between the mother, older sister, brother (donor) and the patient. This seemed to lie dormant for the majority of the time but was activated in times of practical and emotional crisis. Therefore, given a cursory glance, the patient would present as not having any family support, however, this group or constellation comprising the mother, sister, brother, and the patient had a track record of going to great lengths of supporting each other when the need arose. The unpredictability and uncertainty of hemodialysis as well as what he interpreted as its physical abuse and ravaging of his body was reminiscent of his early childhood years growing up with a physically and verbally abusive father. Hemodialysis was the object of transference; the physical object that triggered recurrence of an internalized emotional experience (the uncertain emotional and physical environment of his childhood), which in turn was externalized or recreated in the present through the onset of renal failure. He described during therapy sessions how once again he started to revert to the nervous and anxious young man who had left the family home all those years ago. However, rather than return to the use of drugs to quell anxiety, he masked it by adopting a pseudointellectual (despite having no formal education or employment) manner as a means to differentiate himself from his fellow patients, many were from the lower social groups. A copy of the *Financial Times* accompanied him everywhere, tucked under his arm, although no one had ever seen him consult it. Much to the amusement of his fellow patients he had acquired a number of flamboyant ties and jackets from the local charity shop. A Panama hat, which he wore throughout every season, topped all this off and which he would duly tip whenever he met anyone whom took his fancy.

Our observations were in keeping with a very sensitive man who protected himself from adversity and physical and emotional pain by distancing or differentiating himself (through diverse dress and manner)

from other patients. When this failed, for example if fellow patients became overly familiar and challenged him he would utilize angry outbursts to achieve the same effect.

Despite complying with attendance and the fluid restriction of hemodialysis, the patient's unpredictable behavior had caused him to be seen as noncompliant. Given his history of drug abuse the transplant team had attributed such a presentation in keeping with an ongoing drug problem and had refused to include him on the cadaver transplant list and had serious reservations about a live transplant. Hemodialysis served as an ongoing emotional irritant in his life that he was finding increasingly difficult to cope with. Indeed, hemodialysis had served to re-create an earlier negative mood state and in turn his noncompliant or unacceptable manner had served to differentiate him or insulate him from this mood-state. Therefore, in such cases, noncompliance with hemodialysis could be seen as a means to differentiate from an earlier mood state, rather than an act of self-destruction.

Increased insight into this behavior by the patient and staff coincided in a more amiable manner. When Thomas acted in an unacceptable aggressive manner toward staff they would seek advice and support from me as to how best to manage the incident. Mostly, this resulted in staff responding by first acknowledging within the context of the specific incident that it must be difficult for the patient, but that his outburst was unacceptable. Then informing the patient that they would leave him for a few minutes to before returning, reassuring him and working toward a solution or routine that was acceptable to both staff and patient.

The patient's brother was very keen to be a live donor while the remainder of the constellation consisting of his sister and mother made for a formidable and supportive posttransplant support network. Thomas participated in our posttransplant psychotherapy program and with a successful transplant was seen to be compliant. In this context, change was defined in the manner in which he dealt with situations of uncertainty and willingness to make attachments to others. In short, therapy became a physical and emotional venue to explore different ways of living and coping with real or perceived adversity.

Two years after transplantation, Thomas continues to comply with the posttransplant regime. Following the termination of therapy program, he has utilized our telephone counseling service to retain contact with us. He has also acquired a cat and discovered a flair for interior decorating.

We mentioned earlier how high-profile noncompliant individuals often have an antithetical effect upon fellow dialysis patients, serving to voice and balance their own fear of the uncertainty of their social, emotional,

and medical status. Thomas duly left a great void in the dialysis room after his transplant. As I went about my business, patients from the dialysis room would often beckon me over to inquire about his well-being and progress.

We are not advocating that staff should tolerate the sort of abusive outbursts referred to in the case study above, but they should remember that confrontations that are often provoked between noncompliant patients and staff do not constitute an exchange of equals. In the long term, medical staff might not be the best people to deal with such issues. The staff-patient relationship is characterized by the balance of power, with the transplant team seen as the "experts." If medical transplant staff members attempt to assume a counseling role they would do well to remember that they take on a conflicting role as well. Therefore, if the patient imparts some sensitive information to a member of staff while in their counseling role that they are not truly qualified to interpret with clinical accuracy or apart from their own medical agenda, certainly, they would not be bound by the same code of conduct as the therapist on the confidentiality of such information and might jeopardize the patient's position on the transplant list. Arguably, in assuming an emotionally intimate counseling role, they have may have disguised their power and might feel the need to impart any information received, which they may or may not have interpreted accurately to the rest of the transplant team. Patients are coming from a position of suffering and often experience various degrees of desperation, anger, and emotional volatility. Some staff members are more able to manage patients in this way than others, depending on their own experiences of life and emotional maturity. Unfortunately, medical staff receives little training in managing such incidents and even less support if they find a particular patient difficult to deal with. They may also have difficulty in dealing with issues of transference and countertransference (feelings which the patient evokes in the psychotherapist and which the psychotherapist should make use of in order to understand the patient's own experiences). The reader may by now appreciate the level of emotional intimacy involved in psychotherapy work and the subsequent need for the therapist to have a heightened self-awareness from the start, which requires their ongoing personal therapy. This ensures that therapists are able to differentiate their own thoughts and feelings from those of the patients. That is not to say that therapists or any other mental health professional who undergoes similar training are better people than other members of the transplant team. Rather, it suggests they are often better placed, in terms of their skill base, than other medically orientated members of the transplant team to

address issues where emotions are running high. This is particularly so among patients who have an ongoing or intermittent problem with dialysis compliance and who are not and never will be on the transplant list. In these cases, the course of a patient's compliance behavior is determined by the level of their ongoing psychosocial and medical well-being and ability to renegotiate their definition of the concept of hopes and aspirations for the future. Even the most psychomedically adjusted patient will usually have periods of intermittent noncompliance with dialysis and there is only so much that the staff can do in such instances. However, one thing remains certain: admonishments of an errant patient on the part of the staff very rarely help and in some cases might even cause further non-compliance. While such admonishments are invariably well meaning and evolve out of concern for the patient, they might also represent staff's own frustration with the patient. Staff who have built into their professional supervision hierarchy a means of emotional support and development—as a opposed to just case-load supervision—will quickly gain insight into such issues and are more likely to be able to address them in a mutually constructive manner. The case illustration below describes one such example whereby a patient not on the transplant list due to ongoing medical problems presented with periods of intermittent noncompliance with hemodialysis.

### **Case Study Two**

Natalie is a 36-year-old married woman and mother of an 18-year-old daughter. She had first suffered renal failure 18 years ago after developing preeclampsia following the birth of her daughter. After ten years on the cadaver transplant list her sister had donated a kidney to the patient; however, it had rejected two years later. A subsequent workup of her husband as a live donor had suggested that the patient had developed antibodies that rendered the likelihood of a second transplant virtually impossible. Following these events, 8 years ago, this previously compliant patient had started to develop intermittent periods of noncompliance, which took the form of missing hemodialysis for up to 2 or 3 sessions at a time and a tendency for excessive alcohol consumption.

Natalie had been referred to therapy by the nursing staff after she had missed her third consecutive dialysis session. During referral, the nurse alternated between overt frustration and distress, much of which was centered on the lack of warning that the patient gave before missing sessions and her concern of the medical consequences of the patient missing any number of sessions. Further exploration of the matter with

the nurse revealed that she actually felt quite betrayed by the patient. She had difficulty understanding how Natalie could appear quite settled and content for months and then suddenly not appear for two or three sessions at a time. The nurse became quite tearful as she wondered aloud whether she had *failed as a nurse* with this particular patient in not recognizing the warning signs, or whether the patient was deceitful and not the nice lady that she seemed. Inquiries as to how these periods of nonattendance had ended in the past were met with a roll of the eyes and a deep sigh. The nurse recalled how on previous occasions the patient's husband had literally grabbed her after two or three missed sessions and manhandled her into the car and drove to hemodialysis. In turn, Natalie had bitten and struggled as much as she could but in such a fragile state had not been able to resist. The whole matter was further compounded for the nurse when, after the last series of missed sessions, that patient had declared that in future she would try to do better and be all she could be. This declaration had been followed by a period of more productive initiatives, such as starting to drive again and taking flower-arrangement classes. Both the patient and nurse had hoped that Natalie could settle into a more self-aware and self-appreciating lifestyle and routine.

I had come to know this nurse as a kind and compassionate woman interested and concerned with the well-being of her patients. However, it seemed to me, even before I had seen the patient that the nurse had not recognized that the patient's reality and experience of life was completely different from that of her own. Natalie's definition of "being all she could be" was not necessarily a static concept and might waver and fluctuate from one moment to the next with the course of her illness, her resolve and emotional state and relational variables in her life, into which we had no insight. My initial concern was that, if the patient was to appear for her next dialysis session, what sort of reception would she receive from staff. Further, was it their anticipated negative reception that was now keeping her away from hemodialysis? As if reading my thoughts the nurse asked me what she should do if the patient returned to hemodialysis. I suggested that she just make as little fuss as possible, reassure the patient, and give her an opportunity to talk if she wanted. In the meantime, I said I would consider how best to initiate contact with the patient. Despite being outside the therapy environment one can see how the principles of therapy regarding missed sessions have been translated into the clinical environment. Any potential for resolution of such situations is not necessarily the domain of the therapist, but calls for a multidisciplinary cooperation, understanding, and intervention. The

therapist is often called into such situations after the patient has failed to attend for dialysis or outpatient appointment, during which feelings—or more specifically frustration—run high among both staff and the patient. The role of the therapist is twofold, firstly to ensure that the path back to treatment remains open (not medically, but relationally and emotionally). Secondly, to facilitate recreation of hope drawn from past events in the patient's life and translate them into hope for the present and the future. The way back to treatment should not be blocked or obscured emotionally (by any frustration and/or negative attitudes of staff) or physically (by the closure of their dialysis slot or by not sending a new outpatient appointment). This first initiative is based upon the psychotherapeutic principle instigated when patients in therapy miss sessions. The sessions remain open to them so that they can endure whatever emotional turmoil they are experiencing that keeps them from attending treatment.

We mentioned in the previous chapter how traditionally psychotherapists meet with patients only in the consulting rooms at allotted times. However, in this case, the patient was not attending for hemodialysis treatment so she was unlikely to travel to the hospital to see a therapist, who was unknown to her and whose agenda was unclear. Therefore, I contacted the patient by telephone and asked if it was acceptable to her (emphasis upon responsibility for self, decision making and autonomy) for me to visit her at home, to which she agreed. The key to getting patients to agree to such visits in these circumstances is the staff member's ability to convey to the patient, often very concisely, their understanding of the patient's dilemma from a position of their viewpoint and experience of hemodialysis as valid. Reassurances that many patients find compliance difficult and become distressed at times often console the patient and have a *face-saving* effect paving the way for a return to hemodialysis. During my early days of being called upon to try to intervene with chronic non-compliance, patients would often inquire as to whether other patients had problems with non-compliance. My reassurances that they did followed by the recollection of an artfully and heavily embellished tale or two guaranteed to bring a smile served to lessen the physical and emotional isolation of non-compliance.

On my arrival at the house, I found Natalie lying on the floor wrapped in a duvet clutching a bottle of gin. A quick glance around the room revealed a scattered collection of all the obligatory paraphernalia those who work with or experience chronic illness come to accept as paramount to survival—kitchen roll, iced water, extra pillow, pile of washing up in the sink and a bad hair day. As I sat down on the floor to speak

to her, the apologetic expression soon disintegrated into tears and slow rhythmical side-to-side head shaking.

**Natalie:** *I can't come in (to hemodialysis), I just can't come in.*

**Psychotherapist:** *I have not come here to take you in. Sure, everyone is concerned about you; we thought that you could use a little company. It must be pretty lonely lying here alone with your thoughts.* I paused to allow this information to sink in, before continuing in an attempt to determine some of the home situation.

**Psychotherapist:** *Are you here on your own during the day?*

**Natalie:** *My husband is at work, he stormed out this morning. He said that he is washing his hands of me, he has gone off in a terrible mood. Good riddance, that is what I say, he is just like my father, constantly telling me what to do. What is it about men, always got to be in charge?* The question hung in the air, as the patient seemed to lapse into contemplative thought for a few minutes. I purposely did not distract her, as she did not have enough insight into the patient's thought processes at this time to make any meaningful intervention.

**Natalie:** *Is Maria (the nurse mentioned previously) in today?*

**Psychotherapist:** *Yes, she is.* Gently, it was her who told me that you were not feeling too well at the moment. No reference is made to her nonattendance, why state the obvious?

**Natalie:** *Is Anne (another dialysis patient) in today as well?*

**Psychotherapist:** *Yes, she asked me to give you this note.* Handed over the note of which I had no idea of the contents. My response to the above inquiries was fashioned in a manner that suggested that staff and patients were concerned but not judgmental of her nonattendance. Also through her inquiries the patient seemed to be testing the ground for her return.

**Natalie:** Patient unfolded the note, which had been hurriedly scribbled on a paper hand towel, and sat up and read it aloud. *Get your backside in here, girl, I am fed up with looking at an empty chair.* Patient appeared to perk up and wiped away her tears. In sending such a poignant note referring to her empty dialysis chair, her fellow patient had unwittingly, or not, as the case may be, confirmed that the way was open for her return. *She is a nice lady; we have been dialyzing together for years. I am doing a painting for her, or I was, in my art class that I started going to.*

**Psychotherapist:** Seeing a way to dip into a positive aspect of the past that might prove a source of hope in the future. *Are you quite an artistic person then?*

**Natalie:** *Well, not really, but I like painting. But I am just not feeling like it at the moment. So what have they sent you out here for then? I am not going back, not until I am ready. I feel terrible.*

**Psychotherapist's thoughts:** Ordinarily a therapist would paraphrase or try to capture the mood or feelings of the patient, but I did not feel confident that in the few minutes that I had been sitting with Natalie that I would be accurate enough in my interpretation.



On the other hand, the patient clearly needed to have some insight into my presence on the floor of her sitting room.

**Psychotherapist:** *I have worked with a number of patients on dialysis, all of whom have been struggling to comply with treatment, but sitting here, at this moment, I am trying to image what it must feel like to be you.*

**Natalie:** *It just feels heavy and black, I don't have the energy to get through it, this dark black fog, to get to dialysis again. The drink helps indicating the bottle of gin clasped to her chest, it dulls the despair, panic and it just sends me to sleep. But it's just the same when I wake up again.*

**Psychotherapist:** *Then I suppose my role could be to help you find a way, a path through the dark black fog.*

**Natalie:** *Sounds all right, but how do we do that?*

**Psychotherapist:** *I would like you to make yourself comfortable and close your eyes.*

**Natalie:** Laid back on her mound of pillows and closed her eyes.

**Psychotherapist:** *You have described how it feels to be you: "heavy," lack of "energy," and "black." It is very important to use the patients' own words so that they own the experience, don't try to correct any grammar or substitute one word for another. I was wondering if we could translate those feelings into a visual image.*

**Natalie:** Patient sits up abruptly. *What is this, some sort of hypnosis thing? I don't fancy that, you know.*

**Psychotherapist:** *At pains to look unperturbed. Sometimes it is easier for us to understand things a little better when we visualize them in the privacy of our own minds. It just makes them more tangible, or concrete.*

**Psychotherapist's thoughts:** This technique is not hypnosis but a creative use of visual imagery, but I don't want to get sidetracked into a complex explanation at the moment.

**Natalie:** Patient lay back on her pillows again and was silent for about two minutes. *Well, I can see a big wall of dark fog, I am standing in front of it but I can't see a way through it.*

**Psychotherapist:** *You were just telling me about some positive aspects to your life, your friend Anne who is waiting for you on the other side of the fog and the painting that you have spent so much time on. Try to imagine that these aspects of your life, which allude you at the moment, are on the other side of the dark fog that you have described.*

**Natalie:** Sounding more relaxed and more engrossed. *OK, but I still can't see them.*

**Psychotherapist:** *OK, so concentrate hard (short pause for effect). Try to imagine Anne and your painting classes as two separate fog lights, like you might find on the front of a car. Try to see them shining through at you, beckoning you through a path, from the present through to the future.*

**Natalie:** *Yes, I can imagine light beams, but they are dim, not bright.*

**Psychotherapist:** *Maybe we need to nurture them, encourage them to shine more brightly.*



**Natalie:** Sitting up abruptly. *Or maybe they might go out all together. Patient starts to remonstrate with me. I have not been to dialysis for a week you know. I think that I had better go in tomorrow. Yes I think I will go in tomorrow. You did say that my chair was still there didn't you?*

We met for approximately two hours on this occasion, with me sitting on the floor next to Natalie rolled up in her duvet. Shortly after I had left, she called an ambulance to take her to dialysis. The key to moving her on from this point in time was her interest in painting, her friendship with Anne, and the fear that an old enemy (fellow patient) who had been after her dialysis chair by the window might claim it. We would not be the first to observe that patients take little "holidays" from treatment and there is little that staff can do, but to convey to patients the seriousness and the risks associated with such behavior. The key to effective intervention in such cases also lies in the timing; some patients often need less encouragement to come into treatment after they have missed a few sessions. However, if staff can build up some sort of dialogue with them as soon as possible after their first nonattendance, they will gain insight into motivating factors in the patient's life, which can later be used as a lever to achieve compliance with treatment. At different time points in her life, dialysis was not an option for Natalie. Her collective will to cope with dialysis was unendurable or compressed under the reality of her ongoing chronic illness in the present. My work with patients during such periods of time had suggested that such instances are characterized by feelings of overwhelming depression and loss of hope and often they cannot see a way through such a dense fog of feelings that stands between them in the present and the future. However, often they are unable to draw upon hopeful images, feelings, and accomplishments from the past that might sustain them. The use of visual imagery is quite an effective method when more convention techniques have either not yielded results, particularly when time is of the essence, as in this case. It is not uncommon for patients to confuse visual imagery with hypnosis, primarily because both phenomena rely on a daydream-type state on the conscious mind. However, unlike hypnosis, which is therapist-led while the patient's mind becomes quiet or passive, visual imagery is patient-led and requires the conscious mind to become active. In short, the therapist will respond to the direction of the patient's active, conscious imagery. This technique should not be used in patients with a clear history of psychosis. Her husband's previous heavy-handed attempts at forcing her into dialysis had been well intended and indeed had probably saved her life, but they had also served to underline dependency upon

both the machine and her family. In short, such action had recreated old feelings of resentment that she had felt toward a bullish father, which had in turn been recreated in the present. In this context, she was not only resisting her husband's attempts to encourage her to comply with dialysis, but her father's earlier attempts to control her behavior as well. If such an attitude on the part of the husband prevailed into other areas of her life, it might also be a causative factor to the onset of these noncompliant episodes. In the long term, we were trying to develop a better, more respectful coping strategy, whereby, Natalie felt part of the alliance between family and staff and may hopefully reduce the frequency and urgency of her need to distort the boundaries and resist treatment.

## **STRATEGIES TO INCREASE COMPLIANCE**

### **Patient Empowerment**

There is an increasing trend to involve patients directly in treatment planning which in turn may lead to increased compliance with dialysis. A number of surveys have indicated that patients would like more control over the nontechnical aspects of dialysis (Montemuro et al. 1994). There is clearly a need to increase patient participation in all aspects of their disease process. However, there has been little legislative support for this position (in the United Kingdom, patients do not have a right to choose their physician or hospital of treatment) and little detail as to how staff coax patients toward the communicative and behavioral competence necessary for meaningful empowerment. Empowerment does not come about by some miraculous process of osmosis but through the acquisition of communicative and behavioral competence on the part of both the staff and the patient. These are skills which may well be lacking among patients from lower socioeconomic groups who might be easily overwhelmed by the professional classes and/or whose confidence and selfesteem have been eroded by chronic illness. These patients will need to be presented with empowerment as a multicomponent educational package that may utilize modeling, coaching, feedback and homework assignments, all conducted within a supportive and developmental framework.

To date, empowerment studies have been predominantly concerned with the more compliant and/or independent patient. However, within the supportive and educational framework, the more noncompliant patient might also be considered. Many of the noncompliant or emotionally

traumatized patients featured in this book have developed such a presentation in part, because their personalities are such that they do not perform well within a rigid structured hospital environment. Therefore, they may respond better within the semistructured framework of a patient empowerment program. In contrast, previously compliant patients who might appear to be seemingly obvious candidates for such a program might not do so well in the semi-structured, self-initiating, empowered environment. In short, empowerment programs should be viewed as an ongoing system of personal development, education, and support, with the patient being selected on a case-by-case basis.

In a recent study aimed at the retrospective determination of compliance with medications among patients who had experienced late acute rejection, we requested that they complete a modified version of the Long-term Medication Behavior Self-efficacy Scale (LTMBS-scale) a self-report questionnaire (Baines et al. 2002). The questionnaire, which they were able to complete in their own time, was aimed at determining patient's levels of confidence in taking their medications in a variety of environmental and situational contexts and with a goal of offering supportive psychotherapeutic intervention. In the spirit of self-empowerment, the questionnaire was not "administered" by the physician; rather the statements were aimed to prompt introspection and contemplation of individual patient circumstances and experiences thought to be vital in determining compliance behavior.

We retrospectively analyzed the case records of patients who had their first cadaver renal transplantation at our center during a 6-year period from January 1991 to December 1996. We identified 26 patients who had late acute rejection. All patients received similar antirejection therapy. The Long-term Medication Behavior self-efficacy Scale is a 27-item instrument depicting a variety of situations in which the patient might be required to take their medication. The self-efficacy score was calculated by summing the scores of all items divided by 27. Thus the self-efficacy scores range between 1 and 3; higher score indicates greater self-efficacy. We modified the original scale to a 3-point questionnaire as our pilot study showed that patients found it difficult to discriminate between 5 options. Over a six-year period, we identified 26 patients with late acute rejection, 2 patients had subsequently died. The questionnaire was mailed to the remaining 24 patients (14 women and 10 men), with an explanatory letter; patients were requested to complete the questionnaire anonymously. After two weeks, we called each patient to inquire if they had completed the questionnaire. If the response was negative, we encouraged patients to complete and return the questionnaire. Con-

fidence of each patient was computed by summing up all the responses and dividing by 27. The values range from 1 (least confident) to 3 (most confident). When a comparison of clinical data was needed, t-test was used. Statistical significance was assumed at a p value of 0.05. The mean values are expressed as mean  $\pm$  standard deviation. For statistical analysis and construction of the graph, a software package (SPSS 9, SPSS inc. Chicago) was used.

Our overall results showed a definitive correlation between late acute rejection, and individual patient's perceived low rate of self-efficacy across a variety of contextual or environmental situations. It was seen that patients were only reasonably confident (mean score 2.17) in taking their medication in the above-mentioned contexts. All patients demonstrated significantly lower self-efficacy in relationship to items 14, 20, and 21 (mean score 1.0), the items relating to physical and psychological symptoms (brittle bones and generally feeling "very ill") and psycholog-

**Table 2.2**  
**Demographics of the Population Studied (n = 24)**

		Number (n)	Percent (%)
Age (mean 39.2 +/- 12.9)	<20	1	4.2
	20-29	5	20.8
	30-39	7	29.2
	40-49	6	25
	50-59	3	12.5
	>59	2	8.3
Gender	Male	10	41.7
	Female	14	58.3
Diabetes	Yes	1	4.2
	No	23	95.8
Race	Caucasian	23	95.8
	Asian	1	4.2
	Others	0	0
Occupation	Employed	6	25
	Student	2	8.3
	Housewife	7	29.2
	Unemployed/ Retired	9	37.5

ical symptoms (feeling "sad") that affected their well being. These symptoms were considered to be side effects of either the medications or a response to the experience of chronic illness.

The majority of patients (10 women, 5 men) returned their completed questionnaires before the two-week telephone reminder. However, the seven questionnaires (4 women, 3 men) that were returned after the telephone reminder demonstrated an even lower self-efficacy score (mean score 1.2). The second group of patients demonstrated the same trends in relationship to items 14, 20, and 21 as with the first group of patient (who returned their questionnaire without prompting), self-efficacy scores were significantly reduced for these items as well (mean score 0.5).

The overall results of the study suggested that patients were not confident that they would take their medication if they were liable to experience physical (brittle bones, generally feeling ill) and psychological (feelings of sadness) side effects of medication. These negative physical and psychological states were related to low self-efficacy with the taking of immunosuppressive medications and subsequent noncompliance. In addition, the ongoing nature of the symptoms served to maintain their perspective of themselves as "ill" and therefore different from nontransplant patients or their peers, family, and the general population. Of the patients who received supportive psychotherapy before receiving a second transplant, the aims of treatment were constructed around a shift in patient's ability to tolerate their individual difference (the need to take medications for their lifetime), in relationship to the majority of the population. This was achieved through the utilization of empowerment techniques such as modeling, systematic desensitization (gradual exposure), and homework assignments.

### **Formal Counseling**

Dialysis results in inevitable changes in lifestyle and it is not uncommon for patients to become depressed in response to the loss of their premorbid lifestyle and anxious about their present and future well-being. This is more pronounced if they have a premorbid history of mental illness (Craven & Farrow 1993, Katayama & Kodama 1994, Drummond-Young et al. 1996, Abbey & Farrow 1998). A common means to address depression and anxiety in this group of patients is to implement counseling and psychotherapy programs. The renal and transplant center at the University of Toronto, has successfully implemented a comprehensive counseling and psychotherapy program aimed at facilitating the ad-

**Table 2.3**

**Items Used in the Questionnaire to Study Correlation between Noncompliance and Late Acute Rejection**

- 
1. At home
  2. Pills are large and difficult to swallow
  3. If medicine is expensive
  4. If medication aids are absent
  5. Nobody helps to get ready
  6. While at work
  7. In a weekend
  8. If medicine can make one impotent (male) or decrease interest in sex (female)
  9. If the medicine can cause spots on face and excessive hair growth
  10. Feeling healthy
  11. Alternate day medications
  12. The time for taking medicines do not coincide with meals
  13. Doing a project at home
  14. If medicines give brittle bones
  15. If no one reminds of the time to take the medicine
  16. When there are visitors at home
  17. If angry at a friend
  18. If in pain
  19. While watching an exciting program in TV
  20. Feeling ill
  21. If feeling sad
  22. When unknown people are watching (like in a restaurant)
  23. If sick in stomach
  24. If had an argument with the partner
  25. At a party
  26. While taking a long walk
  27. In a bar
- 

justment of organ (liver, kidney, heart, and lung) transplant patients, while supporting them through psychosocial and psychiatric support. To support patients on dialysis and awaiting kidney transplants, the “While you are waiting” psychoeducational group was formed which comprised of a support and educational program. Group discussions involved living

with a life-threatening illness, preparing to live versus preparing to die, and preparing for transplantation (Abbey & Farrow 1998). However, while beneficial to relatively emotionally stable patients, in keeping with position in the previous chapter, it should be remembered that the "group" work of Abbey and Farrow (1998) placed emphasis upon education and support. They did not describe a group psychotherapeutic process or alliance and therefore should not be considered or directly compared with the findings from psychotherapy group studies, which are aimed at more emotionally volatile patients and which described a psychotherapeutic alliance and process.

At the University of North Carolina, cognitive behavioral counseling was combined with stress inoculation education in an attempt to reduce anxiety, depression, adjustment to illness, and stress and increase compliance to dialysis (Courts 1991). Psychosocial reactions and adherence to the medical regime, interpersonal support, and control, were identified as the intervening variables. The variables were founded on the predetermined belief that while the physiological aspects of hemodialysis were well documented the psychosocial reaction to them would be "unique." Psychosocial change was measured using an assortment or though not necessarily compatible set of scales including: clinical anxiety scale, generalized contentment scale, psychosocial adjustment to illness scale self-report, and the hemodialysis adjustment to illness scale. The findings suggested that a significant number of patients benefited from both cognitive behavioral counseling and the stress inoculation counseling; all patients demonstrated a lower posttest anxiety scores. More specifically, four patients had significantly reduced their pretest depression scores and three had lower perceptions of dialysis stresses. Overall, four out of six patients had a higher posttest adjustment to illness score.

### **Multidisciplinary Approach**

Adhering to an appropriate and adequate diet while on dialysis has been emphasized in a number of studies, as these patients are at a particular risk of malnutrition (DeOreo 1997). At the University Dialysis Center, Syracuse, New York, dieticians and physical therapists combined physical exercise and dietary recommendations to assess nutritional intake in relationship to patient participation in an intradialytic exercise program (DeOreo 1997). Performance testing and nutrition assessments were administered to 16 patients who participated in a self-paced intradialytic exercise program, which included cycling before or during dialysis. Baseline data was collected pre-dialysis, and at 3-, 6-, and

12-month intervals. After 12 months, patients demonstrated significant improvements in physical and nutritional well-being, which in turn was directly related to compliance with dialysis. The role of the social worker among dialysis patients has not received much attention. However, one study gave particular emphasis to psychosocial problems as obstacles to compliance with dialysis. Compliance was discussed with reference to the life cycle stage of the patient; elderly and younger patients were more likely to be noncompliant. This study emphasized the impact of psychosocial environment of the patient as a critical determinant in ensuring compliance (Furr 1998).

### **Complementary Medicine**

This form of therapy does not readily lend itself to traditional research methodology, and therefore, it has been suggested that its effectiveness has not been clearly demonstrated. Despite some misgivings, complementary therapy has been incorporated into traditional medical treatment in a wide range of specialties, including midwifery (Botting 1998), oncology (Howells & Maher 1998), and coronary care patients (Ai et al. 1997). In a study among coronary artery bypass patients at the University of Michigan, complementary therapies have been used to promote psychological recovery, postsurgical anxiety and depression (Ai et al. 1997). Complementary therapies were used successfully to alleviate pain, promote relaxation, and facilitate adjustment to lifestyle changes and as a means to allowing patients some participatory control over their illness and recovery. The parallels between coronary-care bypass patients and our patients, such as the ongoing lethargy in response to a disease process, vulnerability to depression and anxiety, and the need for a change in lifestyle, suggest that these forms of therapy may well be beneficial.

### **CONCLUSION**

Noncompliance with dialysis is not necessarily an accurate predictor of posttransplant compliance and should not always be used to exclude patients from the transplant program. However, patients with a history of noncompliance with dialysis are liable to feelings of fear of a recurrence of noncompliance behavior which might jeopardize their kidney transplant, but over which they feel they have no control. They may have symptoms of anxiety, insomnia, guilt at having received a kidney from a cadaver source, hesitancy regarding the future and low mood. These mood states can be effectively treated using short-term psychotherapy



aimed at increased understanding of past noncompliant behavior. In turn, such insight creates a more stable and productive mood state and facilitates actualization of a better quality of life in the future.

The treatment of noncompliance has been fragmented and lacks uniformity with regards to the identification and prediction of treatment policy. Ultimately, the transplant community needs an inclusive model of compliance capable of detecting and treating noncompliance before it proves fatal. It is hoped that our work will encourage others toward a multifaceted approach using psychotherapeutic principles as a means to detect, understand, and treat this condition in patients on dialysis and in recipients of kidney transplants.

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## **Chapter 3**

# **LOSS, BEREAVEMENT, AND GRIEF IN RECIPIENTS OF KIDNEY TRANSPLANTS AND DIALYSIS**

## **INTRODUCTION**

Transplantation has historically been associated with loss, grief, and bereavement in relationship to the death of the unknown donor (Kemph 1967). In addition, patients also associate graft rejection with loss, bereavement, and grief (Streltzer et al. 1983). The fear of rejection and loss of the kidney has also been considered in terms of an altered body image, side effects of medication, and the residual effects of preexisting illnesses, such as systemic lupus erythematosus and diabetes (Gulledge et al. 1983, Simmons et al. 1981). Other patients consider bereavement in terms of the death of relatives (Alleman et al. 1994) or of fellow patients (Vamos 1997). Therefore, the process of grief, loss, and bereavement associated with transplantation is multifactorial: one or more elements may be dominant in an individual, and the process of therapy or counseling aims to draw these elements out, vocalize, and resolve these feelings.

Patients are also increasingly presenting with intangible feelings of paradoxical loss despite having recovered from an illness or received successful surgical or medical intervention. Such symptoms among transplant patients often prevail despite having gained a much desired and oftentimes long-awaited transplant. In our opinion, this presentation is incorrectly thought to be due solely to grief and bereavement for the unknown donor. Shortly after a successful transplantation, few patients



meet the criteria for chronic depression; rather, they present more in keeping with dysthymia or mild depression. Dysthymia is characterized by the same symptomology as major depression, but the symptoms are less intense. Patients place emphasis on feelings of indiscriminate loss, but unlike chronically depressed patients, they are able to go about their daily business. We suggest that ongoing feelings of loss after successful transplantation might be considered in terms of the time lost to chronic illness what might have been, or the *imagined past*. The imagined past refers to a past (compiled of experiences, sensations and achievements) that transplant patients consider that they might have had, if they had not experienced renal failure. The *imagined past* is largely fantastical, aspirational, and does not exist beyond the patient's imagination.

The *imagined past* is based in a different time zone than more conventional grief and based upon the notion that we can lose what we never actually had. In this chapter, we review the psychosocial and traditional manifestations of loss, bereavement, and grief among both patients with chronic illness and in recipients of organ transplants. We will discuss and utilize case examples of the clinical manifestations of loss in the context of anticipatory loss—or the fear of rejection of the transplanted kidney—and the less tangible concept of loss after transplantation—that of the *imagined past*.

## **A PSYCHOSOCIAL PERSPECTIVE OF LOSS, GRIEF, AND BEREAVEMENT**

Loss, bereavement, and grief have long been considered to be cyclical in nature, as life begins with birth and ends with death. Common to both the experiences of birth and death is the need for separation and a new beginning. However, loss, bereavement, and grief do not necessarily just apply to death. Grief and bereavement have also been considered with respect to other losses, such as redundancy, hysterectomy, vasectomy, divorce, and abortion. This process usually involves a period of social and emotional withdrawal before resolution is achieved.

Loss, bereavement, and grief will need to be contemplated in the context of the lifestyle and experience of the individual at the point of loss. Recovery from all types of loss has been considered within individual and relational variables, such as the intensity and length of the relationship and whether the relationship was perceived as a positive and caring or bad and neglectful relationship. In circumstances where the relationship has been brief without a great level of emotional intimacy, loss is considered in terms of a good, bad, or indifferent memory. While rela-

tionship that has been ongoing and largely negative in nature, leaves a negative memory that translates into the future lifestyle of the individual, which may take the form of hesitancy regarding intimacy in similar situations. In contrast, the separation or loss from largely positive relationships can leave the bereaved yearning to recreate similar relationships with others.

The process of dying and bereavement has been conceptualized in terms of "phases" Kubler-Ross (1969) and "stages" by Collick (1982). Kubler-Ross (1969) described the following six "phases of dying" through which individuals are thought to progress before they come to terms with death: denial, bargaining, anger, despair, resignation, and acceptance. She carried out a series of interviews with patients suffering from terminal illnesses and their widows in an attempt to determine thoughts and feelings of these individuals regarding their coming to terms with impending death. The above-mentioned stages were developed as a means to represent psychological stages of acceptance of both parties. However in a later paper, (Kubler-Ross 1984) adopted a creative and patient-centered approach with terminally ill patients to compile pictures and videos as a means to help them leave a visual legacy behind for their families and friends after their death. She viewed the construction of such personal profiles as a way to extend the impression that their life had made beyond their death.

In a more succinct framework to bereavement, Collick (1982) set out stages of bereavement as follows: shock, unreality, disbelief, yearning, emptiness, searching, anxiety, anger, guilt, remembering, depression, loss of identity, stigma, sexual deprivation, loss of faith, loneliness, acceptance, and healing. When working with the bereaved, one should remember that not everybody will experience all of the above stages and patients can regress as well as make progress. Less-regimented philosophies of loss, grief, and bereavement, while still contemplating the experience within a period of social or emotional withdrawal, have been more concerned with conceptualizing the feelings. These have included feelings of fragility, which manifests daily as a more hesitant or measured pace, as the reality, impact, and implication of death of the loved one resonates into our daily living. Initial shock is followed by sadness, which in this context is termed loss, bereavement, or grief. Thoughts, life events and environmental cues that emphasize the seemingly ongoing loss dwell upon what might have been if the deceased person had lived. This often sustains feeling of sadness.

In an attempt to conceptualize the emotional experience of grief, Arieti and Bemporad (1978) referred to bereavement and grief as a form of

“unbearable sadness,” which manifests in response to the death of another person, which is often accompanied by difficulty adjusting to death. These authors viewed bereavement as a series of “sad reactions” that involved “searching” and “impressioning” of the person that had been lost. “Searching” can manifest as literally futile “searching” for the dead person’s face in a crowd, and fleeting impressions of people who resemble the dead person sustain the grief. This has been likened to an attempt to “recapture” the dead person and to keep him or her alive, utilizing dreams and fantasies. This phenomenon is thought to become less intense in an uncomplicated grief process as thoughts and “impressions” connected with the dead person are reconciled. The gradual realization of the futility of the search was equated with detachment from the dead person and the resolution of grief. This resolution manifests through a change in the thought process in a number of ways. For example, as other significant people in the bereaved person’s life take on skills and activities associated with the deceased, he or she becomes less dispensable. Alternatively, the dead person might come to be associated with positive memories and recollection of the deceased becomes a matter of pleasure. Belief in an afterlife, whereby the deceased lives on in another world, where he or she could be joined at a later date, also helps to lessen the finality of death.

Murray Parkes (1978) conducted an analytical study on the effects and manifestation of bereavement in sixty-six widows from the United Kingdom. In keeping with the work of Arieti and Bemporad (1978), Murray Parkes pointed to the tendency for widows to “search” and also to “call” out for the lost husband. However, this behavior was often denied during initial research interviews, a presentation, which was attributed by the researchers to insight into the reality of their husband’s death. Murray Parkes attributed frenetic “searching” and “calling” to the onset of motor hyperactivity. Restlessness, inability to sit still, and the need to be occupied characterize the surge of activity aimed at finding the deceased. However, ongoing weariness ensures that these activities are quite short-lived. Repeated unsuccessful “searching” and “calling” causes the intensity of these activities to eventually become greatly reduced and to cease or “habituate.” In short, the study considered the process of “calling” and “searching” for the deceased a process of “unlearning” his or her attachment to the lost person.

There is also the emotional distress at being left behind or at surviving the deceased, at not being able to prevent, or in having unwittingly caused, the death of the loved one. This has been referred to as “survivor guilt” by Freud (1917) in his work entitled “Mourning and Melancholia.”

According to Freud, such presentation can manifest both consciously and unconsciously; however, subsequent feelings of sadness are compensated by guilt. He also attributed the ongoing sadness to classifiable chronic depression following bereavement but did not consider that it explained the grieving process in its entirety.

Fundamental to the loss and bereavement process is the recognition of existential death anxiety among patients, or the acceptance of one's own death as inevitable. During therapy, existential death anxiety can be disruptive, as it triggers adaptive responses or resources, which serve to deny the inevitability of death and which have a largely negative effect upon patient's life. These usually take the form of responses that are "manifest" and "self evident" and others that are "disguised" and can be understood only through the analysis of unconscious narratives and themes that the patient brings to therapy. Unconscious defenses can vary in their manifestation of behavior, but they serve a common end in fending off the reality of eventual death.

Experience of chronic illness can serve to prematurely heighten a patient's own death anxiety, a situation which may be reinforced by the death of fellow patients. Often, patients who commit suicide are unable to tolerate their own existential death anxiety and therefore, seek to expedite the process on their own terms. Also, staff should be alert to patients whose existential death anxiety manifests in a more covert manner. Such patients might include those who seek to deny the severity, or very existence of their illness, consistently fail to attend treatment for life-threatening symptoms, or who take extreme risks (such as excess fluid consumption among dialysis patients). However, on a note of caution, defenses and denial also serve to protect from negative and potentially overpowering reality. Therefore, this feeling has to be acknowledged and brought into the open during counseling. We believe that intervention should not be attempted by the lay therapist and should only be addressed within a secure and ongoing psychotherapeutic or mental health framework.

## **LOSS, BEREAVEMENT, AND GRIEF AMONG PATIENTS WITH CHRONIC ILLNESS**

Loss, bereavement, and grief among patients suffering from chronic illnesses have mainly been considered in terms of a terminal prognosis and referred to colloquially as "palliative" care. Some facilities have given considerable attention to educating staff in the communication of "breaking bad news" and counseling skills, ensuring the quality of life

of the dying patient and supporting grieving families in anticipatory grief. Such approaches to palliative care ensure not only the well being of the patients and their families but protect and support the health professionals who care for them.

Among oncology patients much of the data pertaining to loss and grief has been concentrated upon the grief reactions of the family which have been considered in terms of predeath or anticipatory grief (Levy 1991) and grief following death (Benight et al. 2001, Eriksson et al. 2001). Observations of feelings of loss among relatives and friends of palliative-care cancer patients during illness and before death led to the reconceptualizing of this concept to anticipatory grief. However, there has been some concern that there may be a relationship between anticipatory grief, poor cognitive functioning and/or maladaptive bereavement (Levy 1991).

Studies of cancer patients have also incorporated a more traditional or postdeath bereavement course in an attempt to determine grief reactions (Benight et al. 2001) and adjustment (Eriksson et al. 2001) after the death of a relative. In an attempt to better understand different outcomes in conjugal grieving, Benight et al. (2001) analyzed the spiritual, psychological, and physical health outcomes utilizing social cognitive theory in 101 women whose husbands had died of cancer within the previous year. Their findings suggested that bereavement self-efficacy was a major predictor of emotional distress, psychological, and spiritual well-being and physical health perceptions at this time.

Adjustment to a new lifestyle without the deceased can also be greatly facilitated by timely and compassionate input from palliative health professionals (Eriksson et al. 2001). In a sample of 258 family members who were primarily composed of spouses of deceased patients, Eriksson et al. (2001) described how relatives adjusted to life after the death of their relative in relationship to input from staff both during and after the death. Findings suggested that communication to relatives on the part of staff that was honest and direct, coupled with active listening on the part of staff, was more viewed positively by relatives.

Despite the potential for feelings of loss, the need for adjustment, and subsequent loss of quality of life associated with diabetic retinopathy, much of the data in this field is contemplated in terms of cardiovascular disease as a cause of mortality and loss of quality of life (de Visser et al. 2002), or determining factor in the outcome of transplants (Nampoory et al. 2002). In the previous chapter, it became evident that there was a relationship between the onset of cardiovascular disease and decrease in quality of life among the general population. De Visser et al. (2002) set out to determine whether the loss of quality of life is greater among

diabetics than patients with a single diagnosis of cardiovascular disease. They conducted a prospective study involving the completion of a self-report questionnaire over a 3-year period of 161 type 2 diabetics. Their findings suggested that members of the diabetic group were more likely to experience greater reduction in quality of life particularly with regard to the loss of vitality, physical functioning and a decline in general health and well-being. Further, if even these patients maintain sufficient medical status required for transplant, graft survival at 1, 5, 10, and 14 years is thought to be significantly lower in pretransplant diabetics (84, 65, 58 and 58% respectively) than nondiabetics (97, 93, 86, and 82% respectively) (Nampoory et al. 2002).

Many studies on cardiac disease and transplant have not distinguished between diabetic and nondiabetic patients. Nevertheless, a number of authors who have studied both coronary artery bypass (Peterson et al. 2002) and heart transplant (Bohachick et al. 2002) have noticed postintervention depression. Among the heart-transplant patients, such symptoms were associated with loss of control and physical and psychosocial outcomes. Therefore, it is likely that intervention programs targeting issues surrounding loss of personal control such as relationships, social interaction and skills, social support, and dependency might impact upon postsurgical mood states.

Similarly among liver transplant patients, there have been observations of posttransplant depression, which might be further complicated by loss or potential for loss of sobriety. Lucey et al. (1997) in their 4-year follow-up of 50 alcoholism survivors after liver transplant suggested that up to 34% of patients were identified as having lapsed in consumption of some alcohol since their transplant. Loss of sobriety was associated with medical complications, graft loss, and death.

## **LOSS, BEREAVEMENT, AND GRIEF IN RECIPIENTS OF KIDNEY TRANSPLANTS**

Recipients of transplants grieve for the loss through death of the cadaver donor, their own survival, the fear of rejection of the newly acquired organ, and death of fellow patients. However, formal support in the form of support groups is a relatively new phenomenon (Coolican et al. 1997, Riley & Coolican 1999). Donor families, vital to the development and advancement of transplantation, are often referred to as the "invisible group" in the transplant process. Cadaver transplant, with its dependence on the death of a donor to ensure the survival of the recipient, presents the recipient with a "paradox" of hope and fear (Fromant

1992). Survivor guilt, both directly after a cadaver transplant, and with the death of a fellow patient, has long been associated with grief reactions among the chronically ill (Vamos 1997, Fulton 1987) and in recipients of graft survival (Craven et al. 1987).

Family support programs have gained momentum and have not only assisted families upon the death of their relatives (Kemph 1967, Alexander & Sehgal 1998) but also helped to relieve the burden of survivor guilt among recipients. In a unique program, nurses at Hope Hospital, Salford, U.K., organize a memorial service for relatives of patients who died within the past 12 months. This gives the relatives as well as the staff a chance to say goodbye to the deceased and bring closure to the grieving process. It also reinforces the concept that friends and staff care for patients (Ormandy 1998). There are many such ways in which patients and their families can come to terms with the past and contemplate an emotionally stable future.

Some researchers have described long-term dialysis patients who have received a kidney transplant after a long wait as "a return from the living dead" (Abram & Buchanan 1976). Similar statements, such as being given a "second chance" and adoption of the date of transplant as a "second birthday," have been considered in relationship to themes of rebirth (Hackett 1972). However, our observations have suggested that such analysis is not particularly helpful and indeed can have a depersonalizing affect or cause a splitting of the self, which is not conducive to a good quality of life after transplantation. We have discussed this issue in depth in chapter six.

Feelings of helplessness and hopelessness traditionally associated with depression during dialysis often continue after transplantation despite advances in medications, postoperative care and greatly improved graft and patient survival. In a longitudinal study of eleven kidney transplant patients, Eisendrath (1969) found that pretransplant feelings of abandonment by family and friends and fear of the outcome of transplant or the potential for death were linked to posttransplant death in fellow patients. Extreme cases of posttransplant psychological disturbance, such as suicide, have been reported in patients who experience severe sexual dysfunction and distorted body image (Dubovsky & Penn 1980). Engel & Schmale (1967) pointed to a form of premature grief among patients on dialysis, which they termed the "*giving up—given up.*" This phenomenon was associated with the onset of chronic illness and a form of grief that became an obstacle to transplantation. These investigators suggested that pretransplant psychotherapy could instill hope and enthusiasm to-



ward transplantation and eventually lead to a good quality of life for the patient and their families.

Early studies on loss and grief among donors of living kidneys as the date for surgery approached were largely negative. Kempf (1967) reported "emotional withdrawal" and feelings of "harassment," while altruism and the will to help decreased as donors realized that they would lose their kidney and contemplated the potential of death during surgery. These feelings were more common immediately before and after transplantation and were considered to be responsive to psychotherapeutic input. Despite significant surgical and pharmacological advances, recent studies concerned with live kidney donation have also not been very encouraging (Weizer et al. 1989). Suicide of live kidney donors following graft rejection and the death of recipients have been reported, although they are not common. The authors suggested that psychiatric screening before live organ donation should include assessment of donor's coping mechanisms in the event of graft failure and rejection. Less extreme but nevertheless significant emotional ramifications, such as disappointment have been reported in both the donor and recipient when posttransplant quality of life falls short of expectations. Other studies on live donation have been more encouraging (Plant et al. 1999, Johnson et al. 1999). However, they continue to place emphasis upon the donor's willingness to donate as opposed to the recipient's willingness to receive a kidney from a specific donor. Our own research has suggested that recipients are highly likely to have doubts about live transplant and need to be given an opportunity to explore such feelings. The issue of live donation is described in greater detail in chapter eleven—"Live organ donation and the psychotherapist." However, if momentum were to grow for live unrelated nondirected kidney donation (individuals who donate to unspecified recipients), guilt, loss, and bereavement that has been associated with both live related and cadaver donation might be greatly diminished. Attention has also been drawn to less tangible concepts of loss among patients who are second in line for an organ, and who subsequently don't receive the organ, as the recipient first in line was a suitable match (Sloan & Gittings 1999).

Posttransplant, the potential for loss of the kidney, is often referred to as fear of rejection. Streltzer et al. (1983) studied twenty-five patients who had returned to dialysis, following the loss of a kidney transplant, over a ten-year period. Twenty-four of these patients were deemed to have had a good psychological adjustment to dialysis, and fourteen admitted to having undergone a grieving process for the loss of their kid-



ney. Ten were reported not to have undergone any grieving process, a presentation that the authors attributed to denial. In conclusion, they suggested that denial should be recognized, as an effective coping mechanism, for which patients should not be penalized; however, all patients should be offered supportive intervention.

The sense of loss upon rejection of the organ is experienced on a much more personal and internalized level than the loss of another, separate person, however close or positive the relationship. In such circumstances, the emphasis is upon loss, separate and apart from bereavement and grief in the traditional sense. In keeping with most of the colloquialisms that have emerged as a means to encapsulate psychosocial presentations, the clinical presentation is more multifaceted and less tangible than the context in which it is often discussed and should be differentiated from the experience of loss, bereavement, and grief through death. Therefore the understanding and intervention will differ, as presented in the case illustration below.

Notably in the data on both chronic illness and transplant, authors have apparently opted for a systematic descriptive approach to loss, grief, and bereavement in an attempt to portray their findings. There appears to have been a move away from the wholehearted embrace of the “phases” and “stages” of grief described by social scientists and referred to in the beginning of the chapter. As to the chapter moves to contemplate loss, grief, and bereavement among transplant patients, the existence of a cadaveric or live donor for that matter (see chapter eleven, on the live donation and the role of the psychotherapist) introduces another loss (whether it be of life or an organ) to the equation. However, common to all of the above in the definition of the loss, grief, and bereavement is the need to differentiate the onset of chronic depression and the need to determine the factors that contribute to a complicated bereavement and the development of effective intervention.

## **BEREAVEMENT THEORY**

The social constructionist branch of psychotherapy has differentiated between grief, loss, and bereavement (Averill 1979, Averill & Nunley 1992). Grief refers to the manner in which individuals perceive the emotional and social component of such experiences and the cultural context in which they occur. Grief is defined in terms of a series of emotional reactions: shock (feelings of unreality), protest (attempts to stay in contact with the deceased), despair (erratic and uncoordinated behavior), and reorganization (emergence of new relationships). These reactions should

not be considered as progressive stages, but as reactive manifestations that might occur in any number of sequences. However, it has also been suggested that the manifestations that occupy grief are not necessarily limited to emotions and there have thus been some attempts to pathologize grief and consider it in terms of a classifiable disease (Levy 1984). This move may well reflect the increasing involvement of health care professionals in treating bereaved patients.

Loss has been referred to within a social context or more specifically as an indirect component of grief and considered in terms of the loss of a particular reality of daily living and relational interactions (Berger & Kellner 1964, Swann 1987). It has been suggested that the loss of one particular lifestyle or relationship will prompt an individual to seek out replacements or at least adopt a different lifestyle as a means to define meaning and experiences in their lives. This process of adaptation and acquisition has been referred to as a "constructionist" (Berger & Kellner 1964) or "negotiatlional" (Swann 1987) approach. Such approaches place considerable emphasis upon patients finding new meaning and hope in a different set of relational and social experiences. Sewell (1997) developed this concept further as a time-sensitive metaconstructive process. In other words, for patients to adopt new meaning and hope they will need to have some perception of themselves in past, present, and future time. In turn, past and future self-perceptions are thought to formulate the current perception of self.

Bereavement has been viewed less specifically and more as an overall process and manifestation of the physiological manifestations of grief and loss. Despite concerted efforts to differentiate normal grief and bereavement from pathological grief, there are no firm definitions as to how the clinician might determine where normal grief ends and the pathological process starts. Therefore, definitions tend to be defined in terms of individual perception and tolerance for events, which may not only vary from one patient to the next, but also from culture to culture, whereby varying emphasis may be placed upon loss, grief, and death.

## **THE FEAR OF REJECTION OR LOSS OF A TRANSPLANTED KIDNEY**

The use of such trite colloquialisms by transplant professionals to describe patient's ongoing "fear of rejection" of a transplanted kidney tends to have the effect of depreciating or obscuring the complex and often highly diffused clinical manifestation of the phenomena. Rather, the fear of rejection of a transplanted kidney might also be considered in terms

of patients' ongoing anticipated loss of an organ and their inability to tolerate states of uncertainty. Therefore, during therapy any direct or indirect reference to such a dilemma is often differentiated from loss, grief, or bereavement through death. Rather, it is considered in terms of the loss of an object, namely the organ transplant and in terms of the implications of that loss on the patient's life. We should also aim to build up their ability to tolerate uncertainty, by the incorporation of this concept into their thought processes and by the creation of a more certain social living environment. In our experience, failure to actively address such problems in transplant patients can lead to the virtual paralyses of personal development. It is also largely responsible for the feeling of listlessness and having been unable to implement even the most basic life changes, or actualize relational, or vocational aspirations even many years after a successful transplant. This leaves patients wondering whether the transplant had really been worthwhile or had significantly improved their quality of life.

While most transplant patients admit to some fear of losing their transplanted organ, the uncertainty is usually more pronounced in patients who have experienced rejection episodes in the past, or who have a premorbid history of loss and uncertainty in their lives. This might have occurred in the form of the premature loss of a parent through death or divorce, or inconsistent or emotionally unavailable parenting. During treatment sessions, the therapist attempts to generalize out the feelings of uncertainty and fear of loss that patients feel toward their kidney into other areas of their life. It usually becomes apparent that these patients have a history of relational instability and uncertainty, termed an "environmental failure" (Winnicott 1965). As a child, they missed the essential experience of security that will need to be re-created, relived and renegotiated during the sessions. In other words, the patient's heightened awareness of the potential for loss of an organ and the difficulty in tolerating uncertainty needs to be understood in terms of his or her own life experiences.

Patients who have difficulty coming to terms with the uncertainty of their transplanted kidney often spend much of their time "searching" for certainty in every aspect of their lives, not just their transplant. The behavior of "searching" is not dissimilar to the "searching" of the bereaved patients described above by Murray Parkes (1972). These patients describe feelings of hyperactivity, or of a "mind that is racing" (commonly seen in newly transplanted patients). However, among transplant patients, such behavior needs to be differentiated, or placed in the context of life, or specifically their life, as opposed to death. During initial ses-

sions, the therapist needs to intervene swiftly to create some level of certainty in the patient's life. First, they need to acknowledge a certain level of uncertainty always associated with organ transplantation and reassure patients that such feelings are common—thus seeking to align him or her with the majority (certainty in numbers), as opposed to some sort of minority, different and apart not only from the rest of society, but also from other transplant patients. Second, they should reaffirm the role of the therapist as certain to remain with the patient with the aim of creating a more reassuring lifestyle. This is most effectively achieved by offering a set number of sessions within a secure psychotherapeutic framework. Once these two interventions have been established, the patient will be able to indulge in meaningful self-exploration and the therapist better able to intervene from a secure base.

Subsequent therapy sessions will be determined in part by the ongoing medical status of the patient. Therefore, the work of both the therapist and the patient is that much easier if medical test results are consistently good. However, even in patients whose results are suboptimal, or who eventually lose their kidney, some life and personal perspective changes are possible. Whatever the medical position, patients need to be able to come to terms with the past lost to chronic illness and reassess their life in the present. Patients very rarely come to therapy after transplant with predetermined goals. Not only does the experience of chronic illness change an individual's perspective on life, however, the future is also uncertain. We have to say that we have never worked with a posttransplant patient who did not know what he or she wanted in the future.

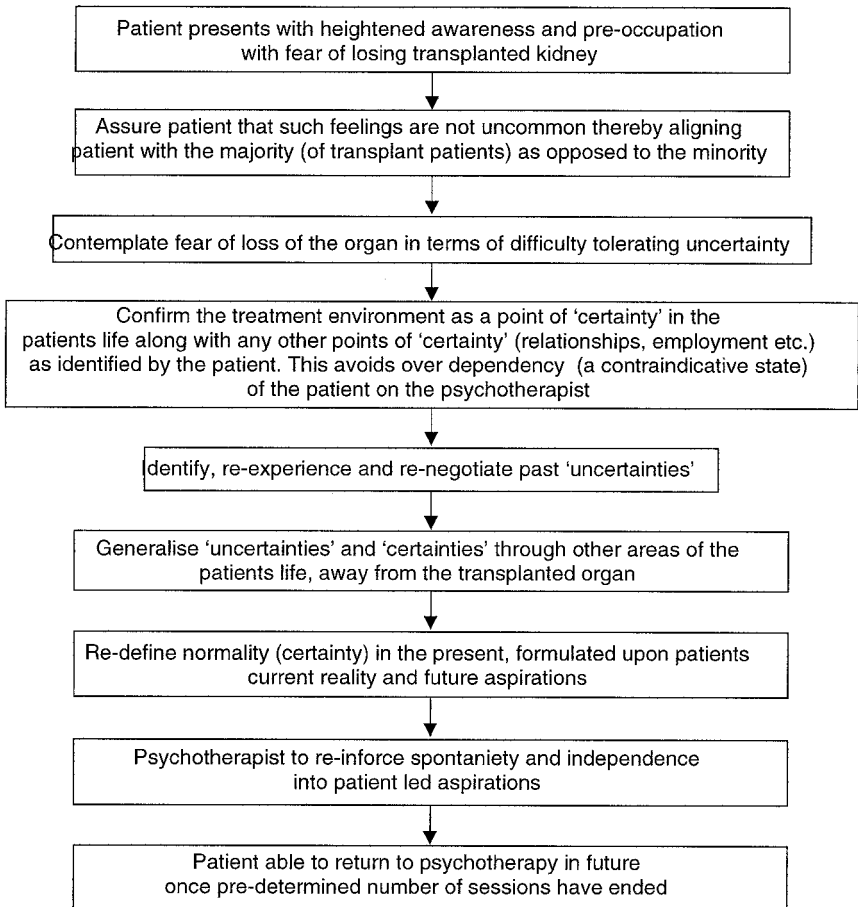
However, the great challenge for both patient and therapist is to find the courage to articulate their thoughts, fears, and aspirations aloud. To vocalize their thoughts is synonymous with daring to hope for more than just to live another day, but to live days, weeks, months, and years and perhaps to realize their aspirations. Much of this work is patient-lead and some patients may need to return to therapy many times in the first year after transplantation for "emergency," unscheduled, or short-notice sessions. It is important that patients be accommodated as much as possible in such situations as a means to reaffirm the certainty that they claim to represent. Some patients will come into therapy quite soon after transplantation with the knowledge that their kidney is not functioning well and that the prognosis is not good. However, it is often possible to use whatever time they have free of dialysis creatively, by encouraging them to actualize some of their aspirations, which are different in every patient. Some patients opt to create a period of calm, gardening, or staying at home, while giving some time to the replenishment of relationships;

others want to travel or study. The key to such work is the need for patients to be able to redefine normality in the present, whereby they achieve their maximum potential with regards to spontaneity and independence. Such patients are liable to define normality in terms of the past—*well my last kidney never really worked properly, so I don't suppose that this one will either*. We encourage these patients into the present, defined in terms of their current medical status and their potential and opportunity available to them even if it is limited in time.

Irrespective of individual patient aspirations, the psychotherapist's role during such session is almost akin to that of a "*good-enough parent*," while the patient assumes the position of the child in a manner that is not dissimilar to psychological theories of human development. Winnicott (1958) spoke of inadequate parenting in terms of an "environmental failure." In other words, failure of parents to provide a stable and responsive environment working toward the child's spontaneity and independence. However, we believe that a further "environmental failure" can also occur at other stages of life in the form of the onset of chronic illness. As with the babies described by Winnicott (1965), patients with chronic illness experience life as having no secure or certain foundation. They will come to rely for a period of time on the therapist to act as a substitute "good enough" parent who will help them move toward a position of independence and spontaneity. Also, on the subject of being "good enough," patients who become emotionally paralyzed by the uncertainty posed by their organ transplant are unlikely to achieve a good quality of life. Some patients who fail to achieve vocational, social, and relational satisfaction may even consider themselves unworthy of the transplant in the first place. Figure 3.1 is a guideline for the clinician to intervene in such cases.

## CASE STUDY ONE

Susan is a 38-year-old single woman who worked as an assistant social worker. She had developed renal failure at the age of eighteen and underwent her first kidney transplant 2 years later, but it never actually worked. After an 8-year wait, she underwent a second kidney transplant, this one successful, and she was off dialysis for 5 years. It was after her third transplant, three years later that she had entered therapy with feelings of restlessness, a mind that was *racing* and fear and anxiety about her kidney despite stable renal function. The transcript below is taken from our first session.

**Figure 3.1****Guidelines to Psychotherapeutic Intervention after Transplant among Patients Presenting with Heightened Sense of Fear of Rejection**

**Susan:** *Ever since the transplant my mind has been racing. I can't settle to anything, I am dreading returning to work.*

**Psychotherapist:** *When you say that your mind has been "racing" can you tell me a little more about what exactly is going through your mind.*

**Susan:** *Everything. That's it, you see it does not stop long enough for me to make any sense of anything.*

**Psychotherapist:** *OK. So let us go with the dominant feeling that this "everything" creates in your mind, as it is "racing" around.*

**Susan:** *Dread.*

**Psychotherapist:** *Dread of?*

**Susan:** Patient became very tearful. *Dialysis, I can't go back to dialysis again. I feel so stupid and childish, like I'm making a fuss for no reason. There are people worse off than I am. I know that my test results are good, but it doesn't matter how many times I hear that my results are good, I just don't seem to be able to get going again. I don't really know if I have got a clear run this time or not.*

**Psychotherapist:** Gently. *These feelings that you describe are quite common after a transplant, but no less real* (indirectly reassuring patient that she is not “stupid and childish,” while aligning her with other patients who have felt the same).

**Susan:** Dabbing her tears away and looking up at me. *Is it?* (Looking for reassurance and certainty from me).

**Psychotherapist's thoughts:** I am not going to answer this question directly, as I do not want to encourage dependence upon me to generate certainty, it is the psychotherapeutic frame that is certain. Instead, I will view it more as a rhetorical question, as we will be aiming at the patient being able to generate her own certainty. *It sounds as though you are in limbo at the moment, unable to go forwards or backwards in your life, in the face of the uncertainty of your transplanted kidney.*

**Susan:** Yes, it is “uncertain” all right. You said that it is quite “common” for transplant patients to feel this way (looks directly at me), so how do you usually treat them, you know help them get over it?

**Psychotherapist:** Well, we create certainty where we can. In therapy, we have a secure, confidential environment where we can explore your feelings and uncertainties (affirming therapy sessions as one certainty in the patient's life, while we look for, or create some others).

**Susan:** Well, I have got plenty of those, “feelings” and “uncertainties,” I mean.

**Psychotherapist:** Well, we have an hour a week for twelve weeks in which to explore them further. We may find some other certainties or we might work at creating some more.

During the next few sessions, we identified a number of premorbid uncertainties in Susan's life. Her mother had been killed in car crash when she was only four years old. This was her first experience that life was by no means certain, and that life could change virtually instantaneously. Initially, she spoke of how she had felt angry and deserted by her mother, although as she grew older she came to realize that the anger was really at her father's somewhat hasty remarriage and resentment that her step-mother was not her real mother. Although Susan appeared to have come to terms with her mother's death, she had become increasingly concerned recently that she had been unable to recall her face. Try as she might, she felt that the *picture* that she had in her mind was fading along with (as the patient perceived it) attachment to her mother. Therefore, in the absence of any photographs, this seemed to be unnerving her

as she felt that she was *loosing* her mother. My enquiry as to whether she had any other sensory images of her mother led to the patient recalling the particular way in which her mother would touch her on the arm. Prompted by me, she closed her eyes and concentrated hard and reported that she could almost recall (feel) the touch. The patient returned to the next session having looked up an old aunt who had told the patient that she had her mother's eyes. Therefore, quite quickly we had reestablished a connection with her mother and along with it the certainty that she would always be her mother's daughter and that her mother could be recalled to her mind.

Further exploration revealed another certainty, that of a good neighbor who had subsequently become a friend. Susan related how they went on trips together, to the cinema and local cafes, all the time concocting stories to placate the friend's overbearing and obstreperous husband on the odd occasion when he returned from the drinking circuit with his friends. One day she suddenly stopped short, as she realized that they had been friends for twenty years and probably would be friends for the rest of their lives. As the patient began to come to terms with the fact that the longevity of her transplant could never be sure, I encouraged her to draw upon the above-mentioned certainties. This gave her the courage to articulate a long-held aspiration to train as a social worker as follows:

**Susan:** *I have to go back to work soon.*

**Psychotherapist:** *Mmmh.*

**Psychotherapist's thoughts:** This is an area that we have not touched upon yet, despite return to work being seen as problematic in the first session.

**Susan:** *At the moment I am an assistant social worker, I always wanted to be a fully qualified social worker, proper, you know, but I couldn't cope with all the extra study, so I settled for being an assistant.*

**Psychotherapist:** *You are not the first patient I have heard talk of having "settled" for less than they wanted in the face of chronic illness. It is one of the great unfairness of disease that is often not represented in psychotherapy or medical literature, primarily because it is not quantifiable.*

**Susan:** *We were talking the other week about creating security and certainties, so I was thinking of asking my boss if they would sponsor my advanced training. They are looking for people to sponsor and now that I am off dialysis, I am pretty sure that they would. Registered social workers get twice as much money and better benefits, so I would be protecting myself for the future if ever have to return to dialysis again.*

**Psychotherapist:** Sat very still.



**Psychotherapist's thoughts:** I am too scared to move in case I break the spell, or the social web that the patient is weaving for herself, literally before our very eyes as she takes her first tentative steps toward a more secure and certain future. It is times like these when patients make such great strides that you just want to leap up and dance with joy for them. So many times when they struggle or don't make it, you feel like crying with them.

**Psychotherapist:** Much restrained, but allowing myself a small smile. *It sounds like you have given this matter a lot of thought and it is very important to you.*

**Susan:** Almost as if she was rising to the occasion, she gave me a big, beaming smile.

The identification of uncertainties in the patient's life was primarily focused around the mother and her distress at the feelings that she might *lose* her mother (as well as her kidney) as she faded *out of my reach*. The reinstatement of her mother in her life through tactile imagery seemed to lead to the realization and recognition of her neighbor as a good friend. Given that exploration of the past and present had yielded and redefined relative certainty in her life and established a baseline for normality in the present (as opposed to the previous rejection episodes), she had been able to contemplate the future, in a spontaneous and independent fashion. She was prepared to cope with any future rejection episodes in the transplanted kidney. Indeed, we had come full circle; the fear of rejection or loss of the newly transplanted kidney and the inability to tolerate any further dialysis had been the starting point.

Susan returned to extended therapy once after her original twelve sessions had ended. Her kidney continues to function well; she is a year into her social work training and continues to take trips out with her neighbor, and to avoid her husband and his friends. She also tells me that she has entered into a series of secret assignments with an eligible bachelor, an attachment which is becoming quite *serious*, but *very definitely not that serious*. Upon reflection, I suppose that would be one certainty too far at this point in time. Sometimes a girl can have too many certainties in her life, or not, as the case may be.

## LOSS OF THE IMAGINED PAST: AN OBSTACLE TO RECOVERY AFTER TRANSPLANT

The manifestation of loss, bereavement, and grief through death or in the form of an object (organ) represents loss in a context, which will appear definite to the reader. However, after a successful transplant, patients often present with feelings of loss which cannot be understood in terms of death, either their own, a fellow patient or the donor. These

patients may be socially paralyzed by anticipated fear of loss of an organ (real or imagined). They also describe feelings that are diffuse and worry about aspirations, experiences, sensations, and achievements that they imagine that they might have had, but are lost due to chronic illness. Therefore, in contrast to the traditional understanding of loss that is based upon the loss of a person or object, loss in this context is less tangible, it is paradoxical, imagined and based upon fantastical experiences in the past that the patient never actually had. We have come to refer to this concept as the *imagined past*.

Our observations are that such clinical presentation may be best explored and resolved within a time-sensitive framework, such as the model of Systemic Integrative Psychotherapy (Clarkson & Lapworth 1992) described in chapter one. Our various research projects among posttransplant patients have suggested that it is virtually impossible to study the emotional impact of transplantation without taking into consideration patient's experience of their immediate past (dialysis) and their long-term past (childhood experiences) (Baines & Jindal 2000 and 2001). During therapy, patients on dialysis often perceive life as being medically, socially (relationships with family and friends), and economically (curtailed employment and subsequent debt) unpredictable, unstable, and centered upon survival and preservation of their family and self. Given these circumstances, patients may develop psychopathology such as depression, stress, and anxiety. While preexisting family relationships may be of help to patients in resolving their difficulties, prolonged dialysis can put relationships under enormous strain and affect their ability to provide ongoing support for the duration of dialysis. The tradition of psychotherapy provides a significant, supportive, unconditional attachment figure, within a responsive and secure environment. Within this relationship, posttransplant patients can explore and recover from emotional problems. As mentioned above, dialysis patients demonstrate an acute sensitivity to time. That is, time lost to dialysis and time that comprises their future.

As mentioned previously, Systemic Integrative Psychotherapy is based upon the therapist's need to identify patient's experiences over a past, present, and future time span. Our findings suggest that segmentation of time during therapy is helpful to understand their feelings of *paradoxical loss* after kidney transplantation. Further, such philosophy lends itself well to the reconciliation of disappointments and fantasies that comprise the *imagined past*, sustenance of patients in the *present*, and provides a baseline for future development. Loss of the imagined past refers to a past (compiled of experiences, sensations, and achievements) that patients consider that they might have had, if they had not developed renal

failure. Loss in this context (posttransplant) is generated as individuals contemplate fantasies, aspirations, and ambitions that were never realized. Clinically, this is expressed during therapy as feelings of low self-esteem, indifference to peers, a life without purpose, and hesitancy regarding the future. Unlike feelings of bereavement and grief, loss is not systematically resolved within a time frame and does not necessarily result in social withdrawal. However, in common with bereavement and grief, feelings of loss among posttransplant patients are in keeping with a change in identity and social status. A change serves to generate expectation of an improved quality of life among patients and their families. In turn, the pressure of expectation can generate stress and anxiety, particularly when a kidney transplant was viewed by the family as a panacea for any negative emotional states evoked during dialysis.

Our observations among recipients of kidney transplants suggest that while grief and bereavement may be recalled among all three of the above-mentioned time spans, it is most prominent in the patient's (fantasy) *imagined past*. Therefore, patients become hesitant and pessimistic about the future and they consider that any future that they might have, will be conducted within an arena in which they are materialistically, socially, and economically disadvantaged, despite their kidney transplant. In summary, the *imagined past* is an entity that was never actualized; the *present* struggles to be meaningful and needs to be redefined; and the future can only be actualized in the face of seemingly insurmountable odds. This scenario manifests in the daily lives of patients as social disintegration, isolation and subsequent feelings of grief and bereavement.

## TESTING THE HYPOTHESIS

As the concept of loss has rarely been considered as an independent entity, we examined this issue without the supporting logic of a scientific measure of change. However, Systemic Integrative Psychotherapy consists of a series of interactions over time, which form the basis of psychotherapeutic change in patients from one mood state to another. Therefore, we have confined ourselves to looking at patterns of change (sequences of interaction and behavior over time), while psychotherapy is viewed as the vehicle of change. To understand the concept of loss, the case study will be presented from three points of time as follows: patient's problems will be defined in the present before psychotherapeutic input; in the past through focused insight into the process of therapy; and finally the future outcome is contemplated.

## CASE STUDY TWO

John is a 42-year-old married man with 3 teenage children. He suffered renal failure 8 years ago and had undergone hemodialysis since then. During dialysis, he felt continually nauseous, suffered skin irritations and had insomnia. However, he had been able to attend work regularly and continue with his love of football, albeit only as a spectator, not as a lead player in his local team. He recalled how during dialysis both he and his wife had assumed that his low mood and irritability would be resolved once he received a kidney transplant. Consequently, immediately after his transplant, the couple started planning holidays and “getting back to normal.”

### Problems before Psychotherapy

John was referred to therapy three months after his second transplant as a result of his noncompliance with antirejection medications. Further, he had been diagnosed with depression. John recalled how the family was having difficulty coming to terms with his emotional state, despite having received a long-awaited kidney transplant. More specifically, during therapy he described panic attacks and an overpowering rage that seemed to engulf him for no apparent reason after which he felt remorseful. It was agreed that John would attend therapy for one session per week, an arrangement that would be reviewed after three months.

### Process of Psychotherapy

John arrived for his second session very distraught and convinced that his marriage would not survive much longer. He had become very aggressive and had an angry outburst directed at his wife the previous evening. The patient's inclination in the first instance was to generalize the incident, merge it with other outbursts, and focus primarily on the present interactional and relational consequences. However, I spent much of the session encouraging John to generalize the incident in keeping with past behavior, on the basis that such a scenario would be part of a recurring pattern of interactions and mood states. After much deliberation, he described how his angry outbursts often occurred when he and his wife were watching television. This was a time when his wife worked on her tapestry. She had quite contentedly set about her embroidery when John had found that he was becoming increasingly irritated. I took the tapestry to be the trigger that preempted the agitated mood state and encouraged him to explore his perception of tapestry. It soon became

apparent that tapestry to John was an activity for middle-aged ladies (which incidentally was an accurate description of his wife). Middle age was not a place where he wanted to be, as psychologically and emotionally as he perceived himself to be eight years younger. However, his wife served to reinforce his advancing years and loss of what he viewed as his more formative years, defined in terms of his football career. This mood state was soon observed in interactions with his children; he behaved as if they were significantly younger than they actually were. He was clearly unsure at how to pitch his interaction with them in the present. John came to see that his relationship with his children had stagnated in time before the onset of renal failure. A further point of social comparison was that his peers had advanced materialistically and emotionally while John appeared to have once again remained stagnated in time.

### Outcome

As with many other posttransplant patients, John's emotional stability was threatened by unreconciled fantasies of an "imagined past." He had defined a return to normal in the present (after transplant) in terms of his past lifestyle, based upon his assumptions as to his future. In his "imagined past," his football career was never plagued by injury, he never tired of attending football matches. Normality was defined in the past as opposed to the present. Our work with John was to help him to accept the past and redefine some form of "normality" in both the present and future, that might be different from, but not necessarily any less significant or less meaningful than, his "imagined past."

The key to psychotherapeutic change in this case was John's ability to deviate from his previously held fundamental assumptions about how his life might have been. John decided to join a health club where he could swim, and work out under the supervision of personal trainer. As a result, he began to interact with other people who accepted him as "normal" and who were not aware of medical traumas that had characterized a significant part of his adult life. There was a shift in both psychotherapeutic perspective and compliance behavior at this point as he used his sessions to contemplate the characteristics of various people that he met during his daily life. More importantly, his new interactions served to indicate his social reintegration into a different, but nevertheless purposeful lifestyle.

### CONCLUSION

If the loss in the context of uncertainty and *imagined past* remains unrecognized and unresolved, the patient's mood state was likely to de-

teriorate leading to medical noncompliance and social isolation. This condition must be differentiated from grief and bereavement that the patient may feel for the donor and donor family. In addition, this condition should not be confused with the ongoing fear of graft rejection, graft loss, fear of death, and side effects of drugs. In working with transplant patients we need to identify the meaning and experience of loss of an *imagined past* for individual patients before it can be resolved. While most chronic illnesses appear to have their own variables and complexities that affect the course of loss, presentation of loss after successful transplant is more complex than loss in the context of more conventional bereavement and might not necessarily correspond to existing models of manifestation or psychotherapeutic intervention associated with bereavement.

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## **Chapter 4**

# **ANXIETY IN PATIENTS WITH RENAL DISEASE AND TRANSPLANTS**

### **INTRODUCTION**

DSM-IV-R groups anxiety disorders into a number of different categories. These include generalized anxiety, phobia, post-traumatic stress disorder, obsessive-compulsive disorder, and phobias (agoraphobia, social phobia and claustrophobia). The phobia with which most of the general population is likely to present for treatment is that of agoraphobia, a fear of open spaces. In addition, many of these individuals will also describe fear of small places and heights. Among the general population, agoraphobia is thought to be more prevalent among women. While it is thought that most members of the general population may find themselves exposed to situations conducive to the development of a phobia, this is very much “a one off” experience and does not cause them to be labeled as clinically phobic.

The essential elements that determine why some people develop phobias and others do not has traditionally been thought to due to individual genetic and behavioral differences. The genetic approach is based upon the suggestion that individual genetic difference makes some people more liable to phobias than others (Eysenck 1994). In contrast, the behavioral approach places emphasis upon environmental as opposed to characteristic variables (Harris et al. 1983). The development and onset of, as well as the experience of living with, an ongoing chronic illness could be considered from either a genetic or behavioral perspective.

Many patients who suffer from agoraphobia also tend to experience panic disorder, or frightening panic attacks, characterized by extreme fear, feelings of loss of control, and physical symptoms (chest pain, shortness of breath, and dizziness). DSM-IV-R stipulates that an individual must experience 4 such attacks within the period of 1 month in order to be classified as suffering from panic disorder. Typically each attack lasts for a few minutes, but in contrast to agoraphobia there is often no obvious stimulus. Genetic factors are thought to play a part in the onset of panic disorder; however, the evidence is more suggestive of environmental variables as the major causative factor. Particularly as a number of studies have suggested that most patients have usually suffered more stressful life events than usual in 3 months preceding the onset of panic disorder (Davison & Neale 1990).

There has also been considerable attention to cognitive theories of malfunctioning and panic disorder (Hibbert 1984, Beck & Emery 1985). Particularly poignant to patients with chronic renal disease or on dialysis is the suggestion that panic attacks are often accompanied by prevailing thoughts of death or chronic illness (Hibbert 1984). However, according to Beck & Emery (1985), patients with panic disorder suffer attacks because they “misinterpret” the symptoms of anxiety (e.g. chest pain) as warning signs of an impending chronic illness (e.g., cardiac disease).

We have seen in previous chapters how anxiety tends to be explored as secondary to depression and not as an independent issue. The anxiety associated with screening, initial diagnosis, treatment, and impending death has been well documented. However, despite the lack of independent consideration in the literature, anxiety can—and often does—present as isolated episodes at different times over the course of chronic illness. Ongoing anxiety over a period of time is often the primary reason for staff making a psychotherapy referral; if left untreated, anxiety can affect the psychosocial and medical course of the illness and is often associated with noncompliance. Therefore, the issue of anxiety despite underrepresentation in the literature is very much alive and well among this patient group and is thus a key concern of health professionals. In this chapter, we present an overview of the traditional presentation and intervention associated with anxiety with which readers will have varying degrees of knowledge.

## **TRADITIONAL FORMS OF INTERVENTION FOR ANXIETY AND PHOBIC DISORDERS IN THE GENERAL POPULATION**

Traditionally, drug therapy alone is not considered an effective intervention and therefore is generally accompanied by any number of ther-

apeutic interventions including cognitive, insight-orientated, aversion, and behavioral therapy. In our experience, the most commonly used is behavioral therapy, a treatment based on the assumption that symptoms develop as a result of maladaptive learning and need to be replaced during treatment intervention with the education or adoption of new skills. Behavioral therapists use classical and operant conditioning to change the unwanted to the more desirable behavior. The most famous example of classical conditioning is that presented by Pavlov (1938) and his dogs. Pavlov's theory was based upon the unconditioned reflex that advocates that there is a relationship between the unconditioned stimulus (the food being placed in the mouth) and the unconditioned response (salivation). Pavlov's work focused on teaching a dog to salivate to a neutral stimulus, such as an audible sound (training stimulus), which served to indicate the imminent arrival of food. Furthermore, when stimulus was presented without food, the dog still salivated—a conditioned reflex. However, Pavlov also found that if food did not follow the sound training stimulus after a few successive initiations, the conditioned response or salivation began to disappear, a scenario he termed "experimental extinction." Behavioral therapists believe that classical conditioning is a major causative factor in patients who develop phobias, or seemingly irrational fears. Marks (1969) described a patient who injured himself badly after he fell down a flight of stairs, and developed a generalized conditioned response not only to stairs, but also to all situations involving heights.

The technique utilized to bring about a reduction in anxiety is generally that of flooding and systematic desensitization. The intervention technique of flooding aims to sever the relationship between the conditioned stimulus and subsequent fear by the utilization of experimental extinction. Flooding aims to position patients in an extreme fear-provoking situation whereby they are literally flooded by fear and anxiety. One such example would be to place a person with a fear of snakes into a situation in which they are surrounded by snakes. If the patient can be coaxed into remaining in this situation for a significant amount of time, the fear should subside. Flooding is aimed at convincing patients that there is no objective basis to their fears and therefore should no longer avoid the object of their fear. This method needs to be implemented only in a controlled environment as the exposure to such intense fear and anxiety can cause the patient to become very disturbed and may well be counterproductive by reinforcing the very fear that they were trying to eliminate.

Systematic desensitization was proposed by Wolpe (1958) as an "alternative" approach to the treatment of anxiety and phobias. Systematic

desensitization is based upon counterconditioning and attempts to substitute the fear response to phobic stimuli with a response that bears no relationship to the fear. Before implementing such treatment, patients are usually coached in deep relaxation skills so that they can place themselves in a relatively relaxed state. Patient and the therapist rate in a hierarchical manner (anxiety hierarchy) objects or situations in terms of fear and anxiety that they produce. For example, for a patient with a fear of heights, one step up on a ladder might be the least anxiety provoking, while standing ten steps up at the top of the ladder is the most anxiety provoking. In contrast to flooding, the patient is not only exposed to the situation in a graded and arguably more manageable way, but to do so in a relaxed state. In the example of the ladder, once in a relaxed state, the patient would be asked to imagine standing on the bottom rung of the ladder until it was no longer anxiety provoking. The treatment would be repeated at each rung of the ladder until the fear response is no longer produced. The major downfall of systematic desensitization therapy is whether the reduction of fear achieved in a treatment situation carries over into situations that patients find themselves in their daily lives.

## **ANXIETY AND PHOBIC STATES: A PSYCHOTHERAPEUTIC PERSPECTIVE**

The concept of anxiety has been of considerable interest to therapists, especially existential psychotherapists, who have viewed anxiety as an essential part of living (Heidegger 1927, Satre 1958, May 1950). Psychotherapists tend to differentiate fear from anxiety, in so much as fear is experienced in keeping with a specific object, while anxiety is less specific and more transient. In this context, anxiety has been described quite aptly in our opinion as the "giddiness of freedom" (Kierkegaard 1846). Normal anxiety has also been distinguished from neurotic and existential anxiety. Normal anxiety is considered to be a proportionate response to the object and can be eliminated by the removal of the threat. However, neurotic anxiety is the opposite, a response that is disproportionate to the object and cannot be relieved by the removal of the object (May 1977). In these contexts, anxiety manifests physically in terms of numbness, trembling and constriction of the throat muscles.

Existential anxiety is a deeply embedded universal response to the uncertainty of life and the temporary nature of our existence. However, death has not necessarily been viewed as having a negative effect on life, but facilitates the living of life in an "authentic fashion" (Yalom 1980). Anxiety manifests in keeping with uneasiness or malaise that is

synonymous with physical and mind-body awareness. We believe that mind and physical body boundaries between themselves and the outside world are especially well defined for this patient group by the virtue of their difference, or their different reality to patients who do not suffer from renal disease. Coupled with the aforementioned tendency of these patients toward relational insularity, it is hardly surprising that renal patients often refer to feelings of *difference* and *isolation* from others.

These concepts tie in with self-consciousness and awareness, particularly in relationship to vulnerability and death. We saw in the previous chapter how renal dialysis and transplant patients are often forced to confront the reality of their own death, that of fellow patients, as well as live with the ongoing uncertainty and loss as a result of chronic illness. Existential psychotherapists do not consider awareness or acceptance of death as a negative aspect of life; rather one that makes life more creative and meaningful. To deny death is unrealistic and at its extreme, a concept referred to as "self-alienation" (May 1961). Therefore, such experiences might well render these patients liable to heightened self-consciousness and mind-body awareness. Some patients manage their anxiety by trying to avoid the thoughts of death through the creation of diversions; however, if they lapse in their avoidance, the reality of life is revealed and patients become anxious once again.

During therapy, anxiety is not as overt as we often think, and can be distorted and may present in many guises. This distorted presentation comes about as patients attempt to hide their anxiety from both themselves and their therapist. While patients may develop many ways to manage their anxiety, they will need to confront these issues if there is to be a successful outcome. The therapist will encourage the patient not only to express his or her feelings of anxiety but also to explore past experiences to determine the origins of the anxiety and how this experience is manifesting in their daily lives in the present. The therapist will question and ask for clarification as well as encourage further exploration of these issues. Therapists do not attempt to remove anxiety from patients' lives but encourage them to confront and manage it better. As patients become better able to manage their anxiety, they become more confident that they can deal with uncertainty and situations that arise as they go about their daily lives. Other patients deal with anxiety generated by renal disease or after transplant by taking a fatalistic, or *back-seat* approach to life. They steadfastly refuse to take any responsibility for themselves assuming the stance that their life course is determined by their illness. During dialysis, these patients are often very compliant, falling unquestionably into the routine and somewhat restricted lifestyle

of dialysis, which often becomes intrinsic to their very identity. They are often considered ideal candidates for transplant; however, they are also the patients who years after successful transplant have failed to develop any meaningful lifestyle. The time previously spent on dialysis just becomes *empty time*.

We often receive referrals from such patients 8 to 15 years after transplant who are stuck in the *routine of nothingness* that becomes increasingly static, desolate, and frustrated. These patients feel that they have not been able to achieve the lifestyle that they wanted. Any attempt during therapy to move these patients on is met with a steadfast inability to change with potential for anxiety. These patients exist in a stifling cocoon, which is secure in its nothingness, apart from anxiety, but apart from a better quality of life. These patients tend to shy away from making choices; the end result is never certain and might involve further choices. However, what these patients often fail to realize is that to not make a choice, is indeed in itself a choice. The “giddiness of freedom” (from chronic illness) threatens to overwhelm their mind, as they know it.

## CASE STUDY

David is a 27-year-old single man who was first diagnosed with chronic renal failure at the age of 25 while living in the United States. Following his diagnosis, he returned to Scotland and to his family and had started hemodialysis. Up until this point he had described his life as quite nomadic, working in Europe and the United States as a plumber. He had planned to try and put his residency status in the United States on a more permanent footing and was contemplating marriage to a girl he had met during his travels.

David had dialyzed a year before receiving a live transplant from his elder half brother. During this time he had oscillated between varying degrees of emotional and medical instability and had spent much of this time as an inpatient on the renal unit. He was considered by medical staff as chronically noncompliant with medications and fluid restriction, and had therefore not been considered for cadaver kidney transplant. His family was forthright in its pursuit of live donation when we actively began our campaign to accelerate and promote live transplant across the West Coast of Scotland. These scenarios involving chronic noncompliant patients, particularly when the patients were young men or women poised a difficult dilemma for staff and it was at this point that he was referred to us for assessment.

### Psychotherapeutic Input

Much of my work with David was conducted on the hospital floor with himself propped up in bed against a pillow with his eyes closed and myself perched with varying degrees of precariousness on the side of his bed. Our meetings were often punctuated with what we came to refer to not so politely as *puke* (when he suddenly needed to vomit) and *whiz* (when he was overcome by dizziness) interludes. These episodes seemed to pass in a few minutes. However, recovery could be greatly accelerated by the application of a cold pack to the head (this was the patient who taught me to make cold packs out of crushed ice and a surgical glove), accompanied by a liberal application of aromatic spray to the face, neck, and wrist. I do not have any qualitative, quantitative or any other sort of evidence to back this up but when patients become agitated, panicky, or upset it seems to do the job for on-the-spot or we-need-to-survive-the-moment variety of relief. On the rare occasions that he was not an inpatient, we would conduct our sessions in my office. The reader will be aware from previous chapters that we do not necessarily subscribe to the view that noncompliance with hemodialysis always equates with noncompliance posttransplant. Writing this chapter retrospectively, having moved from a position of 3 to 25 live transplants per year, we have convincing data that live transplant and supportive psychotherapy is a viable option for some chronic noncompliant patients. However, psychotherapeutically speaking, my approach was the same, to compile psychosocial profile and understand this patient's experience of renal disease.

### Extract from the First Session

It soon became apparent that David had always been quite an anxious person. By his own admission, he had always had trouble committing to relationships, did not like his own company very much and had experienced difficulty settling in one country, having grown accustomed to a nomadic lifestyle. He spent very little time alone and recalled how he had always been on his way to or from some meeting with a friend. During our early sessions, there were numerous referrals to *keeping busy* and parties and seasonal activities. The onset of chronic renal failure, dialysis, and a series of medical complications including ongoing vascular access problems had meant that this lifestyle had been brought to an abrupt end.

**David:** *Dialysis is a very lonely business; you just sit with yourself for hours on end. Not that there is very much of myself left now* (lifting his arm toward me and gesturing



toward a very bruised dialysis access site). *Some of my friends have been coming in to see me but I try to keep them away, I don't want them to see me in this state and my mind is half asleep, I can't hold my own in a conversation any more so what's the point? Anyway, I just think that hearing about all that they have been up to will make me feel worse. I wish that I had made time to put some of my plans into action, such as starting my own business, but somehow I just never got around to it there was always something else going on.*

**Psychotherapist:** *I get a feeling that in the past you were very much preoccupied with filling and marking time with parties and seasonal events. This meant that there was never any time or space to contemplate or commit to the life that you aspired to.*

**David:** *Delivered with some degree of relief. Yes, but now that I have the time I am not able to either.*

David received a successful live transplant from his elder brother and within days he was up and about, walking down to the hospital canteen for fried breakfasts and planning a celebration party. After he was discharged from hospital, he began attending my office for regular therapy. However, he began to adopt a crablike posture, facing sideways and peeping at me periodically. He remained extremely fidgety, wringing his hands and pacing the room from time to time.

**David:** *I am very busy at the moment, organizing this party.*

**Psychotherapist:** *Yes, is this what is making you so anxious?*

**David:** *I do feel anxious here in this session and also at home. They have started asking about my plans for the future. You know, setting up my own business, plans, that sort of thing, now that I am well again.*

**Psychotherapist:** *Are you worried that I might do the same, ask you about your plans?*

**David:** *Yes.*

**Psychotherapist:** *Mmmh. Is that why you are sitting sort of sideways to me?*

**David:** *Avoiding my gaze.*

**Psychotherapist:** *Sounds as uncomfortable as it looks, this enforced bodily stance that you have assumed (a reference to his sideways posture).*

**David:** *Now that I am well, everyone will be expecting me to put some of my plans into operation. The thing is, I was never able to put my plans into action, it was too scary. I mean, it's not like I am going to have a normal life, you know marriage, kids all the rest of it, not now.*

**Psychotherapist:** *So you consider your life to be abnormal?*

**David:** *No, I don't think that I am abnormal, just well, not exactly normal. (looking a bit embarrassed and glancing directly at me). Mmmh. well, yes, I see what you mean.*

**Psychotherapist:** *But what do you mean David?*

**David:** *Thing is, I know what I should be doing, you know setting up my business and getting on with things, but there is always something else to do first and then I never get around to it. You see Christmas is coming up and so I will probably start again after Christmas, yes, that's what I shall do.*

**Psychotherapist:** *I seem to remember us having this conversation last Christmas.*

**David:** Keen to correct me. *Oh no, last Christmas I had gone to ground, wasn't seeing visitors, self-imposed exile* (sheepish grin). David was referring to one of a number of episodes whereby he would barricade himself in his apartment and not answer the door or call anybody, much to the alarm of his family. This had the effect of constricting as opposed to expanding his self-boundaries.

On these occasions when David had not attended sessions for up to six weeks, his slot had remained open and he would appear and pick up his thoughts at the apparently same point as the last session, almost as though his life had stopped for his period of *incarceration*. Despite my attempts, I had never been able to determine exactly what triggered, manifested, or brought to an end these periods in his life and he had never directly referred to them again until now. As much as I sought to pursue this matter, I decided that to do so would interrupt the flow of our interaction. Maybe he knew that and therefore that made it safe to introduce it into the conversation. Patients often master the flow of our thoughts, patterns of intervention, and pet subjects, just as we follow their train of thoughts.

**Psychotherapist:** *I am wondering if one way or another, you manage to keep yourself in an ongoing self-imposed exile, i.e., the life that you say that you want, such as your business that you have talked so animatedly about on a number of occasions.*

**David:** *Thing is, I just need a clear run for that and there is always something else going on.*

**Psychotherapist:** *Mmmh, it seems that when you get a "clear run" or space to develop then you allow something to slot right in and fill up that space. I wonder what would happen if you just allowed yourself to hold that space, feel it, become acquainted with it, try it on for size, rather than rush to fill it. You never know it might suit.*

**David:** *I don't like open spaces, everyone rushes in and starts taking over.*

**Psychotherapist:** *So space renders you liable to expectation.*

**David:** *No, not my expectations, everybody else's expectations.*

**Psychotherapist:** *So maybe we need to look at what your expectations or aspirations for the future really are, not what others expect for you.*

Despite complying with his posttransplant medication regime, David realized that he did not want the kind of regulated life or 9–5 *tedium* of

his contemporaries. He continued to pepper his life with benchmarks in time such as seasonal activities and periods away from home traveling. His family, relieved to have their son well and healthy once again, appeared to have accepted that he would never be the great entrepreneur that they had initially wanted. This has had a calming effect on David and has refrained from his periods of self-imposed exile in his apartment. At that time, these thoughts were quite unfathomable to me, however, in considering these retrospectively now, they probably served as a last resort means to fill up the empty space that he found so difficult to tolerate.

David was able to realize one of his long-term aspirations, that of acquiring a pet dog. While it is a rather well-disposed and handsome dog, who accompanies him everywhere and to which he is devoted, the pet does take up rather a lot of space. But he informs me that his newly acquired four-legged friend takes up the *right sort of space*, that of the *go-at-my-space-don't-generate-expectations* variety.

## CONCLUSION

Traditional treatment interventions for anxiety disorders are based on the assumption that change can occur without the prerequisite of insight into the causes of anxiety. In some patients, this requires quite harsh exposure of one aspect of an otherwise healthy body. While each patient needs to be considered in terms of the origin, context, and duration of the anxiety, we do not actively advocate the use of such treatments in patients with chronic illness and after transplant. This opinion is based upon the experiences as recalled by patients during psychotherapeutic intervention suggesting that many patients have had their sense of mind and physical-body image eroded by the experience of living with an uncertain prognosis. To then impose a graded or any other sort of exposure to situations that trigger heightened anxiety states, we need to first work with them to redefine normality and redevelop their depleted sense of self. In our opinion, the time for graded exposure is after a course of supportive treatment based upon personal development. Very often such environments are no longer, or significantly less, problematic.

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## **Chapter 5**

# **BODY IMAGE, PHOBIC STATES, AND CONCEPT OF MIND-BODY IN PATIENTS WITH RENAL DISEASE AND TRANSPLANTS**

### **INTRODUCTION**

The concept of body image among patients with chronic illness and after transplant has traditionally been considered from a physical, or at least an externally visible perspective. Generally this has manifested among patients with chronic illness and during dialysis and transplant in terms of outwardly noticeable or physical changes or distortions in bodily appearance. A number of authors have made the connection between the removal of body parts as in mastectomy, overall body image and subsequent emotional well-being (Schover 1991). This is particularly so in studies describing oncology rehabilitation whereby patients may have to come to terms with changes in appearance as a result of removal of body parts, which may also be internal, as in the case of the otolaryngology (Bronheim 1994).

More recently studies have demonstrated a greater awareness of the working of the body as a result of a specific organ having failed, subsequent negative body image, and the onset of depression and anxiety. Barsky et al. (1998) described heightened awareness and orientation to resting heartbeat following heart transplantation (Abram 1971), while sensitivity to body mass has been linked to glycemic control and disordered eating among diabetics (Meltzer et al. 2001).

In patients undergoing dialysis, body image has been considered in terms of physical proximity and the subsequent bodily distortion brought

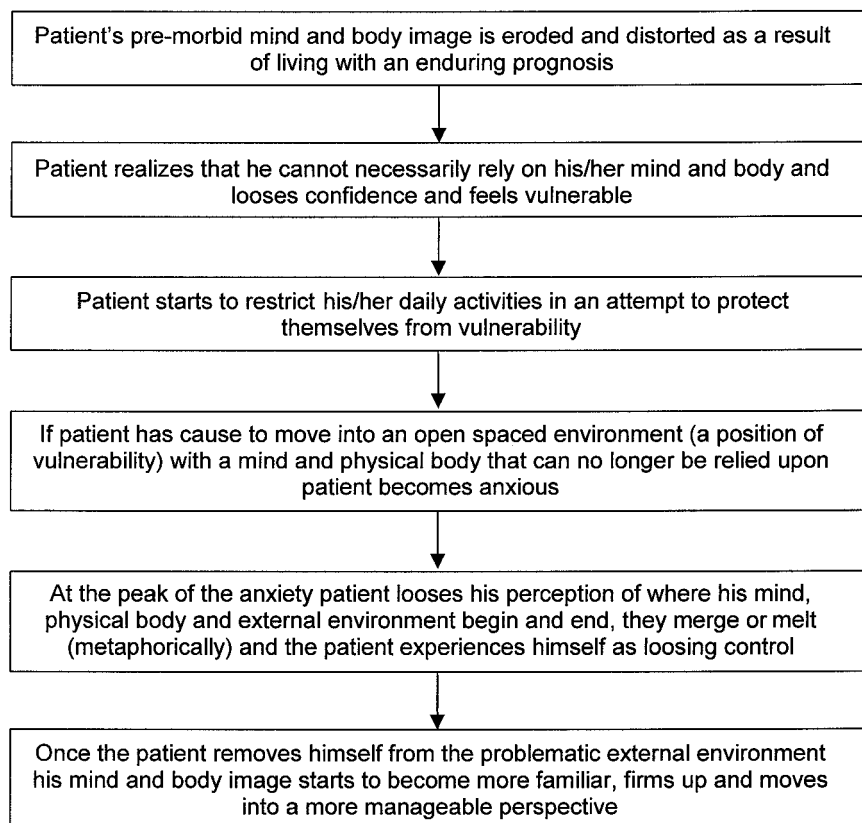
about as a result of various mechanical apparatus needed for dialysis (Locsey et al. 1987), in addition to the general physical deterioration that ultimately accompanies ongoing dialysis (Locsey et al. 1987, Beer 1995). Among recipients of organ transplants, much attention has been given to distortions in physical body image immediately after surgery because of obviously visible intravenous tubes. However, in the long term, other issues causing anxiety and distress to patients are side effects of anti-rejection medication such as weight gain, excessive hair growth, warts, ulcers and bruising, problems of integrating the newly acquired organ into the body, acquisition of personality traits of the donor, and experiences of rebirth (Locsey et al. 1987, Fallon et al. 1997). The latter two issues are addressed in greater detail in chapter six "The integration of the newly acquired kidney into the sense of self."

In this chapter, we discuss body image in patients on dialysis and recipients of organ transplants from a mind-body perspective as a means to understand the clinical manifestations of anxiety and phobic states. We utilize case studies to suggest that the experience of dialysis and transplantation not only heightens a patient's physical (body) distortion or awareness but also triggers a process of interaction between physical and mind (body). Such interaction does not necessarily result in a depressive or psychotic state, as suggested previously, but serves to bring about a momentary merger of the mind, body, and external environmental boundaries, which is not necessarily psychotic. We believe that this scenario provides an explanation regarding the high incidence of phobias among renal patients and serves to ameliorate existing concepts in medicine and psychotherapy of mind-body-external boundaries as separate entities. Furthermore, we suggest that this hypothesis might also be applied to other patients with chronic disease whose illness experience has triggered a heightened awareness of their bodily functions (Figure 5.1).

## **PHYSICAL BODY DISTORTION AND RENAL DISEASE**

In the previous chapters, we have examined the relationship between a number of disabling physical manifestations of ongoing renal disease and emotional volatility. However, in considering matters of distorted body image among these patients, there has been a preoccupation with the physical body while neglecting the mind-body and its interaction with the external environment. Rather, distorted body image among this patient group has become synonymous with physical deterioration, death, and somatic dysfunction. Awareness of physical body changes usually

**Figure 5.1**  
**Linking Mind-Body Image with Anxiety and Phobic States**



coincide with fluid collection, needle access scars, visible protrusion and pulsation of their vascular access site on the forearm needed for hemodialysis, and the external catheter required for peritoneal dialysis. A number of authors have suggested that access sites are responsible for feelings of unattractiveness, disfigurement, vulnerability, and regression (Basch et al. 1981). Disfigurement resulting from dialysis was thought to combine with the social and emotional problems of ongoing illness (Galpin 1992, Beer 1995).

In addition to the preoccupation with access sites, it has been suggested that there are three categories of somatic dysfunction: external disfigurement, alterations in internal body parts and organs, and changes in physiology or somatic functioning. Furthermore, distortions in body image are not necessarily objective. Basch et al. (1981) studied 16 renal



patients using a modified version of the house-tree-person test. The house-tree-person test is a standardized or directive form of art therapy. Patients are questioned about their drawings using a predetermined set of questions, as opposed to a nondirective format, to include opposite sex and internal body analysis. They formed a control group made up of individuals with no known physical illness and comparisons with oncology, cardiac, colostomy, and surgical patients. Methodologically, this was a very ambitious project as it utilized both a randomized controlled and comparative approach, resulting in a multiple or nonspecified control group, making accurate comparison between the groups difficult. Also, by the study authors' own admission the sample size was small, somewhat ironically attributed to the need to exclude a number of patients on their unit due to chronic medical illness. The analysis of pictorial findings suggested a preoccupation with blood (indicated by the profuse use of red in the drawings), trees displaying external roots (thought to be synonymous with the need for external nourishment) and pictures of distorted incomplete people, considered in keeping with physical dysfunction.

Physical deterioration in the most extreme form might be considered in terms of the loss of body parts in the form of nephrectomy (Muslin 1971), amputations (Castelnuovo-Tedesco 1971), disfiguration and loss of use of limbs as a result of bone deterioration, and loss of sexual drive (Simmons et al. 1981). The loss of body organs has been considered as "life-saving" interventions that "restrict" body image, while the addition of a transplanted organ is considered in terms of a "life-enhancing" treatment thought to "enlarge" and heighten awareness as to how the inside of the body was arranged (Castelnuovo-Tedesco 1971) and rearranged or added to, through surgery. Indeed, transplant surgery has been largely credited with the shift in the contemplation of body image from an external to an internal perspective and has subsequently been analyzed in keeping with the work of Schilder (1950).

Physical deterioratory symptoms and distortion of body image deriving from dialysis have been considered to render patients liable to psychological disturbance. This has been considered primarily in terms of generalized anxiety and depression (Alvarez-Ude et al. 2001) and to a lesser extent of phobic-type reactions associated with anxiety. Seregina (1991) described a case of a female patient who was in psychotherapy and suffered from phobic-neurosis-type reactions when receiving hemodialysis. It was suggested that these reactions were triggered by the pathogenic fear of dialysis. Psychotherapeutic intervention took the form of rational talks, hypnosis, and autogenic training. The author reported

that the patient's symptoms were reduced over time using the above-mentioned intervention.

## **PSYCHOTHERAPEUTIC PERSPECTIVE OF MIND-BODY**

The study of the body is not just the prerogative of the medical profession; sociologists and psychotherapists have also long been interested in the experience of being embodied. However, rather than analyzing the concept in terms of medical or somatic outcome, the relationship of a person to his or her body is a central issue in therapy. This manifests during sessions as the contemplation of eating, digestion, bowel movements, shape and size of body, attractiveness, and fertility. Physical and emotional deterioration of the body is a matter that affects us all. However, among renal patients with an enduring chronic illness who often experience loss of function or parts of the body and an accelerated deterioration, this factor is more poignant than the rest of the population. The role of the therapist in such situations is to ensure that patients remain reconciled to, rather than deny their changing body image.

The manifestation of emotional states associated with body image has centered largely upon psychosis and depression, which in turn have been generated by overall feelings of negativity toward the physical body (Galpin 1992). Such theories and hypothesis are therefore fashioned in line with the medical perspective whereby the mind and body are considered in terms of dualism or as separate entities. However, our observations of working with both dialysis and transplant patients with apparent distortions of physical body image suggested a relationship to heightened anxiety and phobic states. Therefore, in order to explore this phenomenon further, we have considered the mind and body, not as separate entities, or as an amalgamated state, but as two interactive entities.

Freud subscribed to a theory of monism, or identity theory, whereby the mind and body are one entity. However, Smith (1995) who summarized this work pointed to a number of occasions when Freud himself appeared to deviate from this school of thought. The most glaring example was during a single case study analysis. Freud referred to a "leap" from a mental process to a somatic innovation, as a "hysterical conversion" that he confessed he failed to comprehend (Freud 1909). A number of writers have seen mind and body as mutual and as different aspects of the same experience. Merleau-Ponty (1962) placed emphasis upon the embodiment of all interaction and perception as a total experience of life, while Heidegger (1927) focused on the "double aspect" of mind and

body as functioning simultaneously but with one aspect liable to be more accentuated than the other at any given time. As far as traditional philosophical and psychotherapeutic schools of thought are concerned, neither monism or dualism has adequately described how their respective states come about. As Cohn (1997) pointed out, a "leap" is by no means a "link." It is this very lack of clarity that has hampered the understanding of psychological manifestations of physical illness and vice versa.

Contemporary psychotherapists have moved to a more pluralistic position in their understanding of the mind and body. They have suggested that the body is not encapsulated and does not just end at the skin. Both Braidotti (1994) and Haraway (1999) questioned the very idea that the skin could function as an insulating "envelope," which in turn might be inhabited and animated by its own soul. In turn, they placed emphasis on the interaction between the mind and body, not only to each other, but also to senses, instincts, needs, and interpersonal relationships with others—in short, to a whole multiplicity of the self, socialization and the social and physical environment in which an individual lives. The body is seen from a mechanical as opposed to a technical perspective in terms of "properties"—walking, smiling, digging, and swimming.

The uncertainty of living with the clinical manifestations of ongoing chronic illness means that patient's understanding and experience of uncertainty, temporality, relational volatility, aspirations, and choices are also subject to change. These aspects of self form the mind-body and are subject to deterioration and distortion, just like the physical body. Therefore, during therapy, patients are not only grappling with the fear and anxiety of a changing or distorted physical body but a mind-body identity as well. In the worst-case scenario, this manifests as an identity, that is diffused and uncharacteristic of their personality as they knew it. The role of the therapist is to help patients to accommodate newly emerging or unknown aspects of their character, that have arisen or presented as a result of living with an uncertain prognosis. Limitation and distortion of character are often the subject of therapy among patients presenting with anxiety and phobic states. If patients' mind-body self-image is unable to expand or contract quickly enough to accommodate change and respond to distortion from relapses and remissions in their illness, then both their mind and physical-body boundaries become destabilized. Destabilization occurs in relationship to the outside world and they render themselves more vulnerable than they already are and liable to continuous or episodic anxiety and phobic states. Many patients have problems with adapting to change, usually as a result of character traits, that limit, distort, or are unable to adapt in a timely fashion. The mind-body is

separate but has the potential to interact through interpermeable and sometimes totally soluble boundaries with the physical body and external environment. Just as a cell needs to be encompassed by a membrane to determine or define its position in time and space, individuals need edges or physical and psychological boundaries to define their very existence.

## **SELF-IMAGE IN RECIPIENTS OF DIALYSIS AND ORGAN TRANSPLANTS**

In previous chapters, we have pointed to boundaries of time (both lost and imagined), in terms of the patient-therapist relationship and the self-imposed boundaries from fellow patients and significant other persons in their lives. All of these are prerequisites for the mind-body equilibrium. These concepts are usually produced in accordance with the limitations and uncertainties imposed upon their life by chronic illness. When working with these patients, we might speak not of a mind-body image, but of a self-image. Self-image is composed of spatial, experiential, and perceptual boundaries, which in turn determines body image. Therefore, when self-boundaries change or need to be modified (e.g., to accommodate chronic illness), self-image will also need to change. However, if the boundaries change and the self-image does not, then individual patient identity becomes incongruent and diffused resulting in an agitated and anxious patient. Additionally, the total dissolution of self-boundaries can come about with intense feelings and sensations exposing patients to the full glare and uncertainty of the external environment. This accentuates a feeling of space and the subsequent awareness of senses, sensations, and emotional capacities than previously experienced, or what has been called an expansion of the mind (Almaas 1996). Psychotherapy is aimed at expanding and accommodating the dissolution of self-boundaries and facilitating self-development in the space that ensues. However, among patients receiving dialysis or transplants, self-boundaries (their sense of self and experiences) have already been challenged in the most brutal of manners by the occurrence of chronic illness or major surgery. Therefore, further potential for change might well be subjected to overt and covert resistance on the part of patients.

If a therapist is going to question a patient's self-boundary, he or she will need to ensure that patient has the potential to fill in the resultant space. Patients receiving dialysis, in particular, can often have limited opportunity for change and can be reassured by the institution of a set routine in their life. In our experience, patients do not respond well initially to physical or emotional sensations of space or emptiness: it

renders them even more vulnerable and needs to be approached slowly and systematically. As a general rule, we try to expand the self-image (spatial, experiential, and perceptual boundaries) before self-boundaries; otherwise the ensuing space will result in ongoing anxiety and episodic phobic states. Somatic manifestations of space in consciousness manifest initially as a gentle tingling sensation on the top of the head and trembling of the body. Almass (1996) suggested that if a person were able to readily accommodate such an experience, these sensations would develop into a feeling of a hole being made into the top of the head.

Inability of the patient to adapt to the newly acquired organ and self-image has been associated with ongoing psychological problems (Penn et al. 1971, Fallon et al. 1997). In a study of 292 kidney transplant patients, all had experienced depression and 58 patients had suffered severe depression. Furthermore, 7 patients had attempted suicide; 2 were successful (Penn et al. 1971). Altered body image resulting from ongoing immunosuppressive therapy, coupled with concerns as to the functioning of the graft, have been suggested to be the main generators of stress after a successful transplant (Fallon et al. 1997).

## **DISTORTION OF MIND-BODY IMAGE LEADING TO EMOTIONAL DISTURBANCE**

We consider the mind and body from an interactive perspective in relationship to the high incidence of anxiety and agoraphobic states among patients receiving dialysis and organ transplants. We propose that this group of patients develop a heightened awareness of their own perilous and uncertain position in life as a result of an uncertain and potentially life-threatening prognosis. The patient turns to resources of the mind-body (past coping strategies, familiar patterns of reassurance) to reassure the physical body. However, he or she is no longer so well acquainted with his or her own mind-body. The mind-body can no longer be relied upon, as it may also have become distorted and subject to deterioration, along with the physical body as a result of the strain of living with chronic illness. Therefore, he or she becomes anxious and develops a heightened state of awareness. At the height of the patient's anxiety, mind-body and external environmental boundaries (where the body and mind end and the external environment begins) merge. This results in overwhelming feelings of loss of control, and more importantly, of any remaining familiar mind and body identity. The feeling of never-ending open space reinforces emptiness and the unknown, for which their depleted mind-body image will be unprepared and unable to cope. This

causes patients to feel that they are losing control of their sense of identity as they know it.

Patients often describe anxiety when they are in large, seemingly open-ended spaces, such as shopping malls. A firming-up of the boundaries and subsequent subsiding of anxiety only comes about in the short term as patients avoid large open spaces. However, patients receiving dialysis often describe phobic or more specifically agoraphobic states in association with their anxiety that is not always directly related to the fear of ongoing dialysis. Sometimes, this is manifested as a fear or reluctance to venture outside home, but increasingly, patients have been describing the onset of agoraphobic states in large open spaces—in which the horizon is seemingly endless, such as large department stores—and crowded spaces. We have come to understand such clinical manifestations in terms of body image. The ongoing physical deterioration is synonymous with dialysis and serves not only to increase emotional volatility and the perception of a negative body image, but to heighten awareness of mind-body environment boundaries.

## THE BODY AND COMMUNICATION

We pay as much attention to verbal as nonverbal communication. Indeed, nonverbal communication often becomes the subject of verbal communication, or forms part of, or reinforces, verbal communication during therapy as demonstrated in the case illustration below. The body communicates and demonstrates emotion both verbally and nonverbally through a series of movements, stance, animations, facial expressions, eye contact, the position of body in space, touch, and personal presentation. Nonverbal communication acts as a means to express emotion or influence another person by any of these means and can be, but is not always accompanied by, verbal communication. Nonverbal communication as well as verbal communication differs between cultures and will be referred to during this chapter, but discussed in greater depth, in context, during chapter ten, "Ethnicity, renal failure and kidney transplantation." While there is no single intercultural code of communication, common to many cultures is the facial expression of the smile to express happiness and a frown to express unhappiness, as well as purposefully raised eyebrows and a wave of the arm to express recognition. While much of this nonverbal communication is intentional and purposeful this is not always the case. This is particularly so when individuals experience a heightened emotional state such as anger and distress and their

nonverbal behavior is visible but unintentional in the form of perspiration and trembling.

It is generally accepted that there are five broad mechanisms of nonverbal communication: facial expression, tone and tempo of speech and context of words, eye contact, position in space, touch and appearance. Facial expression provides a means of both expression and reception of nonverbal communication. Although patients will often try to manipulate their facial expression so as to hide negative feelings, other means of noncommunication will often contradict facial expression. Patients will sometimes try to hide or obscure parts of their face from the therapist. However, therapists who sit facing their patients on a weekly basis often grow adept at reading their patients' facial expressions, in the same way that patients can often read those of the therapist. Therapists also become very attuned to a patient's voice tone and tempo of speech and common choice of words.

The words chosen by the patient often present the primary message that the patient wishes to portray and which may or may not be reinforced by the tone or tempo in which it is delivered. To an experienced therapist, a patient's intonation, context, or frequency of a single word can betray a wealth of emotion that is not registered in facial expression or tone and tempo of the voice. Eye contact—or the lack thereof—is thought to be one of the most powerful forms of social inclusion or exclusion. However, therapeutically speaking, the breaking or maintaining of eye contact between therapist or the patient is much more complex and multifaceted. Cognitively, the breaking of eye contact by either party can indicate deep thought or contemplation, to reinforce or disagree with anything that is being said, or to indicate the need for privacy or personal emotional space. Also in a therapeutic situation, each party will also use eye contact to monitor the reaction and behavior of others. This is especially poignant in an exploratory context as much of our thoughts and feelings will be formulated by virtue of what we see.

The manner and proximity in which patients and therapists arrange their bodies during therapy is probably the most blunt and forthright expression of emotion. The study of personal proximity and space has been the subject of much research in the social sciences and is generally referred to as the study of proxemics. Hall suggested that there were four spatial zones that are thought to be utilized by individuals to unconsciously define or reinforce our relationship to others. These zones were: intimate space (in the immediate proximity to our body), personal space (defined in terms of one-and-a-half feet to four feet from our body), social space (four to twelve feet proximity) and public space



(twelve feet and beyond). Within this context it is generally considered that the closer your physical proximity to another individual, the greater the liking for them. However, while the reader should be aware of such criteria they are often broken in the context of medical intervention. In the therapeutic situation, the patient's position or proximity from the therapist is predetermined by the positioning of chairs in the treatment setting. Often a more important indicator of feelings is the manner in which patients arrange and rearrange their body and which is often observed by the therapist as means to reinforce or contradict what the patient is saying.

In orthodox therapy, touch is discouraged and certainly does not feature much in the patient-therapist interaction as such. However, the therapist will be alert to the patients' use of touch in the context of their relationship to others in their life, particularly if there is incongruence between the amount of touch a patient needs and the amount of touch received. Our body shape and personal style of dressing often determine appearance or personal style and are all thought to determine how we are perceived by others. The therapist, in terms of a patient's change, often observes an informal indicator of patient recovery in personal style and manner of dress. All of the above modes of communication are not mutually exclusive to the therapeutic environment and can easily be observed or utilized in daily life. They also tend to interact with each other to reinforce or contradict the presenting emotions.

## CASE STUDY

Jeff is a 47-year-old married man with three teenage children. He had been diagnosed with kidney failure 5 years previously and had subsequently been receiving hospital-based hemodialysis 3 times a week. He had opted for the night shift to remain in employment as a courier with a local firm. However, he soon developed chronic insomnia and what he described as a *moody, unpredictable, irritable, and anxiety-prone disposition*. He found it a great strain to undergo dialysis through the night and then having to go straight on to a stressful job, particularly when he often felt nauseous and hopeless. The time commitment to dialysis and the ongoing feelings of lethargy had forced him to abandon his career as football player. After 5 years on the cadaver waiting list, Jeff received a kidney transplant. In his words, he thought that life would return to *normal*. Jeff referred himself to therapy 3 months after transplant as a result of what he described as the ongoing burden of his illness and



change in his previously easy-going disposition, bringing his marriage under considerable strain.

At the time of our first session, Jeff had separated from his wife, an arrangement that he hoped would be temporary. He had also been forced to take long-term sick leave from his employment, despite having worked throughout dialysis and initially returned two months after transplant. Despite the fact that the thought of a transplant had motivated him throughout his time on dialysis, he considered that once he had received a transplant, his life in his own words had *fallen apart*. He had not reverted to his premorbid easy-going disposition and had been less able to cope with his employment. Jeff was particularly brutal toward himself, gave himself little credit for having managed to remain in employment during dialysis, blamed himself for his marriage breakup and kept repeating that he wanted to *run away* and, if only he could, return to *normal*.

Jeff's presentation during this first therapy session was of total self-blame for his predicament; he became increasingly tearful and was unable to see a way forward. I spent much of the first half of our first session allowing him to articulate what he called *the whole sorry tale* of his enforced long-term sick leave from his job due to an *incident*. Inquiries on my part as to the nature of the *incident* were met with resignation as he recalled how he had *lost it*, with one of his colleagues—*it*, being his temper, and had from all accounts given his colleague a somewhat forthright account of his negative personality traits.

Our primary concern was Jeff's inability to *see a way forward* in life, even in the short term and his rapidly developing negative attitude toward his new transplanted kidney (from his viewpoint things only went wrong in his life after transplant). If these issues were not addressed, they might well manifest as noncompliance with antirejection medications. Given that we appeared to need some sort of positive foundation upon which to plan for the short term, I encouraged him to take credit for surviving dialysis and maintaining full-time employment.

### **Transcript Taken from the Second Half of Our First Session**

Jeff was sitting in the chair slightly stooped with his arms wrapped around his body, hugging himself and rocking backwards and forwards very slightly at regular intervals, while his gaze remained toward the floor. He retained this stance throughout the rest of the session.

**Jeff:** *All that kept me going throughout dialysis was the thought of a transplant. Now that has happened, my whole life has fallen apart. Maybe, they should have just given*

*the transplant to someone else, as it hasn't done me much good. The rash on my arms has healed up, but I have lost part of my sight (following an episode of low BP, a common occurrence, on the dialysis machine prior to transplant). I still don't have any energy, and my body has swollen up like a balloon due to steroids. I was hoping to get back to some sports again, but it doesn't look like I will be able to.*

Jeff was describing changes in his physical body image and the restrictive and negative impact that these changes have had and indeed continue to have upon his life.

**Jeff:** *What with my Jekyll and Hyde personality, this raving monster I have become, everyone has run away. I used to be easy-going and hardly ever lost my temper, but ever since dialysis started, I have become very volatile. To be honest, I don't really know myself any more, I don't trust myself, I don't know what I am going to say next.*

Jeff was inadvertently describing changes in his mind-body in terms of his temperament and everyday reality.

**Jeff:** *I managed to keep working all the way through dialysis (became tearful and angry). I can't understand how it all crumbled after dialysis; it just does not make sense.*

**Psychotherapist:** *I am wondering if you appreciate the physical and emotional toll that dialysis and transplant has taken on yourself and your family.*

**Jeff:** *Yes, but can't you see, if I had stopped work then everything would have changed. My body is falling apart before my eyes and I am so unpredictable, I don't seem to know myself any more. At least work was part of the old me.*

**Psychotherapist:** *It seems like a part of the old you, like the rest of life, as you knew it, doesn't really fit in with you as you are now, after transplant.*

**Jeff:** *I don't get that, do you? I mean I know what you're saying and it's true. But it defies logic. I spent most of dialysis trying to avoid getting into this state, all that kept me going was the hope of a transplant, then everything else, life as I knew it, but it doesn't seem to have all fallen back into place again. Nobody in the family is speaking to me and everybody at work is probably gossiping about me by now.*

We began to work on the hypothesis that holding on to his job throughout dialysis had been the only way to retain a semblance of his old life and sense of self, as he knew it. The retention of his job also acted as a means to stave off mind-body changes, such as his inability to cope with the uncertainty of dialysis and his newly developed proneness to anxiety and short temper that was alien to both him and his wife. Therefore, Jeff had not really adapted to dialysis (accepted his mind-body changes and limitations and attempted to gain a deeper understanding of them). He had therefore avoided redefining or accommodating any

new aspects (emotional or physical) into his current reality or normality. Jeff became isolated and differentiated himself from his family and friends.

**Psychotherapist:** *It seems that you have been faced with a lot of change throughout your illness, your world as you knew it seems to have quite literally in some cases deteriorated before your very eyes.*

**Psychotherapist's thoughts:** Let us start at the beginning at the risk of stating the obvious and gradually expose the current reality of his situation in time with his ability to expand his mind-body boundaries to incorporate change and redefine normality.

**Jeff:** *Yes, you can say that again.*

**Psychotherapist:** *When you were speaking of your experiences, the physical changes that you have noticed in your body and the temperamental changes, it seems that you have been living in a completely fluid and unpredictable world for five years. Indeed, crouching (reference to his ongoing physical stance of crouched body posture with arms wrapped around him-self) in a different and isolated position to everybody else.*

**Jeff:** *Yes, I suppose that is how it feels.*

**Psychotherapist:** *That somehow by crouching you can protect or brace yourself from whatever might happen next. Almost trying to hold yourself together.*

**Jeff:** Very quiet and seemingly lost in his own world. Yes. *The thing is that I have started to have these funny turns.*

**Psychotherapist:** *Can you tell me more about these funny turns?*

**Jeff:** *Well, my wife calls them panic attacks. It's when I go into that big shopping mall, it's when I go up to the top floor, where you are quite high up and there is a huge glass ceiling, it's like your floating or flying or something.*

**Psychotherapist:** *Can you tell me more about how it feels to be on the top floor of the shopping mall?*

**Jeff:** *Like I said, it feels as though I am flying or floating along.*

**Psychotherapist:** *Like sort of free floating (pause) without any control?*

**Jeff:** *Yes, I'm out of control and it's hot, very hot!*

**Psychotherapist:** *Like you are melting?*

**Jeff:** *Yes, like I am melting into the big space of the shopping mall. It's very scary. I start getting this tingling sensation at the back of my head and then it slowly creeps over the top of my head like a hood. Then I feel giddy and the whole shopping mall starts going round and round. I start getting sweating like crazy and feel as though I am about to pass out. I just have to get out and then I am OK. Last time I just made a run for it and forgot to tell my wife, when I remembered I waited for her outside the shop, as I couldn't face going back inside to find her. I heard my wife talking about it to her sister the other day; they seemed to think that I was going mad.*

**Psychotherapist:** *Is that how you feel, that you are going mad?*

**Jeff:** Rather too quickly. *No, I don't think I am going mad. You should see my wife's sister, now she is mad. Every so often, she runs around the house screaming her head off and smashing the place up, then she goes into hiding for a few months, mad indeed. (reflective for a minute or so). But it is sort of strange; it doesn't make much sense does it?*

**Psychotherapist:** *Well, let's see if we can make more sense of this, on the basis of what we know from your own experiences (pause to give Jeff and me time to recall past experiences before proceeding). Maybe, the first clue to what you have been experiencing lies in your body posture throughout the session.* I gently and slowly arranged my body to reflect the patients, legs crossed and tucked underneath him, arms crossed in front of him and wrapped around the side of his body, the chin on his chest and eyes down, I then looked enquiringly at the patient.

**Jeff:** Having either sensed the movement or some shift in the situation looked toward me, but maintained his posture. *I keep finding myself in this position, whenever I am sitting down quietly and alone, I seem to end up in this position. My wife tells me to sit up straight, but it's rather a comfortable position you know.*

**Psychotherapist's thoughts:** This apparently critical or perhaps the rational voice of his wife is presented in association with any experiences or behavior that might be considered a deviation from the norm. Is his wife really making these remarks? Is he using these statements to balance or even out his perceived irrationality in the eyes of the psychotherapist, or even himself? However, to draw attention to this now would be a complete change of direction, but be aware of these statements and the context in which they are presented in the future.

**Psychotherapist:** Maintaining the same posture. *Yes, it is rather comfortable, also quite safe and protective. I am wondering what does it keep it "safe" from?*

**Jeff:** *I used to have this old banger (car), sometimes it started and sometimes it didn't, it was really unreliable, a real rust bucket, the rust ate away so much of the body work that I don't know how it held together. Now I know how it must have felt. My eyesight has got terrible, I still don't have any stamina now my legs and feet have started tingling, I am getting all hairy and taking panic attacks.*

**Psychotherapist:** *That sounds like some onslaught. It is also as though in wrapping your arms around yourself you are holding yourself together.*

**Jeff:** *Yes, it's as though I might take off and never catch myself again. I have to hold myself in.*

**Psychotherapist:** *Or keep the world out?*

**Jeff:** *Mmmh. The world on the top floor of the shopping mall certainly feels quite threatening.*

Living with the physical and emotional deterioration that is often synonymous with an uncertain prognosis had challenged both Jeff's physical and mind-body identity. He compared his body to his old car, rusting and eroding away, describing the loss of vision, stamina, and deteriorat-

ing sight. In addition, he had moved from an *easy going* to a *Jekyll and Hyde* temperament. Also, his spatial position in relationship to the external environment had been eroded, making him vulnerable to blurring body-environmental boundaries. Jeff had good insight into these changes and sought to protect himself, quite literally by adopting a protective body positioning, which upon reflection could almost be likened to a brace position. He had struggled to retain his job as one of the last threads of what he had premorbidly defined as normality. Sick leave from his job had removed the last familiar and predictable part of his life, which he viewed as devastating. This scenario, by virtue of his unpredictable behavior, had also resulted in the imposition of relational boundaries, in as much as family and friends had begun to avoid him as a result of his unpredictable behavior. That thereby furthered his social isolation at a time when he would have benefited from interpersonal support.

During our therapy sessions, we worked toward Jeff becoming acquainted with a different or a variant upon his old self. As we worked to redefine his life in the present, or within his present reality of uncertainty and a better but nevertheless enduring prognosis, he became better able to distinguish between mind-body-environmental boundaries. Part of this redefinition included taking medical retirement from work and taking up golf. He became a regular at the local golf club. As he began to lead a more active life he was able to rekindle some of his old friendships (those who he had disregarded), and not others (those who had disregarded him) at the onset of his illness. Jeff also instigated a major change in his life when he initiated divorce from his wife. This action caused him great pain but he felt that to continue with the marriage would equate with slow drawn-out pain. The main prompt to such an initiative seemed to be that he felt that his wife was unable to forgive his previous behavior and that years of living with the unpredictability had an irreparable corrosive effect on the marriage.

Eighteen months after a successful kidney transplant, Jeff is doing well and has become a mentor and source of support to other patients awaiting a transplant. At the present time, he is reluctant to enter into another relationship in case he should need to return to dialysis in the future and by his own admission cannot comprehend how he would cope with this prospect again. Therapeutically speaking, of course, one might argue that Jeff is once again bracing himself for dialysis if his transplant should fail in the future, by making an informed choice not to enter into a romantic relationship. We have found this scenario to be particularly common among patients whose previous transplants lasted for only a short time.

## CONCLUSION

During the course of our work, it has become apparent that patient's sense of self and subsequent self-esteem and resolve to survive fluctuate between feelings of security and surety to insecurity and fallibility. Chronic illness, dialysis, and organ transplantation call into question our understanding of the mind-body and our link to the external world whether it be in terms of chemotherapy, dialysis, or physical body distortion brought about as a result of treatment intervention.

Our observations suggest that in order to maintain mind and body equilibrium, while living with an uncertain prognosis, patients will need to embody into their sense of self, issues of uncertainty, temporality, and volatility of relationships, and to fashion their aspirations and choices in keeping with the pace of their illness.

It is increasingly being recognized that the patient's mind and the physical body are not static in time, but dynamic, shifting, and changing over time. The concept of a mind-body has encompassed more than composition of the self, or between one human and another, but also connections between objects, forces, procedures, and elements. We must endeavor to achieve a suitable balance between a totally normal state of health and the consequences chronic illness. Failure to negotiate issues of mind-body anxiety can lead to a crippling fear of life itself, a scenario not conducive to personal development and general quality of life. We can help our patients to realize their full potential by expanding their self-boundaries to accommodate the past, present, and more importantly, the future experience of living with an enduring prognosis.

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## Chapter 6

# INTEGRATION OF THE NEWLY ACQUIRED ORGAN AND THE RECONCILIATION OF ANY NEWLY EMERGING PERSONALITY TRAITS

We have seen in previous chapters how the onset of various emotional states associated with an illness experience can hamper adjustment and recovery from chronic illness and transplantation. Some authors have developed this concept further by virtue of aligning personality traits and types with the onset, maintenance, and recovery from illness. A number of authors have made much of the so-called “cancer-prone personality” (depression, social conformity, suppression of needs, emotions, limited awareness of physical symptoms), which is thought to be a significant determinant to onset of the disease with (Cooper & Faragher 1993) or without a preceding major life event (Schwartz 1993). Among diabetics, personality correlates such as neurosis, anxiety, hostility, anger, depression, self-consciousness, and vulnerability have been aligned with poor glycemic control (Lane et al. 2000). Similarly, cardiovascular patients components of type A (aggressive, uptight, workaholics) are more likely to be at risk of a second cardiac event, while type B (comparatively relaxed and even tempered) are more likely to die (Catipovic-Veselica et al. 2001).

In considering personality traits among heart, liver, and kidney transplant recipients, the concept has been analyzed in terms of the third person—the donor. There have been suggestions that transplant is virtually synonymous with a change of personality that may (Bunzel et al. 1992) parallel the personality traits of the donor. How the personality traits of the donor are infused into the recipient is unclear; although there



has been much contemplation of cellular and systemic memory, we are not aware of any plausible data to support such a hypothesis.

However, this mode of thought has prevailed despite there being little evidence as to how the personality traits of the donor might be transferred to the recipient. Such hypotheses are dependent upon a mutually exclusive dyadic interaction between the recipient and more often than not, an unknown donor, to the exclusion of all other social, relational, and physical elements that shape an individual's identity. However, as the reader will have discerned, such hypotheses are incongruent with the predominant philosophy of this book, as they fail to take into consideration that whether we endure a chronic illness experience or not in our lifetime our identities are in the main socially, physically, and relationally constructed.

Therefore, this chapter is based on the premise that the emergence of any new personality traits are best understood not in terms of the donor, but in terms of the identity of the recipient. Subsequently, the acquisition of an organ is considered more in keeping with an opportunity for, or a process of change, rather than the primary source of change in itself. We suggest that the so-called new personality traits described by recipients might be equated with a fanciful or aspirational self. In brief, patients acquire or develop personality traits that represent how they would like to be, but don't have the courage to be in the presence of family and friends. However, for the reader to understand this concept, they will need to have some insight into the composition of individual identities in terms of the formation and composition of relationships and their values, beliefs, and attitudes. Therefore, some of this chapter is devoted to these issues. We also caution as to the emergence of a dual or split persona (comprising that of the donor and recipient), that might emerge as a result of any of the above personality scenarios. Such manifestations can have a negative impact upon the patient's emotional well-being and therefore we provide suggestions for psychotherapeutic intervention aimed at reconciling such personas.

## **PSYCHOLOGICAL REACTIONS TO KIDNEY TRANSPLANTS**

Muslin (1971) studied the psychological reactions of kidney transplant patients toward their newly acquired organ, which was referred to as "internalization." He described a three-step process by which this came about, from the "foreign body" stage, through "partial incorporation" and finally "complete incorporation." The process is dependent upon assim-

ilation into the self and body image of new object (organ) into the ego, which he likened to a "psychological transplant." During the first, "foreign body" stage, the organ was largely considered as alien or ego separate. Patient's reactions during this time were reported in terms of over-protectiveness and fragility. However, Muslin did acknowledge that a small proportion of patients did not admit being aware of any such feelings, a presentation that he attributed to patients isolating the transplant. During the second, "partial incorporation" stage, the patient's reaction toward their organ was thought to become increasingly less protective; patients spoke less about their transplant as time went on and less purposeful in their protectiveness of it as they went about their daily lives. The final "complete incorporation" stage was characterized by patient's acceptance of their organ to the point of not being aware of it unless questioned. This was interpreted as complete integration of the organ into the patient's internal body image and ego. Muslin also pointed to potential for regression through such stages by heightened protectiveness and fragility during either routine biopsies and/or rejection episodes.

Muslin (1971) considered reaction of the recipient in two parts, reaction to the new organ and the donor. The reaction to the new organ was dominated by the mother-baby analogy in both male and female recipients. He suggested that this manifested with the recipient assuming either the mother or baby role. The emergence of these feelings was largely attributed to references among patients of rebirth and the need to nurse the kidney like a new baby. Reaction to the donor was thought to be unique in each recipient and alternated between elation and what Muslin called "guilt-shame" responses. "Guilt-shame" responses were considered attempts on the part of recipients to justify their acceptance of a kidney from a cadaver or live donor by either minimizing or justifying the donation. Some patients have referred to the kidney in the third person, although it is unclear whether this is related to an internal or external process of internalization. Basch (1973) also made the mother-baby analogy in context of parental donors of live kidneys. He suggested that the act of parental organ donation reevoked dependency and emphasized the maternal role with mothers anticipating that transplant would yield the same rewards as childbirth.

Basch (1973) and Muslin (1971) have pointed to the potential for body and self-image problems among patients who undergo cross-gender transplants. Basch described a male recipient who became concerned that in accepting a transplant from his sister, he might reduce his ability to function sexually. Both authors have raised concerns that interpersonal issues arising from parent to child and cross-gender transplants might

hamper the integration of the transplanted kidney. Medical studies that have sought to determine why males who receive kidneys from female donors exhibit unusually high incidence of rejection and have attributed poor outcome to immunological and technical factors (Vereerstraeten et al. 1999). There have also been suggestions that the age of donor might influence the process of integration (Basch 1973), although more recently older donors have been viewed much more positively from a medical perspective (Kuo et al. 1996). However, according to Basch (1973), the integration of a cadaver kidney can also be complicated by fantasies about the unknown donor on the part of the recipient. He suggested that in contrast to the live donor who is known to the recipient and thereby liable to distance or associate themselves with their persona, the very fact that the cadaver transplant is an unknown quantity allows free reign of the recipient's fantasy. These fantasies were thought to be driven by the recipient's previous attitudes toward death and dying and manifested as a preoccupation with death. There have been no studies linking graft outcomes between cross-gender transplants to problems with image and hence noncompliance with medications. This aspect needs to be clarified in future studies.

There have also been reports of suicides and the complete cessation of medications among posttransplant patients who experience severe bodily distortion and lack of integration. It has also been suggested that if ego and body image are found to be irreconcilable, suicide and discontinuation of medication are seen as a means to reject or "throw off" the kidney. Reports of self-imposed destruction of the kidney through noncompliance with medication have also been suggested by some studies and analyzed in terms of introjections of the donor (Cramond 1967). The feeling by the recipient that the transplant brought about an introjection of donor characteristics, followed by relational conflict between recipient and donor, has been associated with the recipient actively bringing about rejection of the kidney as a means to dispense with these thought processes. Similarly, males may view their sense of maleness being threatened or challenged as a result of receiving a kidney from a female. And women who receive a kidney from a male are liable to worry about their ability to have children. These findings were confirmed a decade later when a pretransplant tenuous gender identity was associated with gender confusion after a successful transplant (Levy 1986).

Feelings of indebtedness have also been found to be fairly common among both live and cadaver kidney recipients. This manifests among cadaver recipients feelings of uneasiness at having somehow contributed toward, or caused the donor's death and among live recipients at having

put the donor at risk of death or harm (Kemph 1970). Some recipients have gone as far as suggesting that they have stolen (the kidney) from the donor (Kemph et al. 1969) and felt the need to reimburse the donor (Muslin 1971). However, in the event of a rejection episode, such feelings can be experienced in reverse as negative feelings toward the donor; for donating a kidney that rejected (Kemph et al. 1969). However, despite these problems there have been consistent reports of improved quality of life posttransplant in the majority of patients (Fallon et al. 1997).

## ATTITUDES TO XENOTRANSPLANTATION

Ongoing shortages of human organs for transplantation coupled with technical advances in the field of xenotransplantation, have led to the consideration of the psychosocial (Sanner 1998 & 2001, Hagelin et al. 2001) as well as the ethical and technical aspects of such a procedure (Bach 1997). While scientists continue to overcome immunological and physiological problems to xenotransplantation, the psychological and relational implications for the integration of an animal organ into a human is still not clear. The main social obstacles have been perceived to center upon religious beliefs and opinions (Hagelin et al. 2001) and the general public's "feelings" and "ideas" toward xenotransplantation (Sanner 2001). That is, despite indications from religious leaders that transplantation is a matter for the individual concerned and that the majority of the general public have no experience of living with the uncertainty of renal disease.

One of the most recent studies aimed at determining the effect of religious beliefs and opinions on transplantation was that conducted by Hagelin et al. (2001). They conducted a survey among university students from Kenya, Sweden, and Texas aiming to explore the religious beliefs and opinions toward xenotransplantation among religious and nonreligious students. The overall findings suggested that religious students were less likely to be in favor of xenotransplantation than their nonreligious counterparts. An intrareligious comparison suggested that Protestants were more likely than Catholics or Muslims to be in favor of clinical xenotransplantation. It would appear that the authors were following indications from the ongoing debate in the field that religion may well be the primary factor in determining social and professional sanctioning of such a procedure. However, given the ongoing controversy as to whether or not clinical trials should be allowed to proceed and the potential for such studies to influence this decision, we feel that it is important for the reader to consider the following three factors aris-

ing from such studies. First, students, whatever the extent or nature of their religious persuasion, do not constitute a representative sample of the general population. As these students were not suffering from renal failure, their opinions are at best speculative. Second, we have seen during the course of this book how an individual's "opinions" and "beliefs" are constructed socially, emotionally, and through their experience of chronic illness. Therefore, it would be wrong to consider religion as the single most formative factor in the construction of "beliefs" and "opinions" toward xenotransplantation. Third, as we have also suggested in the previous chapter, some individual's mind and body image is more permeable than others and is better disposed psychologically, emotionally, and socially toward the incorporation of a nonrelated organ into their body than others. These patients did not display consistent or specific gender, race, or religious characteristics. While this particular research was conducted retrospectively there is no reason to suggest that they would be any less open to organs of animal origin.

In order to provide an accurate public opinion for xenotransplantation, a study would need to be conducted that draws upon the "beliefs" and "opinions" of a representative (every member of the population has a specified nonzero probability of being in the study) or cluster (targeting of hierarchies in the population) sample of the general population. Also, if future studies are to go with the concepts of "beliefs" and "opinions," authors need to be aware that within the social sciences, these terms can be used interchangeably as a means to determine how individuals construct their reality. The reality of a student not suffering from chronic renal disease will be considerably different to that of a renal failure patient who has lived with the impact of an enduring prognosis and the uncertainty of dialysis and transplant. Therefore, we believe that it is these patients whom we should be surveying in the future as to their "belief" and "opinions" toward xenotransplantation.

In a recent study, Sanner (2001) surveyed members of the general public on their attitude toward xenotransplantation. The sample does not appear to have included patients suffering from renal disease. In this study, she constructed a "hierarchy of organ preferences" (human or animal) in which respondents could choose from a variety of situations simulating the need for a transplant. These ranged from an emergency situation, to the status or functioning of the transplant and prompted contemplation of issues, such as the effect of transplant on personality and body image. Sanner's findings suggested that most individuals would be willing to accept an organ, although most respondents preferred a human transplant. Any study of xenotransplantation and attitudes toward

such a procedure would by its very nature have to be theoretical as xenotransplants are not routinely performed. However, we suggest that the above considerations would need to be incorporated into any future research in order to produce the ultimate indicator of likely "opinions" and "beliefs" toward xenotransplantation. Inaccurate and unreliable studies of public opinion may well stunt the development of a potentially life-saving intervention.

## **THE FORMATION AND MAINTENANCE OF RELATIONSHIPS**

The formation and maintenance of relationships come about as a result of interpersonal attraction or the desire that one individual has to be with another. It is the interpersonal attraction that prompts one person to form a relationship with another, and once established, serves to maintain the relationship. However, many instances of interpersonal attraction are only short term and do not develop into a longer-term relationship. Beebe (1996) has summarized the seven component parts of interpersonal attraction as follows: physical attraction, proximity, similarity, efficiency and charisma, mutual liking, relationship potential, and complementary needs. Physical attraction is based upon the extent to which outward body physique appeals to another, or outward bodily appearance. This includes, size, shape, eye color, and hairstyle. It is generally considered that we are more likely to be physically attracted to people who are in close geographical proximity than those who go about their daily lives some distance from ours. Such a suggestion is based upon the fact that close proximity facilitates communication. In addition, we also tend to be attracted to people whose backgrounds are similar to our own. There is a tendency to seek out other individuals who have the same values, beliefs, and attitudes as our own. Similarly, individuals who are efficient and authentic tend to generate charisma and thereby attract like-minded others. In the same way that individuals tend to be attracted to similar people, the very fact that one individual expresses a liking for another encourages the likelihood of these sentiments being returned. Whether or not a relationship develops to the maintenance or long-term stage very much depends upon whether the parties concerned believe that it has potential to meet their needs. This does not necessarily mean that we are attracted to individuals who have similar needs as our own, rather that people are often sought out as their needs complement, rather than reinforce their own.

## **BELIEFS, ATTITUDES, VALUES, AND THE SELF IN RELATIONSHIP TO OTHERS**

The concept of self or individual identity has been discussed in previous chapters and is a recurring theme throughout the book. The self comprises an individual's identity and is compiled of beliefs, attitudes, and values. These provide a vehicle for the self-development of an individual, thoughts, self-esteem and mind and body image, all of which serve as a frame of reference through which we interpret our interactions, verbal and nonverbal communication with others. In order that the reader can have a better understanding of the role of self in the integration of an organ transplant, it is important to be able to differentiate between attitudes, beliefs and values.

Beliefs refer to the manner in which individuals compile their perspective or reality, what is real and what is unreal. Therapists often spend much of their time facilitating an awareness of patients' beliefs and their consequences in their life. Attitudes reflect what is good and true or a learned predisposition to something in a favorable or unfavorable manner. Beliefs are a prerequisite to change, personal development, and the appreciation of a wider perspective of life and values of others. Attitudes and beliefs are essentially different elements and function independently of one another. However, an individual might have a favorable attitude toward something and still believe negative things. For their part, therapists need to be aware of their patients' beliefs in order to access their problems as well as their own beliefs in order to avoid imposing upon the patient. Values tend to be constant determinants of good and bad and right and wrong and are much more difficult to change than attitudes and values.

Attitudes, values, and beliefs affect individual's self-esteem, confidence and self-worth, which in turn influence both our interpersonal (with others) and intrapersonal (with ourselves) communication. We saw in the previous chapter how negative inter- and intrapersonal communication led to poor self-esteem, anxiety, and poor skills as well as ability to deal with open spaces. However, intrapersonal communication can be developed further during therapy by the use of visualization (conjuring up a vision of oneself actually being or behaving in the desired manner) and reframing (redefining past events from a different point of view).

Rogers (1951, 1959) has pointed to the need to understand the distinction between "self-concept" (the self that is experienced in the present) and the "ideal self" (the self that an individual would most like to



be). The greater the discrepancy between the "self-concept" and the "ideal self" the more dissatisfied and despondent the individual is likely to be. During childhood beliefs, values and attitudes are mainly incorporated from those in a position of influence, such as parents and caretakers. This process is known as "introjection" and forms a prerequisite for the individual to experience self-worth. Compliance to the values, beliefs and attitudes and subsequent approval is known as "conditional positive regard." The self can also be considered materialistically (consists of possessions, body or a home) and spiritually (introspection of values and morals).

As a best-case scenario, an awareness of self can bring purpose and meaning to life; however among renal patients, the experience of chronic illness can often challenge any previous purpose and meaning of life leaving the patient feeling devoid of such qualities. Such a presentation can be likened to concept of an "empty self," devoid of meaning and purpose (Cushman 1990). The concept of self not only varies from one individual to the next but from one culture to another. In the Western world, the predominant culture in which psychotherapy has been developed, there has been emphasis upon independent, autonomous individualism with a tendency toward strong personal boundaries and inner private self. In contrast, in nonwestern cultures, the sense of individuality might not be so strong. Conversely, concepts of shame, honor, and virtue in terms of family and social networks are more likely to abound in such cultures.

## THE RELATIONAL SELF

The relational self is developed through our relationships with others as a direct result of our verbal and nonverbal communication with them. However, the nature of relationships and the manner in which they develop is dependent upon a number of factors: circumstance, choice, trust, intimacy, and power. According to Beebe et al. (1996), relationships are formulated on the basis of circumstance or choice. Relationships of circumstance are devoid of choice and spontaneity in their formation. They tend to come about as a result of some aspects of our life overlapping and primarily consist of family and friends. In contrast, relationships of choice are actively sought out and formulated and tend to consist of friends and spouses. Once a relationship has been formed the intensity accorded to it depends very much on the degree of trust, intimacy, and power that characterizes the relationship. The trust that we accord to a relationship is determined by the degree of safety that we feel in the



context of our interaction with another person. High levels of trust should be determined by the ability to display vulnerability, confidence, and intimate emotional information about oneself and not the social role assigned to the other person. Beebe et al. (1996) suggests that relationships can span from the intimate to the nonintimate, irrespective of social role. Intimacy is the characteristic used to describe the degree to which we can be ourselves in the presence of another person and whether or not the relationship can endure such a disclosure. One of the most influential aspects of relationships is the ability that one person has to influence another. The heightened presence of resistance and rejection in a relationship tends to suggest an imbalance or withholding of power by one or both individuals.

Numerous investigators have studied the development of human relationships (Knapp et al. 1980, Wood 1982, DeVito 1989, Ruben 1992). These have been summarized as follows: "preinteraction awareness," "passive strategy," "initiation," "exploration," "intensification," and "intimacy" stages (Beebe et al. 1996). The preinteraction awareness stage consists of awareness of another person's presence but without any direct interaction. This may progress to the collection of information about the person through indirect sources and still without any direct contact. Berger and Bradac (1982) termed such indirect interest as a "passive" strategy. This is often termed a point of no return, as it is impossible to return to the "initiation" stage since by this time you have established a relational history. Sociolinguistically, any communication during this time is characterized by routine questions and answers, during which the public persona is presented. It is the "exploration" stage during which more in-depth personal information will be exchanged. However, this stage is devoid of physical contact and time spent together will be limited and can be actualized at the same time as the "initiation" stage. It is the next stage, "intensification," that is marked by the development of mutual dependency, shared activities, more time and becomes emotionally and physically intimate. During the final stage of "intimacy," both parties in the relationship emotionally and socially reaffirm their commitment to each other, are synchronized and are highly sensitized to the other's nonverbal communication.

This process can be reversed; "turmoil" or "stagnation" characterizes the beginning of a breakdown in a relationship. This is accompanied by an increase in conflict and faultfinding, while the relationship becomes less clear and mutual acceptance starts to decline. The next stage of "deintensification" is characterized by a reduction in interactions, conflict and faultfinding. The persons involved in this relationship will then begin

to separate. During the next stage (separation), the individual makes a conscious decision to separate—a process that is complicated and often difficult as each individual has an awareness of intimate details of the other; a situation that decreases as time advances and new relationships are formed. The final separation stage is termed the “post-interaction” stage, which although physically over, experience of the relationship will have a lasting effect upon the self.

## **THE INTEGRATION OF THE ORGAN INTO THE SELF**

Working therapeutically with these patients, it has become increasingly apparent that any newly developed aspects of self, whether they be personality traits, attitudes, values, or beliefs, need to be interpreted in terms of the recipient's past and present experience and aspirations for the future, not the donors. In our experience, if they develop apart from, or are not integrated into the self, then patients develop a split or dispersed identity, which is very difficult to reconcile even after long periods of therapy. This would need to incorporate their relational, cognitive, social and subjective experience of past and present and their aspirations for the future. Not least, the experience of living with the uncertainty, anxiety and corrosive effects of chronic illness, all of which will be inter-dispersed with hopes, fears and expectations of the transplant. Patients who receive a transplant after prolonged periods of dialysis often find that their sense of self, as they knew it, has eroded or been challenged as a result of the uncertainty of living with a chronic illness. Therefore, following a transplant, some patients will be faced with a process of transition or the seemingly insurmountable task of reconstructing the sense of self and redefining normality in the present as opposed to the past, or how they used to be before dialysis.

With the future (on dialysis) looking increasingly bleak, dialysis patients spend much of their time trying to retain their premorbid sense of self, lest they fall under the tide of chronic illness. Therefore, dialysis patients' sense of self is much more rigid and less able to respond to personal and medical crisis as they present in their life. After a successful transplant, patients often present to us clutching the remnants of a self, or the shadow of a self that was, and have little confidence to undertake any change in their lives. Consequently, redefining normality or “getting back to normal” and defining and actualizing future aspirations can take time.

The acquisition of new personality traits after a successful transplant

are more in keeping with this "aspirational" or "want to be" self of the recipient. In other words, how the patient thinks or speculates that he or she might like to be a fanciful self. The aspirational self emerges and is shaped within the context of a largely depleted and stagnated self that has lived with the stress and uncertainty of dialysis. Therefore, after a successful transplant, the patient experiences comparatively less stress, anxiety and a potential once again for autonomy and personal development. Therefore, after a transplant, newly emerging personality traits, values, attitudes, or relationships occur after a period of stagnated personal development. Alternatively, some patients contemplate purposeful change after transplant, usually things that they want to do differently or goals that they want to actualize, but often they do not have the confidence to present aspects of their "fanciful self" to family and friends. This is usually because such feelings are out of keeping, or a variant on, the predominant culture (social roles, expectations, values and traditions) in which they live and might be viewed negatively by significant others. Therefore, such aspirations and changes are presented or aired under the guise of the donor's persona. Furthermore, patients who do not know the age or gender of their donor will often construct an identity of the donor, which complements their own personality. In such cases, there is usually a point of perceived commonality between recipient and donor "I think that the donor had blond hair like me" and a point of supplementary difference "I think that the donor must have been better educated than me." Therefore, patients after transplant are essentially reframing their personalities.

In the first instance, the donor or the donor family has by virtue of the act of donation indicated a notion of life beyond their death (cadaver donor) or a life apart from their own (live donor). This is in itself a powerful form of communication directly from the donor to the recipient, which brings with it expectation on both sides of the relational equation. Secondly, at the time the kidney is transplanted, a tentative relationship between the donated organ and recipient comes into being. The nature and characteristics of that interaction and the degree to which the concepts of trust, intimacy and power develop, depend upon the medical course of the transplant and the recipient's concept of one's self. The organ and recipient often develop high levels of intimacy and trust. However, the power to keep the patient off dialysis and to stay alive is very much in the hands of the transplanted organ. If it is perceived by the recipient to abuse its power (early rejection, pain, exaggerated bodily distortion, consistently poor creatinine results, and the need for biopsies),

then trust and intimacy between the donated organ and recipient will not come into being.

## CASE STUDY ONE

### Background Information

Edward is a 36-year-old man with a transplant of 16 years standing. He had dialyzed for a year before receiving his transplant and described how he had felt a natural affinity with his kidney, characterized by mutual respect and trust. He mentioned how he had known other patients from his dialysis era who had lost their transplant in a short time, or who had received “unreliable” kidneys. Following his transplant, Edward had taken a position as a store man in a local warehouse. However, he reflected that his renal failure had interfered with his schooling and that remained a source of regret as he had never really achieved his full vocational potential. He had lived with his mother, until her abrupt death from cancer 2 years previously. He had two relationships with women, the first, had lasted for 10 years and the second and current relationship with Melanie was initiated by his late mother.

Edward contacted me requesting to be seen following a conversation with a nurse in the outpatient clinic. He later told me how he had come to confide in a nurse about the *breakup* of his relationship with Melanie. He later recalled how he had become tearful and distraught and felt *completely alone* having so recently lost his mother as well. The nurse had suggested that Edward approach me. During our meeting, he continued his recount of how Melanie had asked him to move out of the flat as she felt that they had moved in together too soon. Also, she had stated in no uncertain terms in a recent argument that she had found him *deceitful*.

### Transcript Midway through the First Therapy Session

**Edward:** Learning toward me looking perplexed and wringing his hands. *How can she call me deceitful, I bend over backwards not to upset other people. I think to myself, should I tell this person that and well no, maybe I had better not in case I hurt them. My family (a few cousins and an aunt) don't get on with Melanie, then there's my ex-girlfriend (Lauren), she wasn't too happy when we split up, so I try not to mix them up.*

**Psychotherapist's thoughts:** I need to establish who Lauren is, but I also need to determine his past and current relationship patterns and the context in which Melanie believed that he has been *deceitful*.

**Psychotherapist:** *It all sounds almost like you have to compartmentalize your life, relatives and friends all in their place and never the twain shall meet. Is this manner of living your life, stage-managing relationships, somehow connected to the accusation of “deceit?”*

**Edward:** *I bumped into my ex-girlfriend a few weeks ago; she got upset again so we went for a drink. I didn’t tell Melanie because I thought that she might think that I was seeing her again. Then someone must have seen us because Melanie starts asking me why I didn’t tell her.*

**Psychotherapist:** *Do you know why you didn’t tell her?*

**Edward:** *I thought that she would think that we were back together again and that Melanie would dump me. Melanie is so precious to me, she means everything too me. She says that I am very secretive and don’t tell her other things as well. Cast an expectant look at me, possibly for a cue to elaborate further.*

**Psychotherapist:** *Can you give me an example of this secretive behavior?*

**Edward:** *She says that she tells me everything, but that I keep things from her.*

**Psychotherapist:** *Anxious not to be seen as persecutory. Things?*

**Edward:** *My family argue all the time and are constantly causing trouble, so I sometimes don’t tell her that I have seen them. But she seems to find out. I don’t want her (Melanie) to have to have to put up with all that like I did. I tried to shake them (his family) off after I got the transplant but they hold on. My relationship with Melanie is too precious for that.*

**Psychotherapist:** *Thoughtful and slowly. Mmmh. It’s almost as though what you have with Melanie is so precious it is almost as though you have formed a protective bubble around the two of you.*

**Edward:** *That’s what my friend says.*

**Psychotherapist:** *It’s not so much to keep Melanie in, but to keep the others out.*

**Edward:** *Looking exasperated. I am not being deceitful.*

**Psychotherapist:** *In the context of this session, we can give emphasis to why you behave in such a manner. However, seeing from a position outside of this session do you think that in the cold light of day that it might appear deceitful?*

**Edward:** *Looking deflated. Yes, but does it also not show just how much I care?*

**Psychotherapist:** *Purposefully not answering the question. It is almost as though you care so much that if you let Melanie see all of you, then she might be overwhelmed or not like what she sees.*

**Edward:** *I might not like what I see.*

**Psychotherapist:** *So are you saying that if you allow yourself to be the fully-fledged, top gear Edward, then you might overwhelm yourself as well as other people.*

During the next few sessions, Edward reflected again as he had done when we had first met as to the trauma of dialysis and how appreciative he was of having received a *good and durable* kidney after such a short period of dialysis. He reflected on more than one occasion how the kidney and himself had *settled down* together almost from the outset. I went on to emphasize that the manner in which he spoke about the kidney was characteristic of a trustworthy, one-to-one relationship. I went on to draw an analogy between the dyadic or one-to-one interaction that he had with his kidney and the other meaningful relationships in his life, with his mother and Melanie. I pondered whether Edward might feel more comfortable in one-to-one relationships as he could control how much of himself that he could reveal at any one time.

Once Edward had come to accept this pattern of relational interaction, he started to bring examples of his behavior and reenact encounters virtually verbatim, instances when he felt that he might have acted differently. We would often role-play the different responses and behavior patterns to situations as well as visualize what might happen if he had responded differently. Later, Edward developed an acute awareness of his own mode of communication and its consequences both in relationship to himself and with others. This shift in self-awareness was generally noted with appreciation by his friends and made relationships more relaxed. Over time we hoped that many and multifaceted compartments of his life would become more integrated and less compartmentalized. However, the effect upon his relationship with Melanie was not so positive as she did not find it easy to relate to more insightful Edward. I suspected that this was mainly due to the fact that change in awareness in Edward called for reciprocity or expectancy that there would be a similar shift in self-awareness from Melanie—a challenge she found difficult or was unable to meet.

## Summary

Edward stated that the relationship with his kidney was meaningful, trustworthy, and reliable. This relationship appeared to form the core of his self-identity and the point from which he interacted with others. The one-to-one nature of the relationship with his kidney had served him well in the years preceding the transplant, as it seemed to feed into his somewhat secretive nature. In so doing, he was not isolating his kidney; rather his kidney and his self had aligned as one of the many compartmentalized aspects of his life.

## CASE STUDY TWO

### Background Information

Martha is a 32-year-old woman who had received a kidney transplant three months previously, following 12 years on dialysis. She did not work since leaving school but had lived and *kept house* for her boyfriend, Angus of thirteen years standing. The relationship was by her own admission a turbulent one. There had been a number of occasions when, during violent outbursts, Angus had quite literally thrown her out of the house along with her peritoneal dialysis equipment. During these periods of separation, she would move in with her parents and wait for Angus to come and collect her. However, the accommodation at her parent's apartment was far from ideal—it was very small and she was forced to sleep on the living room couch. During these periods at home, she would also become involved in family disputes, which appeared to be very antagonistic. Her father was an alcoholic, had an open affair with another woman in the village, while her mother, who she described as a *weak* woman was powerless to do anything about it. Also, she felt that she became overburdened with childcare duties and babysitting of her sister's children, while her sister went to college.

A junior doctor referred Martha as she was in a distraught state in the clinic. This was during one of her *enforced separations* from Angus and a week of sleeping on her parent's couch. She was keen to return to Angus, as that was the only hope of getting away from her parents. However, the primary source of the distress seemed to be that he had not come to collect her after a few days separation as he usually did. Apparently he had disappeared and she had been unable to get into the house as it was locked and deserted. We started our sessions at a time when Martha was living with her parents and apart from Angus.

### Extract from the First Session

**Martha:** *The more time goes on, the more I wonder whether I want to go back to Angus. I don't want to stay at my parents flat. I have spoken to the social worker and she is trying to find me a different accommodation.*

**Psychotherapist:** *Why not branch out on your own?*

**Martha:** *Mmmh. thing is I have never been on my own. I went straight from my parent's apartment to Angus's house.*

**Psychotherapist:** *How do you feel about taking this step?*

**Martha:** *Well, I don't think that there is much else that I can do. It was becoming very difficult with Angus anyway. Angus always said that I had become too independent and*



*bolshy since I had this transplant. The donor must have been well educated, because she can speak up for herself and use fancy words.*

**Psychotherapist:** *You said “she” when you mentioned the donor, do you know if you received a kidney from a female?*

**Martha:** *No, but I just have a feeling that she was a woman, like me, you know, blond hair, same age, like me (point of similarity) but better educated (point of supplementary difference). I always wanted to go to college but I was ill through the last part of my secondary schooling. So I left school, started dialyzing and moved in with Angus. But you should hear the long words that I can come out with since I have had my transplant, my family all laugh their heads off and call me lady muck. Since you have had this transplant Martha they say, you have gone all posh.*

**Psychotherapist:** *It sounds as though the donor was the sort of lady that you might like to be; perhaps you should enroll in college?*

**Martha:** *It’s funny that you should say that because I have already got the prospectus and I am going to speak to someone at the college next week. My parents are furious; they don’t think that I should be worrying about college. They think that I should be trying to find Angus so that I can get back with him.*

**Psychotherapist’s thoughts:** Who she wants to be is a variant upon her common culture and family background. Also, if Martha goes to college there might be a shift in the balance of power and interactions with Angus, her parents and her sister.

**Psychotherapist:** *What do you think?*

**Martha:** *Before (with the restrictions of dialysis) I only really had two choices, dialysis and Angus or dialysis and my parents, but now I have got another choice, me, with a new kidney (represents opportunity for better quality of life) and college, no Angus and just a little bit of parents.*

The first session ended at this point. Martha did not keep her next two appointments but came into the office for a session three weeks later. She entered the room looking flustered and informed me that Angus had brought her into hospital and was waiting down stairs ready to take her home once we had finished. Although he was not physically in the room with us, his presence was very much in evidence.

**Martha:** *Sorry that I missed my last two sessions, but Angus came to get me and I was busy moving back in with him.*

**Psychotherapist’s thoughts:** Oh no. I was very well aware that she was likely to be hurt, however, I was pleased that she recognized the empowerment and autonomy that is synonymous with education. A whole stream of women and men passing through my office who had remained in relationships with inconsiderate and ill suited partners had hurt themselves emotionally and financially.

**Martha:** *He is already getting on my nerves; still he said that he would change this time.*



**Psychotherapist:** Deliberately thoughtful and inquiring, but not accusatory. *There seems to have been a bit of a shift in your thinking since we last met.*

**Martha:** *Oh, I have changed my living arrangements, I am not with my mother any more. It was hell there and the social worker said that I might have a wait for housing. I mean how long can you wait? So I thought that I would give Angus another go. Sadly, nothing much has changed though. He doesn't mind me going to college, because you know that is why he threw me out last time.*

**Psychotherapist:** *No, I didn't know that.*

**Martha:** *He said that he is happy for me to go to college, but that I would have to get a job as well as he can't afford to keep me. The problem is that we live in a village in the middle of nowhere, there is very high unemployment and I am not sure what sort of job I would get.*

**Psychotherapist's thoughts:** Is Angus just setting her up to fail? If so, is she aware of it?

**Psychotherapist:** *I wonder what sort of job Angus had in mind (given that there is high unemployment in your area and you have no work experience or qualifications).*

**Martha:** *Well, he knows that I won't be able to get a job, any job, living where we do, let alone a job that fits in with my college classes.*

Martha did not attend for any more therapy, but she did call to say that she did not feel that she needed to come any more. She had decided to put off going to college for now as her family and Angus felt that she should stay at home and recover from her transplant. Martha was to return to therapy a number of times when the above scenario of events and reflections were played out, almost verbatim. However, each time she would miss sessions after her reconciliation with Angus. Whenever she telephoned to inform me that she did not plan on returning to therapy, she always ended the conversation with the same refrain, *I am keeping an eye on that kidney though, she gives me all sorts of ideas and gets me into trouble.*

## Summary

Early in the case study, we get a feel for the lack of autonomy, independence, and real choice afforded to Martha throughout her life—not least of which is the manner in which her illness had impinged upon her education and later her social, economic, and relational independence. Similarly, her adult sense of self was not well developed and she was in danger of following the path of passivity that she so resented in her mother. The instability characterized by her relationship with Angus was worrying and she had been unable to move on from this either parent's

or Angus' choice of living arrangements. The relationship with Angus may or may not have started as a relationship of convenience (by virtue of providing accommodation apart from her parents) while dialyzing. However, by the time she had received a kidney transplant, the relationship was familiar, a known quantity, and comparatively safe.

Martha had credited the kidney transplant with persona of a lady she might like to be. In her eyes, the donor needed some point of similarity (a woman with the same color hair as her) and a point of supplementary difference (better educated). However, Martha's self-esteem had not developed sufficiently to facilitate such a transition. In short, the gulf between the lady that she was and the lady that she might become was from her perspective insurmountable. However, Martha kept this fantasy donor persona alive in her own mind and in the minds of those around her by playful verbal communication *I am keeping an eye on that kidney though, she gives me all sorts of ideas and gets me into trouble*. My main concern was that the kidney continued to exist apart from Martha's real-life persona, and could not therefore, become fully integrated into her sense of self. Rather the kidney existed as an alternative self that could well antagonize her real self.

## CONCLUSION

There is no definitive evidence at the current time as to how personality traits, attitudes, values, and beliefs come into being or are formulated after transplantation. In truth, we may never be sure. To be fully certain, we would need to be able to tease out the premorbid personality traits from those that develop as a result of living with an enduring prognosis and subsequent survival. Even if we could determine personality types or traits over these time points, we have no way of knowing whether an individual's personality might have or have not changed anyway as they developed and matured, as the case may be.

Therefore, readers will have to make up their own minds from the data pertaining to cellular and systemic memory and the scenarios that have been recalled above from our experience of working with this patient group. However, our hypothesis differs from any other hypothesis that we are aware of concerning the relationship between donor, graft, and recipient in the following three ways: First, it is the only hypothesis that we know that has been systematically compiled from the recipient's perspective as opposed to that of the donor. Second, it has identified the potential for the development of a dual persona (that of the donor and the recipient) and its largely negative impact upon patient's well-being

is not addressed. Third, we have paralleled our hypothesis with a framework for psychotherapeutic intervention.

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## **Chapter 7**

# **GENDER DIFFERENCE, FEMININITY, AND HOMOSEXUALITY IN RENAL DISEASE AND TRANSPLANTATION**

### **INTRODUCTION**

Common to both the social and medical sciences is the consideration of gender as a variable in relationship to outcome. The social sciences have given primary credence to gender in the context of social inequalities in terms of access to health care, emotional expression, and experiences of illness. Meanwhile the medical sciences have featured gender in terms of the epidemiological differences in clinical presentation, prevalence, and prognosis, a trend reflected in the existing data pertaining to chronic illness. However, among renal disease and transplantation, gender has, with a few exceptions, become more of a secondary consideration and is often one of a cluster of epidemiological variables under investigation in relationship to medical outcome, making direct intergender psychosocial comparisons of renal disease difficult.

We are particularly concerned with female issues as they have received little attention in the context of renal medicine and transplantation. Studies have shown that women fare worse in terms of access to transplant waiting lists (Bloembergen et al. 1997) and are less likely to be recipients but more likely to be donors of organs for transplantation (Khajehdehi 1999). Women recipients also experience higher levels of acute rejection (Meier-Kriesche et al. 2001) than their male counterparts. Socially and relationally, women are not so well placed either. Studies of social ties and social support among patients with renal disease have suggested that

these women are less likely than disabled men to be married, while they are more likely to be single parents and socially disadvantaged (Kutner 1987). Devins et al. (1998) showed that where a member suffered from renal disease, the experience adversely impacted on their spouses, siblings and other family. Women reported that they were more likely than their male counterparts to take responsibility for adapting the family environment to accommodate the impact of renal disease. However, in our experience there is a general lack of awareness on the part of health professionals of the difficulties women have in incorporating chronic illness into their lives and a lack of supportive intervention to help facilitate such an integration.

We do not deny that men on dialysis and after transplant have gender-specific issues as well. However, we have some way to go if we are to support the gender-specific social and relational needs of our female patients in the same manner of our counterparts working in other areas of chronic illness, such as cancer, diabetes, and cardiovascular disease, who have long since realized that analysis of medical and psychosocial aspects of gender differences can lead to an increased understanding of the disease process.

In an attempt to better understand the experience of women and renal disease, we draw upon psychotherapeutic theory that places women as the primary point of analysis within their social networks. We aim to enhance existing data in both renal medicine and the social sciences that has suggested that living with an enduring prognosis has a largely negative effect on their relationships with both men and other women. Renal disease impacts on a woman's many social roles, such as those of a wife, mother, sister, and daughter and subjects them to compromise in relationship to both men and other women with or without a chronic illness. We also consider the disruptive effects on women of childhood or adolescent onset of renal disease on body image, the ability to form relationships, and sexual orientation in adulthood. In short, we suggest that renal disease compromises a woman's femininity to the point that women are not only different from men but are different from other women as well. This renders some women with renal disease an isolated and powerless anomaly in both the context of chronic illness and everyday living.

## **GENDER AND CHRONIC ILLNESS**

Researchers in oncology have realized for some time that men and women have different psychosocial experiences of cancer. In terms of etiology, more men than women are liable to contract and die of cancer,

while those who do survive do not tend to adapt as well as their female counterparts. Nicholas (2000) accounts for this clinical and outcome trend in terms of gender differences in role-socialization patterns, suggesting that behavior patterns associated with traditional male socialization would align factors rendering them liable to cancer risk, avoidance of early help-seeking, and poor psychosocial adaptation. In addition, gender has emerged more blatantly in terms of sexuality in the field of oncology with analysis of impotence (Bokhour et al. 2001), and gynecological (Maughan et al. 2002) and coping behaviors (Baider and Bengal 2001).

Among diabetics, a great deal of attention has been given to the different physiological implications of diabetes in women and men that can result in similar emotional outcomes (Willhoite et al. 1993, Jovanovic 1997). While the social and emotional aspects of the impact of diabetes in both men and women have been detailed in chapter one, major concern once again is sexual and reproduction health. In terms of cancer patients, this manifests as impotence among men, while the need for prepregnancy counseling and education has formed the primary focus pertaining to gender and diabetes (Willhoite et al. 1993).

Gender differences in referral and compliance rates among women with cardiovascular disease are much lower than those of their male counterparts despite women being more likely to die of cardiovascular disease (Halm et al. 1999, Seils et al. 2001). Seils et al. (2001) have pointed to the lower referral rates of women for invasive cardiac procedures and suggested that gender plays a role in the physician's decision to make such referrals for their female patients. There also seems to be a similar trend regarding referrals to cardiac treatment programs, with men being more likely than their female counterparts to be referred for such intervention, even when they are less likely to comply (Halm et al. 1999). Problems with compliance among females in this study were attributed mostly to the lack of education. Neither of the studies considered women's participation behavior in terms of their family commitments or availability of childcare facilities. However, as we have seen in previous chapters, psychological distress is associated with both men and women in relationship to a cardiac episode. Women are more likely to experience distress from the strain of employment, psychosomatic symptoms, and insomnia than their male counterparts, while men are more likely to exhibit Type-A behavior, particularly hostility and anger (Billing et al. 1997).

The transplant community has given little attention to gender as a significant variable in terms of access to or the eventual outcome of



transplants. We have no way of knowing whether the problems mentioned above regarding women's comparatively low referral and compliance rates for cardiac rehabilitation are reflected in transplantation as well. However, susceptibility of women to alcohol-induced liver disease appears to have prompted their inclusion as an independent variable in studies of long-term liver transplant survival rates, which are significantly better than in men (Jain et al. 2000).

Women appear to fare worse than their male counterparts with regards to onset, maintenance, and recovery from chronic illness, particularly cardiovascular disease and cancer. However, there is a paucity of data on transplants to determine how women fare regarding referral, acceptance, allocation, and outcome of the transplant process. However, in both men and women there would appear to be a need to overcome the previously documented obstacles to screening and preventative interventions in order to identify high-risk individuals at an earlier stage and offer appropriate intervention.

## **GENDER AND RENAL DISEASE**

Bloembergen et al. (1997) analyzed data from the Michigan Kidney Registry and the Organ Procurement Agency of Michigan to understand discrepancy in favor of men receiving transplants. Their retrospective analysis included all patients of up to 65 years of age who had started ESRD over a 5-year period (1984–1989). They followed 1,626 patients (40.1% female), of whom 37.7% received a transplant. After adjustment for age, race, and diagnosis, females were 25% less likely than their male counterparts to receive a cadaveric transplant. Further analysis showed that the likelihood of a female receiving a transplant decreased over the age of 45 to 55 years (33%) and 55 to 65 (29%) years and they were less likely to be included on the transplant waiting list than their male counterparts.

Women are less likely to be recipients; however, they are more likely to be donors. Khajehdehi (1999) analyzed 149 hemodialysis patients of whom 114 were on the transplant waiting list. Potential live donors, as they came forward, were interviewed and followed over a 4-year period to determine differences in need and access between cadaveric and living related transplant in keeping with gender, age, and social status of the recipients and donors. Women were much more likely to feature among the hemodialysis and donor group and much less likely to be recipients. In particular, women featured highly as nonrelated donors and were much less likely to present for follow-up. While mortality rates following

transplant are thought to be similar across the genders, there is thought to be some differences in terms of graft survival rates. Meier-Kriesche et al. (2001) examined gender-specific overall 8-year graft survival rates for graft loss secondary to acute rejection (AR) and chronic allograft failure (CAF), defined as graft loss beyond 6 months. The findings were further analyzed in keeping with immunosuppressive regimen, donors and recipient characteristics. Their results suggested that the overall graft and patient survival rates were indeed similar. However, females have a higher risk of AR (10%) but a lower risk of CAF (10%) than their male counterparts; the risk of CAF increased with age for both males and females, but particularly among males.

Soskolne et al. (1989) studied dialysis patients and their spouses to determine psychosocial distress and any subsequent adjustment to living with renal disease, in relationship to gender. Their findings suggested that psychosocial distress and adjustment were common to both patients and their spouses. Also, female patients and their spouses were liable to suffer greater distress than their male patient counterparts. Indeed, in some instances, the partners of female patients seemed to experience greater problems than male patients. In a general exploratory study to determine the subjective "meaning" renal patients attach to their illness, Caress et al. (2001) analyzed patient's ability to cope and adapt in keeping with age and gender. Patients were asked to select words that best described their ability to cope and adapt from an eight-item schema. The results suggested men rather than women were more likely to view renal disease as a "challenge" and have a more positive outlook than their female counterparts. This may explain why women often record a consistently lower quality of life than their male counterparts, particularly with regards to poor self-image, both before and after transplant (Johnson et al. 1998).

Female-specific health issues have been considered in terms of gynecological manifestations in patients receiving dialysis (Rush et al. 2000, Jang et al. 2001, Keller et al. 2001), outcome and effect of pregnancy (Armenti et al. 2000), and the incidence of breast cancer after transplant (Cervelli et al. 1999). Rush et al. (2000) suggested that more attention be given to gynecological problems in hemodialysis patients than the general population. They further hypothesized that as female dialysis patients have more contact with medical professionals, their health issues might be better attended to than women in the general population. They found that only 55.4% of their patients had received gynecological care in the previous year. More specifically, 50% had undergone a Papanicolaou (PAP) smear in the past year and 55% had undergone a mam-

mogram in the past 2 years. The authors suggested that there were indications that many of the women in their survey might benefit from HRT, but only 11% had ever been offered such intervention. There appears to have been a number of concerns as to the underutilization of HRT and reproductive health issues in female dialysis patients. Jang et al. (2001) studied the menstrual status, prevalence of menstrual and climacteric symptoms, and gynecological screening in relationship to the prevalence of comorbidity that might benefit from HRT among females receiving hemodialysis. They found that only 8% had been prescribed HRT, 26% had not had a PAP smear in the past two years and 38% had not received a mammogram in the same period. They concluded that despite these women being in more frequent contact with medical practitioners, they received inferior gynecological care.

Pregnancy during dialysis and after transplant is increasingly becoming an issue among patients with renal disease. There have been particular concerns relating to use of various medications during pregnancy and dialysis dose adjustment postpregnancy (Keller et al. 2001). Armenti et al. (2000) in a report from the National Transplantation Pregnancy Register have suggested that despite the mother and baby health taking priority over the transplanted organ, pregnancy does not appear to cause excessive or irreversible problems with graft function, when the transplant is stable prior to pregnancy. The authors suggested that pregnancy needs to be considered and responded to on an individual patient basis and caution a 2-year posttransplant period before pregnancy. However, they point to successful pregnancies in patients with grafts of less than 1 year standing. As with Keller et al. (2001), Armenti et al. (2000) were concerned with the ability of the physician to accurately adjust blood levels of antirejection drugs. Posttransplant pregnancy involves the adjustment of immunosuppressive medication, which in a few cases has resulted in graft rejection. Female transplant recipients have consistently demonstrated high incidence of low birth weight and prematurity compared to the general population. While there does not appear to be any specific pattern of malformation or defects among this patient group, long-term follow-up has been recommended.

The experience of mothers of children with renal failure was considered in a qualitative study to determine the impact of the "uncertainty" their child's illness caused (MacDonald 1995). The theme of "uncertainty" was a factor in a three-stage process of adaptation in the following areas: finding out, learning to live with chronic illness, and worries and aspirations about the future. In recent years, there has been some explo-

ration regarding the taking of antirejection medications and incidence of cancer among both men and women (Vogt et al. 1990). However, specific to women there has been concern that renal transplant might increase the risk of breast cancer (N'zi et al. 2001, Stewart et al. 1995) and malignancy in general (Vogt et al. 1990). N'zi et al (2001) conducted a comparative study to evaluate the risk of breast pathology in a group of kidney transplant patients. They studied 120 women (30 posttransplant patients and 90 of the general population who presented for breast evaluation) over a 5-year period. They classified the outcomes of the evaluations as either normal or abnormal. Group comparative analysis took into consideration patient's age and relative risk of breast pathology. The results suggested that 93.7% of transplant patients and 83.3% of the general population group presented with benign breast pathology. They concluded that within their study there was no significant risk of breast pathology among transplanted patients. However, other studies have suggested that transplanted women were at risk of breast and other malignant pathology (Stewart et al. 1995). These authors studied the incidence of de novo breast cancer in women receiving immunosuppressive therapy after kidney and heart transplant. They studied 25,914 immunosuppressed women for between 1 to 11 years, during which time 86 women developed breast cancer. They noted that the incidence of breast cancer was particularly low in the first year (0.49) rising to 0.84 in subsequent years; incidence was also higher for other cancers in immunosuppressed women.

It is becoming increasingly clear that women with chronic illness are less likely to obtain access to or receive medical intervention. More specifically, among the data pertaining to renal disease, gender has manifested among renal patients in terms of social support, changes in family environment, marital status, gynecological screening, and other female-specific health issues, such as menstruation, pregnancy, and susceptibility to breast disease. There is clear evidence to suggest that women with renal disease are more liable to early menopause, cardiovascular disorders, and bone fractures. Furthermore, women on dialysis are less likely than women in the general population to be offered Hormone Replacement Therapy, adequate screening, and/or the provision of specialized psychosocial support. The psychotherapeutic literature pertaining to gender—although not specifically developed with chronic illness in mind—may provide some insight as to how inequalities in gender arise in the general population and how they might be compounded in women living with an enduring prognosis.

## PSYCHOTHERAPY AND GENDER DEVELOPMENT

Psychoanalysis provided a biologically determined developmental process of gender differentiation into masculine and feminine identity by virtue of their different experience of the “Oedipus” complex (Freud 1924). As a result, masculine personality came to represent the denial of relational needs, seeking virtual independence from the concern to feel connected to others in preparation for the public world of work. In contrast, feminine personality is defined in relationship to others, in the case of her mother, and is often a lifelong attachment. Adult women are less individuated than men and characterized by their more flexible “ego” boundaries.

However, a number of Freud’s contemporaries have argued that such differences do not come about solely as a result of a biological pre-determination but are reinforced as a result of women’s socialization and their role as primary caretaker of children (Mead 1949; Dinnerstein 1976, Chodorow 1978, 1989). While these landmark papers were written some time ago, contemporary research suggests that despite considerable advances in their social position, women tend to retain responsibility for these aspects of family life and are more likely to become depressed than their male counterparts (Gutierrez-Lobos et al. 2000).

While Freud (1905) focused on the “Oedipal” father, feminists (Dinnerstein 1976; Chodorow 1978, 1989) constructed the concept of the “Oedipal” mother to explain female development and gender identity, and thereby, started a trend in psychological development with emphasis on the importance of a more socially integrated theory. According to feminists, the gender dilemma for girls was how to become feminine like their mothers, yet separate and active like their fathers. The disparity between the masculine concept of autonomy and the feminine trait of dependency was thought to persist unconsciously throughout a girl’s lifetime. Similarly, Horney (1932) argued that it was a woman’s less powerful position that constituted the primary influence on her psychology. While Freud saw individuals as doomed to conflict, she viewed people as striving toward self-development and knowledge, proposing that children whose needs were met on a regular and consistent basis would grow up psychologically secure. If children sensed that their environment was unresponsive or hostile, they would feel insecure and develop feelings of anxiety, isolation, and helplessness. To cope with these feelings the child would develop a variety of strategies for dealing with other people. He or she would try to decrease his or her security by moving toward

or away from people. In a healthy person, these three stages are integrated and balanced, but in an insecure person, one or more of these strategies is exaggerated. Therefore, an insecure woman becomes either overcompliant and docile, withdrawn and isolated, or overly aggressive.

Interpersonal relationships have been identified as a prerequisite to psychological well-being. Thompson (1942) focused on the personal, social, and cultural complexities of a woman's life. She viewed personality development as an accumulative process dependent on individual experiences during maturation, as opposed to a process of transforming sexual energy and repression. However, she disagreed with Freud's biological views on female personality. Supporting the position that culture, as opposed to biology, accounted for "penis envy" and women's feelings of inferiority, she suggested that women envied male status and felt inferior as a result of the social disadvantages. This was the first time that competition between the sexes was not considered to be any different from other types of conflict that existed between individuals in society. Other writers (Adler 1928, Thompson 1942) disagreed with Freud and did not believe that people were driven by sexual instinctual urges alone, or that they were at the mercy of events that occurred in their early childhood. Instead, Adler gave emphasis to the importance of the powerful human desire for social contact with others. In a more optimistic tone than Freud, he believed that the majority of people wanted to preserve relationships, and therefore was motivated to behave in a manner in which everyone would be satisfied. While Adler felt that men were psychologically damaged by their social conditioning for dominance, he felt that women were far more affected as a result of the prejudices against them. Interestingly, he did not see dissatisfaction with their role as a problem.

A number of theories have suggested that men and women would never be equal until men assumed increased responsibility for child rearing. In a more complicated version of Freudian adapted theory, Chodorow (1978) shared Dinnerstein's belief that gender differences were not entirely biologically determined, but that they are also cultivated through an individual's experiences of social relationships and society. He believed that it was through the mother-daughter bond that women reproduced mothering relationships for one another. Men, in contrast, were much less likely to maintain mutually nurturing relationships. As a result they have trouble mothering because they become independent and emotionally detached from other people. In breaking away from their caretaker, men fail to obtain the same high-level responsiveness that is developed through the mother-daughter relationship, and sustained by

women through their relationships with each other. Therefore, in their roles as husbands, partners, fathers, or colleagues, most men are much less responsive to the needs of others, and they do not see the need to give up as much of themselves in order to meet the needs of other people. This in turn may prevent men from being emotionally intimate.

Other relational-based theories of femininity include those of Flax (1978) and De Beauvoir (1968), who both went to lengths to exploring the societal influence upon mothers. Insight was offered into the difficulties of being mothered by a woman who might find herself socially, politically, and economically compromised. Flax invariably discussed women in relationship to their mother, or to their female partner, as opposed to their perception of themselves. From her point of view, society encouraged men to develop the traits of separateness, achievement, and aggression, while it encouraged women in the role of connection, caring, and accommodation. Similarly, De Beauvoir suggested that boys were brought up to "do," who risk their lives and have projects, while girls were trained to "be," that is, be passive, compliant, a mother, and housekeeper. However, we suggest that in reality, given the right social climate, both sets of characteristics have the potential to be amalgamated into either a man or woman. While women in contemporary society are encouraged to achieve and have careers, this is often in addition to their primary role as care-giver.

It has generally been considered that a woman's core identity and primary motivation of psychological development existed within the context of her social networks. Repeatedly, it has been suggested that women thrive in closely-knit relationships (Miller 1976, 1984; Robb 1988). However, this is true only if women perceived these relationships to be empowering, honest and close, and that they enhanced women's lives with social support and feelings of self-worth. Unlike boys who consciously separate from their mothers in order to develop their masculine identity and more rigid ego boundaries, girls develop their identity as a female within the existing framework with more flexible ego boundaries. Consequently, females rarely become as psychologically distant from the nuclear family unit as males. Girls and women appeared to remain more psychologically connected to their actual or substitute mothers even when these relationships were profoundly troubled.

Therefore, the above theories not only describe gender development but a process of gender individualization, which results in men being considered the norm and women as "different." Women's sense of being different from men combines with the influence of the mother, and this reinforces women's lack of individuality, expressed in terms of women's



dependency. We have seen how feminists writing some decades later felt that Freud's theories failed to reflect women's experiences of gender differentiation. So they began to offer alternatives to his classic works. However, we believe that contemporary feminists have failed to improve the representation of women in psychotherapy. This has been primarily a result of their ongoing dialogue with the traditional Freudian framework and their tendency toward inter- as opposed to intragender differences.

The reader will not be hard pressed to draw parallels between traditional psychotherapeutic thinking regarding the plight of women in the general population and that of those women represented in the data presented above pertaining to gender and disease. While both groups of women are liable to social, emotional, and medical disadvantages in contrast to their male counterparts, women with renal disease and organ transplants who take immunosuppressive medication may be more prone to cancer. Both the disease-related and psychotherapy-related data suggest that women benefit greatly from dyadic, confiding relationships, a position that is enhanced when they feel emotionally and economically secure. However, female renal patients are less likely to be married but more likely to be in a position of socioeconomic disadvantage than their female general population counterparts.

Psychotherapeutic data has consistently suggested that despite recent social and economic gains by women in society, their primary source of identity remains that of motherhood. However, renal patients are less likely to have their reproductive health needs met compared to the general population. In addition, we would like to add that patients generally are not comfortable in proceeding with pregnancy for fear of destabilizing a dialysis regime or jeopardizing a transplant. Therefore, we suggest that the above-mentioned dilemmas might all serve to reinforce differences of this group of women in comparison to the general population. Generally, this difference is often thoroughly negative and can leave women feeling isolated, frightened, and with overwhelming feelings of failure and in some cases, clinging to premorbid relationships that no longer work for them but rather against them.

## **GENDER-SENSITIVE PSYCHOTHERAPY**

The above-mentioned work of feminists notwithstanding, there is little evidence that these developments are being incorporated into practice. In research studying gender stereotypes, Spence (1984) identified 54 characteristics that psychotherapists have associated more frequently with women than men. For example, women were assumed to be more



affectionate, submissive, and sentimental than their male counterparts, while men were assumed to be more independent, ambitious, and forthright. This tends to suggest that despite the emergence of contemporary feminist theory, psychoanalytical practice remains fundamentally unchanged, reflecting the gender stereotypical values that it set out to dislodge.

The gender-specific nature of women's problems when undergoing psychotherapy has prompted studies that have explored the relevance of patients having male or female therapists (Tanney and Birk 1976). Although these authors did not disclose how they determined this factor before treatment, their findings were in line with psychoanalytical developmental theory. They found that gender of the patient was less important than that of the therapist. The therapist of choice for young children was usually a female, presumably because the mother is usually the primary caregiver during early infancy. During adolescence, for both boys and girls, the male therapist became the clinician of choice, in keeping with the boys' affiliation with, and the girls' aspirations toward the father figure. However, feminists have encouraged women to use female therapists, who would be more sensitive to the complexities of their lives (Kronsky 1971, Chesler 1972, Rice and Rice 1973). Chesler suggested that such findings would only apply if the therapist were both a woman and a feminist. Fuller (1964) studied patients of both sexes to determine whether a patient's preference regarding the sex of the clinician changed before and after treatment. She found that female patients with relationship problems preferred a female therapist both before and after treatment, and similarly male patients preferred male therapists. While these studies indicate clear patient preference, they do not determine whether such choices are more effective, or merely serve to reinforce gender stereotypes. More than a decade later, Stricker (1977) examined existing research on the treatment of women in relationship to sexism among therapists. He found that although sex-role stereotyping existed in therapists of both sexes, it tended to be spasmodic and not systematic. Stricker also pointed to the way in which fathers receive praise for moving away from male stereotypes, while a mother risks social isolation if she does not comply with essentials of the maternal role. Little data exists in which the role of therapy among women has been considered in direct relationship to the social, political, and economic infrastructure of society. However, in one such study, Homer (1977) identified a tendency of mental health professionals to use the "sick" label to describe women who acted in variance to the social order, as a means to justify their opposition toward social change. She con-

cluded that the effects of therapy were not in the best interests of women. Although she did not discuss her findings in direct reference to Freud, she concluded that psychotherapy was aimed toward producing social stability by virtue of its enforcement of sex-role conformity, which in turn served to deprive women of social power.

Despite consistent indications that women have a tendency to become dependent on medications (Weissman et al. 1988), there has been a trend toward combined psychopharmacology and short-term psychotherapy as the treatment of choice for patients with depression (McCullough et al. 1988, Elkin et al. 1989, Jensen 1994). The Collaborative Study for the Treatment of Depression (Elkin et al. 1989) evaluated three known treatment strategies (cognitive psychotherapy, interpersonal psychotherapy, and pharmacotherapy) versus a placebo (pill) as control. They found that both models of therapy were effective in treating patients with depression, but they did not discuss their findings with reference to gender, or differentiate between a diagnosis of chronic depression and dysthymia. Much has been made of the collaborative nature of the study (between three centers), along with the size of the study (160 respondents). However, as with the Vanderbilt (Strupp 1980) and Temple (Sloane and Staples 1975) studies discussed above, they presented generalized findings at the expense of individuality, bereft of clinical benchmarks for the practicing clinician.

The clinical complexities associated with women's sense of primary relatedness can hinder lifestyle changes, and become an obstacle to treatment. Alternatively, if a woman manages to implement changes in her life there may be ongoing anxiety and stressful consequences for her as a result. The situation is further complicated as women's self-esteem is often dependent upon the judgments and opinions of men (father, spouse)—and key women (mother)—from their social networks. In turn, the attitudes of key members of a woman's social network will be largely determined by the culture in which she lives. Therefore, the ability to focus upon themselves, and separate their own needs from those of others, may become part of an ongoing process of working through and reflection. Currently, the structured time-sensitive format of short-term psychotherapy was likely to collide with their initial unwillingness to reflect upon the negative affects of the social networks through which their identity is determined. Women's need for approval from significant social network members is reflected in psychotherapy and the difficulties that women have in claiming their own authority. It should also be remembered that these social networks that have the power to label women as mentally ill are likely to be psychologically unstable themselves.

Psychotherapy goes a considerable way toward reinforcing the above problems liable to be observed among women presenting for treatment. The tendency toward sex-role stereotyping has been well documented in psychotherapy literature (Tanney and Birk 1976). However, due to the generalized nature of this data and the lack of systematic empirical evidence it is less clear how this discrimination influenced clinical judgment. The study authors also suggested that such stereotyping was more commonly found among male therapists. During treatment, a woman needs to be able to reach beyond her assigned gender role stereotype in order to incorporate major themes in her adult life and also her childhood experiences. For some women the move into an independent adulthood has traditionally been positioned by virtue of the relatively powerless sex roles of marriage and mothering which entail the unconditional nurturing of others. Compliance with these subservient and grossly undervalued and undermined roles have been discussed as they relate to anger and frustration in women, and as common motivating factors among females seeking therapy (Miller 1976).

The degree to which autonomy and independence can be actualized in any women's life will be determined by the culture in which she lives (as discussed later). Thus therapists should be particularly sensitive to a woman's internal perceptions without losing sight of the social, political, and economic realities of her everyday world. However, psychotherapy efficacy studies have not included independence or autonomy as an outcome of treatment. The situation was further compounded by the increased trend in combining psychopharmacology with psychotherapy, as the aim of combined treatment has used medication to further social role compliance, social stability, and gender-role conformity (Markowitz 1992).

We are not so naive as to believe that health services have the necessary resources to sustain long-term traditional analytical psychotherapy. However, a clinician faced with a middle-aged woman socialized into a lifetime of submissive and compliant behavior, who transferred her dependency needs from her parents to her husband, and suddenly finds herself single again, may appreciate a little prolongation on twenty-sessions of psychotherapy. There may be a danger that within such a limited timeframe, the clinician may direct the woman to look inside herself, as opposed to her social environment for the source of her unhappiness. Our own experience suggests that women cannot radically change their behaviors as their primary dependence and relatedness to others may carry financial or social penalties. Rather, they might need time to consider the practical as well as psychological ramifications of

change to weave it into their roles of wife, mother, sister, and friend. A woman may need encouragement from the psychotherapist over time to enjoy and feel comfortable with any newfound independence.

Informal “policing” is often implemented by patients’ social networks, particularly family members of patients admitted to the hospital, with whom well-meaning clinicians often inadvertently collude in order to determine when a patient’s premorbid behavior has been reached. Therefore, psychological stability was often perceived by the family as the patient having recovered from mental illness. Formal policing could be implemented within the treatment setting by virtue of prioritizing issues that women bring to sessions. Both formal and informal measures appear to determine the external results of treatment, without giving consideration to the private reflections of their patients. Therefore, patients may take their cue from a sensitive therapist and disregard the importance of their own thoughts.

## CASE STUDY ONE

### Background Information

Millie is a 45-year-old married woman with a 22-year-old daughter. She had symptoms of renal failure following the birth of her daughter, when she had suffered from eclampsia. She started hospital-based dialysis 5 years later and had found it difficult to combine her role of wife and mother with attendance at hemodialysis. Initially a dialysis machine had been installed in her home, but had found it difficult to allocate time to dialysis during the day; during the evenings she felt tired, poorly motivated, and concerned that dialysis would impinge upon her time with her husband. She had returned to hospital-based dialysis a few years later, but over the years the side effects from dialysis such as nausea, dizziness, headaches and crumbling bones became progressively worse. It had become increasingly difficult for her to feel well enough to cook an evening meal and spend time with her husband and daughter on the days that she dialyzed. These routine domestic chores had become important as she wanted to fulfill what she saw as her role of wife and mother in the absence of a professional career.

The residual nausea and dizziness from dialysis rendered her unsafe to drive most days and therefore, she found herself delegating more household tasks to her sister. She also worried about the effect of her illness on her marriage. She described herself as worried that her husband would *have enough* of her constant feeling unwell and her physical

bodily deterioration. However, as he didn't leave her she worried that he had stayed only for the sake of their daughter.

After 10 years of hemodialysis, Millie received a live kidney transplant from her sister. She had initially refused this gesture of a kidney from her sister, whom she felt had increasingly taken over the mothering of her son. However, she came to realize that a live transplant was her only way out of dialysis. Millie recalled how she had been so optimistic about the transplant and the positive impact that it would have upon her life. However, the transplant never really stabilized, it rejected within a year and Millie had become distraught and sunk into what she later described as a *deep depression*. Since this point in time her attendance at dialysis had become subjected to periods of intermittent nonattendance. Millie would often attend dialysis sessions regularly for months at a time before and then without any apparent warning miss up to six dialysis sessions. These periods of absence were very stressful for staff, family, and, of course, Millie herself. During this period, Millie seemed to close down physically and emotionally and exist in a world that was inaccessible and incomprehensible to all concerned and take up residence on her couch. Staff could only keep her dialysis slot open and along with myself try to encourage her to return to dialysis via voicemail messages. However, these situations invariably were brought to an abrupt end by what became euphemistically known among those involved as her husband's "grab and dash" raids. A burly hockey player, when diplomatic channels had failed, he would quite literally "grab" Millie from behind and bundle her into the car and deliver her to the hospital. Millie, with her slight frame was overpowered. However, once she arrived at the hospital, she would readily agree to dialysis and would quickly become lucid and orientated. Describing these times retrospectively during one of our sessions, she referred to these times as "dark" periods of her life where she could not find her way through the quagmire that had become dialysis. Two issues concerned us. First, that during these "dark" periods she was not only inaccessible to those around her, but inaccessible to herself as well. Second, that Millie did not equate dialysis with life; therefore, she was saying "no" to dialysis and "no" to death. It was almost as though during these times she needed others to make the decisions for her, in other words, carry the load of chronic illness for her.

Her husband later came forward as a live donor after the couple had become aware that a number of spouse-to-spouse live transplants had been carried out in our hospital; however, he had not been a suitable match due to blood group incompatibility. Over the next few years it became increasingly unlikely that she would receive a cadaver transplant

as result of her poor health. Millie was referred to psychotherapy service for her low mood and erratic attendance at dialysis.

### **First Session**

During our first session Millie presented as a petite lady who appeared frail and tired, but well coifed. Indeed, over the three months that we worked together, I came to know Millie as a woman who measured her state of well-being, not in terms of creatinine or fluid levels, but in terms of her ability to maintain her own personal standards of decorum in face of seventeen years of dialysis and a failed transplant. Emotionally, she described intermittent periods of insomnia and low mood, along with the difficulty motivating herself to further dialysis without the hope of a transplant.

Relationally, she described the emotional upset that had surrounded the advice of her physician fifteen years ago against attempting to have another child while on dialysis. The sense of loss that she associated with this aspect of her life had been reinforced for her recently, having observed a number of younger fellow patients enjoying apparently trouble-free pregnancies. Millie also became distressed as she spoke of the way in which she had been unable to care for her daughter as she had wanted and was left with little option but to allow her sister to assume much of the care for her daughter, while she was younger. Currently in her late teens her daughter had become a great source of pride and practical and emotional support to Millie. However, Millie was unable to stop comparing herself to other mothers of teenage daughters, feeling that the deterioratory effects of dialysis left her looking much more like her grandmother. In addition she described feelings of uncontrollable jealousy toward her sister for having such emotionally intimate access to her only child, but she consoled herself with the fact that if somebody had to do it, then it was better that it was family.

An ongoing issue throughout our sessions was also the matter of her marriage, or rather her husband's ongoing affair with a family friend. Like many women with whom I have worked living with, or without, the encumbrance of renal disease, Millie had an eye for the ironic and pragmatic business that is life, particularly where their men were concerned. On her better days she reasoned that her husband had not bargained for the type of married life that he had experienced. If she was not well enough to do all the things that they had planned, then who was she to stop him? They had great plans as newlyweds, all of which had been scuppered with the onset of renal disease. However, on a bad

day it was as much as she could do to get out of bed. Millie had never broached the matter of the affair with her husband despite being urged to do so by her family. She reasoned that she could do very little about it and in any case worried how she would manage financially if he left. She had no means of earning a living and prolonged periods of complications that necessitated in-patient care meant that she would be unfit for work. She described how her relationship with her husband had long been one of platonic friendship, which although not ideal, was very valuable to her.

However, recently she had felt the ground rules begin to change in the relationship, or more specifically, his ability to tolerate what she thought must be mundane for him but meaningful for her. Millie described a routine whereby her husband had always stayed until the last thirty minutes of visiting time when she was in hospital. During this time he would help her into bed and ensure that she could reach her glasses, bottle of mineral water, night-light, and all the other quintessential paraphernalia that accompanies the indisposed. The significance that Millie had attached to this spousal routine throughout her numerous stays in hospital, had been that of reassurance, that *they were in this* (renal disease) *together*; and that in this context, he remained supportive. However, she had become increasingly concerned as this routine had started to be missed, along with the odd visiting session. Millie referred to such rituals as *markers of reassurance* that life was as well as it could be in her world given the circumstances. She wondered aloud whether the affair was becoming more serious. However, given that she was currently bed-ridden following a recent fall there was little she could do. Consequently, she had become increasingly frustrated and described waves of helplessness and anger. The anger appeared to be directed primarily at herself and her illness, which she felt rendered her inept and hopelessly ineffectual as a wife, mother, sister, daughter, and a woman.

It soon became clear that Millie's concern as to the apparent escalation of the affair was not only for herself, but the effect that any marital separation might have upon her daughter, who was in Millie's words *lumbered with a disabled mother*. The fact that they had maintained a stable family unit throughout was to Millie one of her greatest life achievements. *Mum and dad are here* they had always said to their daughter when she had been younger and not so young in times of trouble. Therefore, it was the threat to the family unit as a whole and her lack of appetite for the emotional and physical upheaval that such a separation would bring that had made her very upset. This is the next part of her story.



**Millie:** *I sit up all night and I can't sleep at all. My mind is racing as I keep going over things in my head. I need to keep busy, but there is only so much that I can do stuck in this wheelchair. I just feel stupid, dirty. . .*

**Psychotherapist:** *You seem to be giving yourself a bad time. "Stupid and dirty" that doesn't seem to fit with the solicitous, ruminative, and stylishly attired lady that I see before me.*

**Psychotherapist's thoughts:** While personal appearance is subjective, it can be helpful to the patient if their comments about themselves are blatantly different to your observations. This sort of intervention prompts further inward reflection and serves to reinforce the reality or perception of others. By the time that most women reach their forties, they are well aware of their positive and negative points. It is not a good idea to deny something obviously negative (particularly about their appearance) as patients just feel that you are insincere.

**Millie:** Looking visibly pleased. Well, I try my best with the outside, but inside I am churning.

**Psychotherapist's thoughts:** However, there is a more important intragender issue here that is of a personal nature between a female psychotherapist and female patient and that is not reflected in the above-mentioned gender-sensitive research. That is, my personal belief that when one woman counsels another, if the relationship is to be effective, then the patient must see the psychotherapist as a person who provides a point of self-enhancing difference. In short, contrary to popular belief, when a female patient looks at her therapist she does not want to see a replica of herself, just the better parts of herself on a good day (appearance, presentation, manner, intellect, values, beliefs).

This perception always needs to be accompanied by a different but enhancing (to the patient) aspect of the therapist (appearance, presentation, manner, intellect, values, and beliefs). Many patients will bask in this difference and utilize it, as a sounding board to implement change in their own life, but will not necessarily adopt it for themselves. If this aspect of the psychotherapeutic relationship does not exist, then the patient will not respect her female therapist and will not expose her vulnerability or give serious contemplation to the therapist's intervention. A female patient needs to be especially sure that she can trust a female therapist not to compromise her socially and emotionally as society and other women may have done in the past.

**Millie:** *I have developed a bit of routine at night when I can't sleep. I maneuver my chair into the bathroom and fill up the basin with warm water, with a good helping of Clean Easy disinfectant. Then I take the face cloths belonging to my husband and son and start a ritual of cleaning and rinsing. I think that I am becoming obsessive but it is very comforting.*



**Psychotherapist:** *I was wondering what goes through your mind while you are completing this routine.*

**Millie:** *Ohhhh. Clean Easy has such a nice clean smell. My mother always used to put some in our bath water when we were children. We had very little money when I was young. Indeed, when I think about it, I don't really know how we survived. But my mother was good to us and took good care of us and probably went without essential things herself. Of course, mothers were much stricter in those days and my dad ruled the roost.*

**Psychotherapist's thoughts:** This does not appear to be the sort of repetitive behavior associated with obsessiveness and anxiety, but a calculated and measured routine that comforts and soothes. However, I felt that there was more to this routine and started to contemplate the ads for this well-known brand of disinfectant.

**Psychotherapist:** *As you were speaking, I started to think about the advertising campaign for this disinfectant and its claim that it kills all known germs. The ad depicts a mother with young children cleaning the work surfaces where her children might be exposed to germs. Caring and protecting her children.*

**Millie:** *Yes, I know the one that you mean, mum runs about the room with her mop.*

**Psychotherapist:** *Trying to pull it all together. I was wondering if you have your own image of what a good mother should be like (slight pause to ensure that the patient was following me), a sort of updated version of your own mother. Not dissimilar to the mother and wife for that matter in the Clean Easy advert.*

**Millie:** *Well, I am never going to be like that, am I, bounding around the room?*

**Psychotherapist:** *Well, you are a different person than this fanciful woman with a different set of experiences and needs.*

**Millie:** *You mean cut cloth accordingly and all that?*

**Psychotherapist:** *Well, I was thinking more along the lines of be true to yourself, be all that you can be within the context of what each day brings, in terms of your health. Maybe your perception of being a wife and mother needs to be more fluid, so that you can redefine your role on daily basis in terms of your health.*

**Millie:** *Yes, on some days I can manage more than others. On good days, my daughter takes me to the shopping mall.*

**Psychotherapist:** *Mmmh. Yes, you enjoy the shopping-mall days, but don't beat yourself up on days that are not so good. Save your energy for when those days come around again.*

The later sessions were largely taken up with her role as a wife and fear that her husband might leave her. Millie once again reflected upon what she felt was her inability to act firmly on the obvious affair her husband was having and his new aggressive behavior. Her husband had also started accusing her of not trying hard enough to get well. During these times, her mother tended to side with her husband, which caused her to feel betrayed. We pondered as to whether her husband recognized

the importance that Millie had come to attach to their nighttime ritual of *settling her down* for the night. In regard to the outbursts of aggression, I began to wonder whether her husband was finding it difficult to cope with her rapid physical decline. Whether indeed, he felt helpless in the face of her constant pain, suffering, and discomfort and it seemed that he was projecting his anger onto his wife. Whatever was happening, it was having a devastating effect upon Millie and we needed to find a way to contain it. I decided to mirror Millie's own approach to her physical deterioration and refer to it indirectly as follows:

**Psychotherapist:** Delivered as if deep in thought, almost in an abstract ruminating manner, to spare the patient direct confrontation if she was not ready for it. *It must be difficult for your husband to watch someone you have shared most of your adult life with suffering.*

**Millie:** *Yes.*

**Psychotherapist:** Tempted to give the patient a quick glance to see if she was advancing with me or retreating. This might have broken the silence and so I had to pay attention to the patient's tone as a positive or negative indicator. *There must be times when you feel like closing your eyes to it?*

**Millie:** Conspiratorially toned. *Yes.*

**Psychotherapist's thoughts:** I ventured a fleeting glance at the patient. She was looking straight at me with apparent trust. She knows we are going somewhere, she doesn't know where, but she is depending on me to get her there safely.

**Psychotherapist:** Bringing her eyes slowly to rest on Millie. *I can almost feel the anger and sense of helplessness building up inside, to the point where you want to lash out.*

**Millie:** *Yes.*

**Psychotherapist:** Coming in to land. *I wonder if that is how your husband feels and somehow his anger gets projected onto you?*

**Millie:** *I wondered that too. Thing is, what to do about it?*

The answer was not as clear-cut. I reflected that Millie was able to take the initiative and be quite active in most of her relationships, but her relationship with her husband was characterized by her own passivity. Over the next few months, I suggested a way of interacting with other members of her family. This was to first acknowledge the act that someone was able to do for her, before stating that she felt she could manage. On her own initiative, Millie started to conspire toward this more interactive stance with her husband. *Don't worry about visiting tonight, love, you must be tired after being at work all day, why don't you come tomorrow instead, they are having Christmas carols on the ward and it will be all festive.* This tactic played into her husband's apparent need

for some respite from hospital visiting and gave him a controlled window of opportunity, if indeed he was having an extramarital affair. However, more importantly, it had a positive effect on her mood as she felt that she was doing all she could do to keep her marriage together, for the remainder of the short period of life that was remaining to her. During the time that we worked together, Millie grew increasingly frail until she died of acute myocardial infarction during dialysis.

Millie's experience of renal disease without a successful transplant greatly affected the course of her life and in many ways it actually became her life. She had never really had a professional life that would have brought her into contact with different types of people. She had retained a dependence on her mother for practical and emotional support at an age in her life when she might not have expected to be so tied to the maternal apron strings. Particularly hurtful was the manner in which her mother tended to align herself with her husband, seemingly against Millie. This tended to suggest that Millie could not always rely on her mother, one of her few sources of support. Therefore, she did not have these experiences upon which to reflect and draw upon in later life. There were also economic implications associated with her lack of employment, which increased her dependency upon her husband for food and shelter. To be fair, the marital relationship had been compromised on the part of both husband and wife, as neither had experienced the married life that they had expected.

Certainly from Millie's point of view, her expectations of her husband had changed as her illness progressed. She had been discouraged from attempting a second pregnancy only to stand by and watch the next generation of dialysis patients become pregnant and give birth, an experience that she, along with many of the female dialysis patients of her era, had been denied. As her physical health deteriorated, she had worried about her physical appearance and the manner in which this impinged on her ability to care for her family. The subsequent ritual of face cloth washing had been reassuring and comforting to her. It was also an example of how daughters retain an association with their mothers and continue rituals and the use of certain products through the generations. Mothers with unstable renal disease who worry that their daughters might not remember them often draw upon rituals and the use of certain phrases, mannerisms, or practicalities passed down through the generations. I often tell these women that your mother's presence is always with you, in the things that you say and the things that you do, long after you can no longer recall her face or feel her touch.

As we go about the daily business of ours that is renal disease, as

either patients or staff, we will meet many such women like Millie. Women of Millie's era may be incomprehensible to the younger doctors and nurses. Dialysis and transplantation was much less technically advanced than it is now and the options for these patients regarding live or cadaver transplant were more limited and survival rates much poorer. These patients who did not receive successful transplants will often present as physically frail and emotionally exhausted with a tendency toward periods of noncompliance and many will no longer be fit enough for transplant. In many cases, we will never truly understand the full impact of what these patients have endured. Years of dialysis often renders them stoically defensive and private and they will only let you into compartments of their life, on a need-to-know basis. There is a tendency to be judgmental about any erratic attendance and apparent unwillingness to reason with us. However, their point of reasoning is different than ours and is a culmination of years of dialysis. There might be a temptation among fellow patients to look away in case they see what they might become. However, if we treat them with the empathy that they deserve, they can become knowing and supportive to fellow patients and will be more liable to reach out to staff when they need help.

## **WOMEN AND HOMOSEXUALITY**

There is increasing evidence that females who become ill with a chronic illness to reach puberty later (Pozo and Argente 2002). This commonly manifest in terms of compromised relationships with peers, reduced self-esteem, social skills, and body image. They are also more likely than their male counterparts to suffer some psychosocial developmental delay as a result of treatment intervention and side effects (Zeltzer et al. 1980). This commonly manifest in terms of compromised relationships with peers, reduced self-esteem, social skills and body image. They are also less likely to have married or have children (Schover et al. 1990). More specifically, in our work among women who became ill during childhood, irrespective of whether or not they go on to receive a transplant, we have observed a pattern of homosexuality developing as a result of a culmination of the above-mentioned factors impacting upon their lives. This scenario is documented in the case study below.

So far in this chapter we have referred to gender as means to differentiate men and women. However, gender can also be utilized within the context of homosexuality, or gay and lesbian identity. Among homosexual patients who are diagnosed with a chronic illness, there have been higher rates of depression, but fewer problems with partner cohesion,

body image, and sexual activity (Fobair et al. 2001). There is also some evidence of antigay discrimination, which is thought to generate stress and subsequently poor health outcomes. However, consideration of homosexuality within the context of renal disease has been limited to patients with human immunodeficiency virus (Obayomi et al. 1995, Barbiano di Belgiojoso et al. 1998). However, we have not been able to find a single paper regarding the psychosocial aspects of renal disease for homosexual patients.

This is of particular concern as the various pragmatic and emotional necessities that arise during the course of any chronic illness may necessitate homosexuals who may not have been previously open to family and friends about their lifestyle, or even the existence of a long-term partner, to publicly declare their sexuality before they were ready.

Among the social sciences homosexuality is well represented. The homosexual community is as pains to educate its heterosexual counterpart as a means to dispel largely negative myths and misunderstandings. First and foremost, the homosexual community is keen to elaborate on what Marcus (1999) calls the "butch-femme" perception of homosexual relationships, that is, in short, which partner, if any, assumes the husband and wife role; as in heterosexual relationships the traditional male and female roles are no longer so rigid and may shift from one situation to another. However, common to most research is the fact that society is generally hostile to homosexuality. Therefore, many such couples find themselves having to conceal their sexuality at a time when they are struggling to come to terms with their own negative feelings about their sexual orientation. Freud's work on gender development and differentiation has been largely credited with its early pathologization of homosexuality and emphasis on treatment as a cure. However, the continued emphasis placed upon gender roles since its declassification in 1974 in medical literature, has done little to cultivate a climate of cultural diversity. The continued preoccupation with motherhood, which is undeniably a female experience, is suggestive of women's ability to have children as central to the definition of womanhood. However, society not only assumed or expects even that a woman will be a mother, but that she will be in a relationship with a man. The increasing decline in marriage and trend for many women to delay motherhood or choose not to have children at all, has done little to abate such assumptions. In the face of such societal pressure, gender stereotype research among lesbians suggesting that one-third have been heterosexually married, while half of these women would have had children, is not especially surprising (Kirkpatrick 1987).

In the past, lesbians and gay men often found themselves marginalized in society in terms of access to health care (Garnets et al. 1991). However, recent research has been more encouraging suggesting that gays and lesbians are increasingly entering into counseling and psychotherapy treatment with satisfactory outcomes (Jones and Gabriel 1999). Historically, there has been an assumption among psychotherapists that the needs of gay or lesbian patients will be different from their heterosexual counterparts. However, the realization which has been slow to dawn, is that some of homosexuals' problems maybe much the same as those of heterosexuals. However, presenting differences among homosexuals tend to manifest in terms of anxiety around issues such as accepting their sexual identity, bias, or hostility on the part of a heterosexual psychotherapist, family hostility, sexual problems, coping with HIV (Marcus 1999) and body-image disturbance (Hart and Heimberg 2001) and the tendency toward poor self-esteem and high suicide rates among homosexual adolescents (Sanders and Kroll 2000).

Some authors have gone as far as to "classify" problems encountered by gay and lesbian men and women who enter into psychotherapy as either "internal" to the relationship or "external" to negative social biases (Bepko and Johnson 2000). Therefore, in an attempt to address such needs there have been a number of lesbian and gay psychotherapy services and educational initiatives established in the last few years. It has been suggested that specific to lesbians are tensions that arise as a result of dyadic female interactions and internalized homophobia (Igartua 1998). However, on a more positive note a number of research studies among this patient group have identified the emergence of a "family of choice" into homosexual social networks (Green 2000). The "family of choice" is compiled of close friends and associates.

Psychotherapy has undoubtedly made progress toward meeting the needs of homosexual patients and has taken initiatives to sensitize heterosexual psychotherapists to gay and lesbian culture, family-life cultural literacy model. However, homosexual members of the community may still encounter problems finding psychotherapists sensitive to their needs.

## CASE STUDY TWO

### Background Information

Valerie is a 36-year-old lesbian with a transplant of 18 years standing. She had first started dialysis at 8 years of age before receiving a transplant at age 20. Since her transplant, Valerie had suffered from agora-

phobia and had been unable to leave the house for most of this time. This meant that she had been unable to attend the majority of her outpatient visits, despite which her kidney had remained stable and in good health. Valerie had a long-term partner of twelve years, Jane, whom she referred to as her “carer,” who attended to all matters that required leaving the house. Jane was an aspiring writer and had taken to a direct communication of her emotional state with her physician via email. This online interaction had continued for some years until Valerie had requested to see me. The major obstacle to her treatment was the matter of her needing to leave the house to attend therapy, particularly as she lived some distance away from our hospital. At first, Valerie suggested that she send her partner Jane with the idea that she could somehow undergo treatment by proxy. I explained to her that this would not be possible as sessions required direct interaction with the patient. I suggested that a community psychiatric nurse might attend the house to set up a systematic desensitization program to overcome her agoraphobia, prior to her attending the hospital.

Valerie was able to attend my office within three weeks of receiving community psychiatric support. However, this required a complex series of maneuvers involving a sequence of transport arrangements planned with military precision, the execution of which was dependent upon her synchronized arrival at her front door with the taxi, which backed up to the doorstep temporarily blocking the footpath to pedestrians.

### **First Session**

As Valerie entered the room for her first session her affected walk was immediately apparent. She repeatedly made a shrugging movement with her shoulders as she walked, an affect that continued while she was seated. It occurred to me that the movement resembled that of someone trying to shrug off an unwanted weight. Also her slight elfin-like appearance, tailored clothes, and short hair conjured up the image of a young boy as opposed to a young man or woman. Her mother and partner escorted her to this and every other session, waiting in the room while we met. According to my observations, they never spoke to Valerie or to each other or myself and maintained a blank expression and a rigid stature, almost like robots. However, the manner in which they unfailingly accompanied her and always fell into place on either side of her as they sat or walked, suggested that Valerie was knowingly or unwittingly queen bee of this little trio.

Valerie had dialyzed through most of her teenage years and missed



much of her schooling. Most of her fellow patients had been male and she felt that she had very little contact with women at that time, with the exception of her mother. As a result of ongoing dialysis through her teens, Valerie's puberty had been delayed and therefore she had not begun to develop breasts or menstruate until age 20 after her transplant. She felt that this had been just as well as it meant that she was better able to fit in with the boys during dialysis. Indeed she was at pains to point out that she had often been mistaken for a boy at this time in her life.

**Valerie:** *I never really had much to do with other girls. I always had dialysis with the boys. Other girls always teased me for my flat chest and anyway I never had a boyfriend so the whole girly thing didn't seem for me. I was always different, needed to be as different from other girls or else I would not have survived.*

**Psychotherapist:** *Do you think that you were denied the opportunity to try the girly thing?*

**Valerie:** *I didn't really have much choice.*

**Psychotherapist:** *Quite!*

**Psychotherapist's thoughts:** Valerie seems to present as quite a "butch" lesbian while her partner appears more of a "femme" lesbian. Are these roles static or do they shift back and forth in different situations and if so, what particular situations? Her appearance and manner are suggestive of an alignment with masculinity but more importantly, one that is virtually polarized from femininity. Was this decision forced on her following the onset of renal disease? Also, what is it that she is trying to shrug off (reference to her routine shrugging movements which resulted in an almost sideways lurch as she walked), masculinity or femininity?

**Valerie:** Following a short silence. *You mentioned on the telephone that I might want my partner or mother to attend the sessions.*

**Psychotherapist:** *Yes.*

**Valerie:** *Well, I don't.* Silence followed while she stared at the floor deep in thought. *Don't get me wrong, my mother is OK. I mean she's always there, you know, cleaning, hovering,* (delivered with disdain) *but otherwise she is not much use.*

**Psychotherapist's thoughts:** Is it her mother that she is trying to shrug off?

**Psychotherapist:** *Not much use?*

**Valerie:** Shoulders began frantically shrugging as if in an uncontrollable spasm. *You know, pathetic!*

**Psychotherapist:** *Can you tell me a little more?*

**Valerie:** Delivered aggressively. *Well, pathetic is pathetic isn't it?*

**Psychotherapist:** Delivered nonchalantly. *Is it?*



**Psychotherapist's thoughts:** If I can conjure up an image of exaggerated passive femininity for a moment, seemingly like the perception of her mother, it may prompt her to let down her defensiveness for a moment and let me peep inside.

**Valerie:** Almost pressing her nose up against mine almost like one does up against a shop window to view the display. *Are you for real?*

**Psychotherapist:** *What's real?*

**Valerie:** *Bloody guts and balls to get things done, that's real.*

**Psychotherapist's thoughts:** Good job I am not of a delicate disposition.

**Psychotherapist:** Resuming a more animated manner. *Are you saying that your mother is not for real?*

**Valerie:** Delivered in a slightly calmer tone. *She could never stand up to my father. Dropped me in it all the time, as if I didn't have enough to contend with.*

Her mother had been subjected to physical abuse from her husband. Valerie remained in contact with her mother but could barely contain her contempt for the woman who had been unable to leave her abusive husband. Over the following weeks, it became apparent that after transplant she had found herself in what she described as a genderless state: neither male or female. However, as the transplant had stabilized she had started to menstruate and develop breasts and was faced with a gender decision. She viewed this gender decision in terms of becoming feminine and “*pathetic*” like her mother, or masculine and “*powerful*” like her father. She had chosen the later. However, I hypothesized aloud from time to time, that her ongoing shrugging-off movement tended to serve as a means to keep any tendency toward femininity at bay, an interpretation that she denied. She also often referred to her partner in disdainful and distant manner from time to time and I often wondered whether this served to keep her and their femininity at a distance. Valerie supported her partner financially and therefore, economically at least her partner was dependent upon her.

Valerie's gender decision had served to maintain the difference from other women that she had known during hemodialysis and aligned her with the male dialysis community. It had also served to differentiate her from mainstream society. The subsequent hostility of some sections of society toward homosexuality had *driven her underground*. While she was quite open about her lesbianism she came to see mainstream society as hostile toward her, a dangerous place, and had taken refuge in her house. Over time she had become what she called a *hermit*, unable to venture outside of her house without much psychological preening and preparation.

## CONCLUSION

These two cases serve to underline detrimental effects of inter- and intragender differentiation experienced by women with renal disease. However, for both Millie and Valerie, the onset and course of renal disease had served to formulate their profile and experience of femininity, which was largely negative and lonely existence.

While Millie spent much of her time trying to retain her femininity, Valerie chose to deny hers, at least in the conventional sense. Millie experienced the impingement upon her femininity in terms of her roles as wife, mother, and daughter in the most straightforward manner and in a way that the majority of women with or without renal disease might relate to. In addition, she had never really had a social or professional life after marriage that would have brought her into contact with other like-minded or different types of women, although, even if she had formed such relationships, my experience suggests that it is unlikely that they would have endured her illness. Valerie's reproductive aspect of her femininity was delayed as a result of her illness, after which time she aligned herself with men and male power. In contrast to most lesbians with whom I have worked and who spend much of their adult life denying their lesbianism, through fear of losing their job or children, Valerie seemed to spend much of her adult life denying her femininity lest she end up like her mother.

However, common to both women was the presence of the domineering and largely negative effect of their fathers on their own lives and that of their mothers. In Millie's case, this led to her mother being unavailable throughout her illness and her mother's alignment with her husband who was no longer faithful to her. And for Valerie this led to feelings of disdain toward her mother, which combined with the experience of dialysis through her formative years to serve to keep her femininity at bay by aligning with masculinity. This alignment endured despite her experiences of social disapproval toward lesbianism. Indeed her development of agoraphobia served to keep her excluded from this world. Consequently, both women experienced their illness from a point of differentiation from other women (a phenomena not adequately represented in the psychotherapeutic literature) and from men (a phenomena adequately represented in the literature) who appeared to determine the emotional, social, and financial well-being of these women. Despite the implications of renal disease on gender and the social, relational, and economic complexities of these women's lives, their plight remains barely acknowledged in either research or clinical practice.

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## **Chapter 8**

# **RENAL DISEASE AND EATING DISORDERS**

### **INTRODUCTION**

Unlike the majority of emotional manifestations described in this book that are technically unclassifiable, “eating disorders” is an umbrella term for four classifiable disorders used to describe disturbed eating habits. These generally manifest in the general population in childhood or adolescence and persist into adulthood. Eating disorders are subdivided into anorexia nervosa, (starvation), bulimia nervosa (gorging and vomiting), pica (eating nonnutritional substances), and rumination disorder of infancy (regurgitation). However, despite their classifiable status, there is little psychosocial data as to onset, treatment, and outcome among patients on dialysis and after kidney transplantation. Further, we are not aware of any hard data concerning the incidence of eating disorders among renal patients. However, in our experience, it is a significant problem among renal patients that emerges during psychotherapy. If not the primary reason for the referral, these disorders are still usually long-standing in nature. The majority of the literature pertaining to eating disorders and renal patients has focused on biochemical issues (Mira et al. 1984) and the relationship between eating disorders and the onset of renal disease (Abdel-Rahman & Moorthy 1997).

Eating disorders also appear to have become a cause for concern for patients suffering from other forms of chronic illness. Cancer-related anorexia has been cited as one of the most troubling concerns among



patients with advanced cancer and often difficult to distinguish from the loss of appetite, nausea, and vomiting associated with palliative care (Jatoi & Loprinzi 2001). The weight loss associated with anorexia has been associated with cardiac complications (Eidem et al. 2001), while the comorbidity of diabetes and eating disorders is well documented (Herpertz et al. 2000). However, as with renal disease, official statistics as to the prevalence and most effective treatment interventions among this patient group remain illusive.

In contrast, the psychotherapy literature has produced a vast amount of data pertaining to the efficacy of therapy for eating disorders and may provide some inspiration for health professionals working with patients from any of the above chronic illnesses. These include the relational-developmental approach (Maine 2001), antidepressants versus psychological treatments (Bacaltchuk et al. 2001), and other approaches such as empowerment (Ventura & Bauer 1999), attachment processes (Ramacciotti et al. 2001), a combination of cognitive and nutritional therapy (Hsu et al. 2001), family therapy (Lemmon & Josephson 2001), the use of therapeutic e-mailing (Finfgeld 2000), food exposure, and integrative painting therapy (Steinbauer et al. 1999). However, the treatment of choice for eating disorders among the general population is generally considered to be that of Cognitive Behavioral Therapy (CBT) with or without Interpersonal Psychotherapy [IPT] (Dalle Grave et al. 2001) or Nutritional Rehabilitation (Ventura & Bauer 1999).

Eating disorders manifest during adolescence and tend to place importance on body weight and shape. However, our experience of utilizing therapy to treat eating disorders among patients receiving dialysis and after transplantation has suggested that the onset is likely to coincide with the beginning of renal disease, not necessarily during adolescence. While renal physicians have placed emphasis upon body weight (defined in terms of fluid gain), patients tend to be more concerned with body shape (food and commonly centered around the breasts and stomach). We suggest that CBT, a largely inflexible treatment regime, far from being the treatment of choice can actually reinforce the debilitating effect of ongoing adherence to dialysis or the posttransplant regime.

Many of these patients are able to describe quite graphically how they watch their bodies expand (with fluid) in between dialysis sessions and their sensitivity to comments from family and friends. However, by the very nature of renal disease, even the most compliant of patients have little control over their body weight. However, food intake can be curbed, hence asserting some control over body shape. This is particularly important in a society concerned with uniformity of body shape and that

is intolerant of any variant, or difference in bodily form. Given such circumstances, the reader might imagine that the manifestation and treatment of eating disorders among renal patients compile a multifarious and difficult task. However, among renal patients who present with eating disorders, we have found that psychotherapy can go some way toward stabilizing this disorder during dialysis, and with greater progress being made posttransplant. After an overview of eating disorders, we will utilize a case study to advance the understanding of eating disorders in this group of patients. We have differentiated between the onset, maintenance, and outcome of eating disorders among dialysis patients from the general population. We explain why we consider that CBT might not necessarily be the treatment of choice among this patient group and describe interventions that we have found helpful in our practice.

## CLASSIFICATION OF EATING DISORDERS

The Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) refers to the classification of eating disorders as being characterized by “severe disturbances” in eating behavior and in the main, it focuses upon anorexia and bulimia nervosa.

### **Anorexia Nervosa**

Patients suffering from anorexia nervosa are identified by virtue of their inability to maintain a normal (for age and height) body weight, their fear of increasing their body weight, and their being liable to perceived disturbances in body weight, shape, and cessation of menstruation in females. These symptoms are not accompanied by loss of appetite. The primary aim, therefore, of the anorexic patient is that of weight loss and fear of gaining weight. This is achieved by a reduction in food intake, particularly high calorie food, or self-induced vomiting or even laxative abuse. Patients may consider that they are generally overweight or may fixate on certain parts of their bodies. However, one of the major obstacles to treatment, the aims of which are weight gain, is that anorexics view weight gain as failure and weight loss as success. Early manifestations of the disorder usually include the adoption of a limited diet, which is restricted to a few food items. DSM-IV also points to additional aspects of anorexia which may include difficulties of eating in public, feelings of ineffectiveness, need to control the social and physical environment, rigid thought processes liable to inflexibility and limited, or restrained emotional expression and initiative.

Current DSM-IV guidelines suggest that 90% of those suffering from anorexia are women. Although eating disorders have been primarily associated with young girls, both anorexia and bulimia nervosa can develop for the first time during middle age and upwards (ages 40–60). The onset of the disorder during mid- to later life has been associated with the same issues of feelings of unattractiveness and societal pressure as their younger counterparts. However, their position differs in so much as men who mature are considered more attractive, women are considered less so. This dilemma has been referred to as the “double standard of aging” (Sontag 1972). Therefore, women may well become focused on their bodies as a means to retain their attractiveness and their value in society.

### **Bulimia Nervosa**

Patients suffering from bulimia nervosa are characterized by repeated episodes of binge/purge-type behavior to prevent and avoid weight gain. They achieve this end by self-induced vomiting and have a heightened awareness of body weight and shape. However, in contrast to anorexic patients, they maintain a steady and appropriate body weight. DSM-IV stipulates that in order for an individual to be classified as suffering from bulimia nervosa this binge/purge eating pattern must be maintained twice weekly for three months. During periods of bingeing, the individual will usually consume large amounts of sweet or high calorie foods often in a frenzied state. A bingeing episode will come to an end by virtue of self-induced vomiting when the individual feels physically full or becomes uncomfortable, after which relief is almost immediate but may be followed by low mood. Diabetics, an apparently high-risk group for the development of bulimia nervosa, may not take or reduce their insulin to reduce the metabolism of food consumed during binges.

### **Bingeing**

Bingeing is thought to be triggered by interpersonal problems, lack of control over the social and physical environment, intense hunger following dieting, and negative image of body weight and shape. Also, those suffering from bulimia are more likely to have a history of being overweight and depression, most notably dysthymia, than their anorexic counterparts. However, as with those suffering from anorexia, women are more likely to suffer with the disorder, with 90% of sufferers thought to be women. Once again the onset of bulimia is generally during adolescence after a period of dieting.

## **SOCIAL ASPECTS OF EATING DISORDERS**

Research in the field of anorexia nervosa among the general population has consistently pointed to the role of contemporary society and the emphasis placed upon body profile, defined in terms of ideal size, weight and image and this is of course a scenario to which any patient with chronic illness is not immune. The media in particular targets women with numerous dietary regimes and fitness programs aimed at weight reduction (Guerro-Prado et al. 2001). In turn, mental health professionals are finding themselves increasingly inundated with patients suffering from eating disorders, which are difficult to treat, in some cases can be life threatening, from which patients often relapse and which often co-exist with other psychological disorders. The difficulties facing health professionals in treating eating disorders were first highlighted two decades ago by Garfinkel and Garner (1982). They analyzed the outcome of 25 follow-up studies. Their findings suggested that 30% of patients suffering from anorexia were either dead or still in the chronic stage of their illness. Of those who had gained weight, as few as 17%–40% had made a full recovery. Furthermore, the quality of life after recovery tends to be characterized by poor interpersonal relationships, sexual concerns, dependency, anxiety, and depression. Almost a decade later in a ten-year follow-up study, Halmi et al. (1991) were less encouraging and suggested that only 14% of patients ever recovered fully from an eating disorder. The latter was one of a number of studies to suggest that recovery was associated with participation in aggressive treatment regimes. However, comorbidity with other psychological disorders, such as depression, anxiety, obsessive behavior, substance abuse, and borderline personality disorder are frequently present as well. Multiple problems often hamper treatment by complicating clinical presentation and eroding family and peer support (Edelstein & Yager 1992). This does not bode well for renal patients who are particularly vulnerable to develop other psychological problems, thereby rendering themselves liable to developing an eating disorder and further undermine their already vulnerable state.

We have seen in previous chapters how among both renal patients and the general population the body acts as both a vehicle and expression of our experiences, feelings, and emotions. It is through our body that we organize and communicate our experiences, form our attitudes, values, and beliefs and define our internal from our external world. However, a number of psychoanalytical studies have suggested that patients with eating disorders experience a mind- and physical-body split which prevents or impairs them from verbally expressing their feelings (McDou-

gall 1989). Therefore, they have no means of expressing their stress or anxiety verbally, so they channel them through their bodies. They suggested that they “vomit up” their feelings (bulimia). Alternatively, if they try to deny their feelings and physical body presence and form, this might be achieved through starvation (anorexia). The data presented in this book suggests that health professionals treating renal patients would need to be alert to both “vomit” and “starvation” scenarios.

Other theorists have pointed to the role of parents in the onset of eating disorders, which have been presented from the point of gender differentiation of Freudian psychoanalytic theory discussed in the previous chapter. Selvini-Palazzoli (1978) and Johnson (1991) suggested that as a young girl develops an adult female form, she associates and experiences herself as aligned with her mother and is unable to develop her own individuality. In extreme cases, young women may stop eating as a means to halt the development of the female form and thereby differentiates herself from her mother, or in the case of renal patients from dialysis. In such cases, the manifestation of anorexia is paradoxical as if in an attempt to starve herself the young girl is trying to live. For a woman, the dilemma is to find another way to develop her own individuality while retaining some connection to her mother, dialysis, and wider social networks.

In contrast, in a society where mothers continue to take the majority of responsibility for childcare, fathers are often considered by young children to be nurturers of both mother and child. However, as McDougall (1978) points out, the father exists in a “non-mother world,” which might be seen by a young child as altogether more powerful and glamorous. However, the father’s accessibility to his children within family units can often be dependent upon the mother’s ability or willingness to include or exclude him from her world. Exclusion of the father can often deprive a young child of a positive male role model and source of support. In our experience, it is often a father’s lack of self-esteem or lack of stamina as a result of side effects of treatment that prevents him from being the father or husband that he wants to be. Role of the therapist is to try to help the patient bridge the gap between the father that he wants to be and the father that he can be. The role of the father in the primary family social network is discussed in greater depth in chapter nine.

In the last few years there has been increasing interest in eating disorders among males. Jonsson (2001) administered a sociometric questionnaire aimed at determining the attitudes and values of concerning the effect of treatment on 48 teenagers, 28 were boys. The majority of the boys made positive associations with treatment interventions that they

had received and pointed to the need for early involvement of child psychiatry. However, when compared with girls, it was found that boys were much more reluctant to accept inpatient treatment and were less autonomous than their female counterparts. Findings suggested that these boys were more liable to suffer fertility problems in later life. In contrast, O'Neill (2001) presented a single case study of a male anorexic in long-term therapy. The patient associated the meaning of food with his mother and that his "fear" and "confusion" around food represented his feelings for and against fusion with her. However, both these studies are small and therefore their findings should be considered as indicative for future larger scale studies. Increasingly, we have come to understand eating disorders in terms of wider social, political, and economic factors.

Much of the data presented in this section considers patients with a single diagnosis of eating disorder. However, in treating patients with chronic illness and an eating disorder, health professionals will need to draw upon the various aspects and experiences of renal patients described throughout this book as to how the above-mentioned variables might be further compounded in their daily lives.

## **RENAL DISEASE AND EATING DISORDERS**

Much of the data pertaining to renal disease and eating disorders has been concerned with biomedical status (Aperia et al. 1978), prevalence (Brotman et al. 1986), or as a cause of renal failure (Copeland 1994, Abdel-Rahman & Moorthy 1997). Other studies have considered insulin-dependent diabetes mellitus as a risk factor in the development of eating disorders (Engstrom et al. 1999, Herpertz et al. 2000, Nakai & Koh 2001). Much less attention has been paid to psychosocial issues or treatment intervention in this group of patients.

Studies of eating disorders among dialysis patients have generally been limited to the study of malnutrition among this patient group in relationship to low eating drive. However, Bergstrom (1996), although unable to explain apparently lower eating drive among patients undergoing dialysis, suggested that insufficient dialysis, gastric retention, and metabolic effects might contribute to this problem. In contrast, biochemical abnormalities and a reduction in renal function have been associated with ongoing eating disorders (Mira et al. 1984, Boag et al. 1985, Brotman et al. 1986, Copeland 1994, Bergstrom 1996). In one such study of anorexia nervosa, it was suggested that up to 70% of patients were suffering from renal problems (Brotman et al. 1986). The most common indica-

tions of malfunction were a reduction in glomerular filtration rate, renal concentrating capacity partial diabetes insipidus, pitting edema, renal calculi, hypokalemic nephropathy, and electrolyte abnormalities. The authors suggested the need to implement a treatment plan that placed emphasis on stabilizing the nutritional and blood volume status of this patient group. However, they stopped short of actually describing how they might do this. In a report studying the onset of renal failure in four young women with eating disorders, no other causative factor could be found. In addition, they pointed to the existence of long-standing hypokalemia in all 4 women. While 3 of the 4 women studied were found to have below-average-sized kidneys with above average cortical echogenicity and multiple small bilateral cysts. More specifically, Copeland (1994) pointed to the relationship between long-standing laxative abuse by eating disorder patients and the onset of renal failure. As discussed previously, patients with eating disorders often misuse laxatives to rid themselves of excess food. In a study of a 27-year-old woman with a long history of eating disorders and laxative abuse, the author pointed to the role of hypokalemia and volume depletion as leading to a potentially life-threatening situation. We have been unable to find any studies that have analyzed renal function after psychotherapeutic intervention in patients who have eating disorders and are on dialysis.

## **PSYCHOTHERAPY AND EATING DISORDERS**

Psychotherapeutic treatment for eating disorders has been largely centered upon either CBT and/or antidepressant medication. CBT is the behavioral approach that focuses upon the process of learning through operant and classical conditioning, as discussed in chapter one. However, a recent in-depth review of randomized controlled studies of these treatment modalities suggested that a combination of CBT and antidepressant medication was the treatment of choice for eating disorders (Bacaltchuk et al. 2001). Questions have been raised as to the sequence, timing, duration, and choice of pharmaceutical intervention that appears to require further investigation (Mitchell et al. 2001). Nevertheless, during the course of this brief overview, we will present findings from a selection of psychotherapeutic frameworks. All of those have been shown to be both effective among patients with eating disorders.

Tuschen-Caffier et al. (2001) utilized manual-based CBT as a means of both treatment and intervention in a group of 73 female patients treated in an outpatient center for bulimia nervosa. The authors used the number of bingeing episodes, restrained eating, body dissatisfaction, and



depression as outcome variables. They reported significant improvements at termination and at 1-year follow-up, in all outcome variables among the 66 patients who completed treatment. They concluded that manual-based CBT was an effective research tool and means of intervention that was sustained over time. CBT has also been combined with nutritional therapy in a controlled study of 100 female patients suffering from bulimia nervosa. Hsu et al. (2001) compared the effectiveness of cognitive therapy, nutritional therapy, the combination of cognitive therapy and nutritional therapy, against a control/support group. All three psychological interventions as well as support group produced significant improvements in reducing binge/vomit episodes. Whenever there was a cognitive intervention with or without another therapy, the respondents were more likely to show significant improvement, complete the course of treatment and these patients were more likely to remain stable.

In contrast to CBT, the stepped-care approach, which is comprised of self-help and psychoeducational intervention, is more flexible and responsive to individual patient needs (Dalle Grave et al. 2001). Therefore, patients have a personal intervention program, which is styled to their own needs. To date, it is probably fair to say that the stepped-care approach has been used as a second in-line intervention when CBT has failed. However, one of the advantages of this approach is that it consists of a number of treatment modalities including interpersonal therapy, nutritional therapy, education and pharmacological intervention, all of which can be implemented in a patient-specific manner. In contrast, Dialectical Behavior Therapy is a 20-session manualized therapy designed to teach patients to express or block their emotions, as a way to prevent maladaptive eating (Safer et al. 2001). This form of therapy was developed within a psychoeducational framework and as a means to treat eating disorders using emotional regulation. The authors present a single case study of a 36-year old woman with a history of binge eating who had previously undergone 2 years of counseling. However, by the fifth week of therapy, binge eating had ceased and she remained in remission through the course of therapy. At 6 months follow-up, she had reported only 2 binge and purge episodes.

The advent of the Internet has had a great impact upon the delivery of treatment for all psychological problems, not least that of eating disorders. Consequently, there have been a number reports on the use of e-mail therapeutic intervention among this patient group (Finfgeld 2000). Patients made significant clinical improvement and gave positive reports concerning the e-mail sessions; results are promising to warrant further exploration on a larger scale.



The attachment and interaction patterns of patients with eating disorders have been considered at length in terms of treatment outcome. This has manifested in the consideration of the role of marriage, or more specifically marital satisfaction, and severed relationships in childhood (Mahon et al. 2001). Woodside et al. (2000) considered marital satisfaction (defined in terms of physical and emotional intimacy) of patients with eating disorders over the course of intensive day-hospital treatment. The Waring Intimacy Questionnaire was administered to the patients and their spouses at the beginning and at termination of the treatment program. Their findings suggested that patients were liable to record less satisfaction at both the beginning and end of treatment than their spouses. However, the patient's rating did improve over the course of treatment, along with their eating disorder. However, in the absence of long-term follow-up, the authors were unable to determine whether these changes had been sustained over time.

Primary and extended families of patients with eating disorders have long been considered as important factors in the onset and eventual outcome. Yet it is not entirely clear whether maladaptive family interactions and behavior cause the eating disorder or the eating disorder causes behavioral problems. Certainly, it may well be that different scenarios hold true for different patients. However, whichever scenario is applicable family therapy involving an assessment and treatment of the entire family is often put forward as a valuable treatment approach for patients suffering from eating disorders (Lemmon & Josephson 2001).

The dropout rate for treatment of eating disorders is thought to be high, but it is not a well-researched area. Some studies have chosen to calculate dropout rates within the context of their studies (Zeeck & Herzog 2000), while others have attempted to predict pretreatment dropout factors (Mahon et al. 2001) and dropout in relationship to commitment to treatment goals (Mussell et al. 2000). In patients suffering from anorexia nervosa who were receiving an integrated treatment program, reasons for termination of treatment by patients include attainment of target weight followed by patient-initiated termination of treatment (20%) or termination by the treatment team (Zeeck & Herzog 2000). The authors pointed the fact that 43% of their sample continued in some form of treatment after discharge. In a retrospective study of 111 women presenting to an outpatient treatment facility for eating disorders, Mahon et al. (2001) sought to determine pretreatment dropout factors. Dropout was considered in terms of patient characteristics and their perception of the psychotherapeutic alliance. However, the authors found that it was a

combination of patient characteristics and access to the therapist that determined longevity of treatment—namely, witnessing parental separation or other childhood trauma, demographic characteristics, waiting times and distance traveled for therapy determined whether or not the patient would dropout.

Other authors have looked at the effect of treatment, defined not in terms of the efficacy of the various treatment modalities, but in terms of social gain and loss, of their maladaptive eating behaviors upon their social networks. In terms of loss of friendship and support, anxiety and tenuous attachments, fear of abandonment and problems dealing with autonomy serves to isolate women from their peers (Ramacciotti et al. 2001). Such schools of thought have led to the emphasis on altering women's relationship with food, by incorporating their wider social experiences (relationships, powerlessness, low self-esteem) into the treatment plan (Maine 2001).

We have seen above how the traditional manifestation of eating disorders has been considered in terms of the patient's wish for, and fear of, fusion with the mother, the quality and consistency of other relationships including those with the father, spouse and friends and issues of power and control. While there have been a number of approaches to treatment, CBT with or without pharmacological or nutritional intervention has emerged as the treatment of choice. However, while the above findings appear to be heavily weighed in favor of CBT we would urge readers to treat the above positive outcomes with some caution. The variable quality of trials that in the main had been conducted among small sample sizes should be noted. One cannot ignore the fact that the whole-hearted embrace of CBT has come about in part because CBT techniques can be learned in a relatively short period of time and that it is a quantitative research tool that is guided by manuals and are not always sensitive to individual patient experience. There is need for a larger-scale studies and better evaluation of other less-intense psychotherapies which have shown potential and which tend to more accurately reflect the everyday lives and experiences of patients.

## **RENAL DISEASE, EATING DISORDERS, AND PSYCHOTHERAPY**

There are a number of reasons why CBT might not be the best treatment choice in patients with renal disease and eating disorder. First, CBT is generally a rigid and uncompromising regime, not dissimilar to dial-

ysis or the transplant process. If we accept that ongoing exposure to such a regime triggers the onset of eating disorders in some renal patients, then subjecting them to another such regime is hardly likely to be curative. Second, if they are to survive, renal patients will do so through adherence to either the dialysis or transplant regime, therefore they are subjected to repeated stimulus to which they respond with maladaptive eating. According to CBT, if such behavior is ignored and regular eating patterns reinforced, then those eating patterns will prevail. Third, while CBT appears to be able to bring about change of overt, visible behavior, it does not accommodate well the *invisible*, namely the often unvoiced, experience of renal disease. This may not sit well with those preoccupied with quantitative measurement, but as we suggested earlier, many of the psychosocial aspects of renal disease really only lend themselves to qualitative or combined quantitative/qualitative measurement. Fourthly, the highly active CBT therapist style resembles the all-knowing role of the medical doctor, which often is the very dependent experience that such patients are trying to escape.

As the reader will have observed, CBT is very much based in the construct and understanding of present time and does not tend to accommodate the concept of time in terms of the past and the future. This, as we have suggested previously, is a prerequisite to understanding the reality of such patients. In short, it does not allow for the appreciation of the social, emotional, and relational impact of renal disease on a patient's life, over time. CBT has been described more of a mechanical than an intervening framework of comprehension. It aims to mend people quickly through management, control, and follow-up. However, as we have seen so far, there are no quick fixes for renal patients, who will need to live with the reality of their illness for the remainder of their lives. Therefore, they need durable yet flexible solutions to accommodate the uncertain world in which they conduct their lives.

In the following case study, we attempt to advance the therapeutic understanding of eating disorders in renal patients by pulling together the strands of eating disorders and renal disease, in concert with Systemic Integrative Psychotherapy. We will demonstrate the complex manifestation of anorexia in a young female patient and how anorexia served to differentiate her from her mother and sisters, while holding the attention of her partner and medical staff. We describe how she moved from anorexia to intermittent bulimia over the course of two years of therapy and the dilemma of the psychotherapist as she found herself to be unwittingly colluding with the patient.

## CASE STUDY

### Background Information

Sue is a 35-year-old petite woman who had first suffered renal failure at 20 years of age and had dialyzed for 2 years before receiving a transplant. The transplant had been successful and had lasted for 10 years before she had been required to start hemodialysis again at 32 years of age. Although no formal diagnosis was ever attributed to this patient she displayed symptoms of anorexia all of which appeared to coincide with her return to dialysis. Already very petite and slight, she had lost 42 pounds in the first four months of recommencing hemodialysis. We describe how the patient had an intense fear of gaining weight and demonstrated an intensely distorted perception of her body shape. We will also describe how she moved from anorexic- to bulimic-type symptoms as she resumed eating and although great improvements were made toward a more regularized eating pattern, she maintained a fairly restricted diet.

During her first period of hemodialysis she had given birth to a son, followed by a daughter 3 years after her first transplant. Reluctant to return to her unskilled job in a factory, she had begun training part-time as a beautician once the children had started school. She had hoped that a better job would ensure that she could afford to move in a safer neighborhood, but she had been unable to complete this training before her transplant failed. The family lived in a minuscule 1-bedroom thirtieth-floor apartment in one of the most deprived housing estates in Glasgow. She attended dialysis sessions at night in order that she could have the one bed in her apartment during the day to recover. Sue had a long-term partner, Edward—also the father of her children—who lived with her and the children for 3 days and with his mother for the remainder of the week, an arrangement ostensibly necessarily to comply with social security requirements.

We occasionally gained glimpses into her everyday hardship, when she made passing references to her trips to the pawnshop with her jewelry when experiencing financial difficulties. Sue loved to adorn herself in her jewelry and would often appear for her sessions with a dozen or so gold bangles and an assortment of rings and necklaces. Therefore, they were conspicuous by their absence during what we came to politely refer to as *financially challenged* periods of her life. There were also occasions when she was unable to make it to our sessions when the local

drug dealers had temporarily rendered the elevators in her block inoperable, or the debt collectors were being particularly persistent.

Although her social situation was difficult, the concern of the nursing staff was her ongoing weight loss, coupled with successive trips to the bathroom at the end of dialysis, which often coincided with her having eaten a single sandwich. Further exploration of nutrition and emotional issues had determined that there had never been a family tradition of eating a balanced diet. She could not recall herself or any of her family ever eating fruit or vegetables, preferring convenience and highly fatty foods. Also, there was no history from childhood of ritualistic eating or ever sitting down for a family meal. It seemed that each family member ate outside of the home or at different times and it appeared that there was an emphasis upon snacks rather than meals, as neither her mother, father, sisters, nor herself were able to cook. Therefore, the patient had grown up with a limited diet, no cooking skills and a view of food as a means to survival, rather than something to be respected and enjoyed. Sue had continued this pattern of eating through to adulthood and was replicating it with her own children.

### First Session

Sue arrived promptly for her first session, smiling broadly, purposefully removed her coat and sat down in a business-like fashion. I barely had time to introduce myself before she launched into a ten-minute monologue. She told me that her boyfriend, Edward, was waiting down stairs in the car and his parting words had been "*you just make sure that you tell that therapist what's going on in this house.*" It seemed that they had been watching a television show featuring eating disorders between the time of her referral to our service and the initial session. She recalled how she had identified with the guests on the show and had started to feel better disposed to the idea of coming to therapy. With minimal prompting, she went on to describe how she had a fear of becoming *fat, like her three sisters* and had been inducing vomiting after her one and only meal since her second stint of dialysis.

Sue described how the day before a dialysis session, her face would be *puffed up* with fluid. Looking in the mirror at herself with a *puffy face* reminded her of her sisters, *it is like looking in the mirror and seeing my sisters* (a reference to their obesity). She went on to emphasize what she considered to be her childlike appearance, given that she considered that she did not have any breasts. She did this by standing up and brushing her hand down toward her body, to demonstrate how when she

looked down at her body all she could see was a bulging stomach. This *deformity* of shape, as she had come to perceive it, had stopped her going out socially as she felt that she looked a *freak* in the latest fashions.

It became evident to me that despite having lost 42 pounds since recommencing dialysis four months ago it was the patient's perception of her shape, having small breasts, that was her main focal point and more importantly an obstacle to treatment. Further, that if we were going to be able to progress in treatment and explore other aspects of her life, we were going to have to find some working hypothesis regarding this aspect of her body shape. I think that it is important to point out that the patient's breasts appeared to be small, but in keeping with the rest of her body, as she was a very petite and slim lady. However, while the patient perceived them as small there was little that we could do in the context of our therapy together to physically change her shape. We could only hope to change her perception of herself. However, in order to do this we would need a better understanding of her physical perceptions within a wider context—that is, within the context of her daily life, the effect of the perception of others upon her, and other areas of difficulty and distress. We came to accept (for the short term anyhow) that maybe her breasts were not quite as small as she had thought, certainly in proportion to her petite frame, but that her stomach might be a little more bloated than normal, given the dialysis and the extra fluid. Therefore, when she looked down at her body, it was not so much that her breasts were small, rather that her stomach was slightly distended.

Sue went to speak about her childhood and how her mother had been very strict and her father had been an alcoholic. However, she became very angry when she recalled how her mother had left them when she was 20 years old, pregnant and on dialysis, to move to the United States with her brother-in-law. However, she also recalled how her mother had regularly locked her and her sisters in a small room and not allowed them out until they had completed all the ironing and other household work. When her father returned to Scotland, he often came home drunk and violent arguments between the parents had ensued, forcing all four sisters to lock themselves for safety in the same room, where their mother had locked them to do the ironing. After their mother had also left, her 3 sisters had quickly married and this had left Sue at home with a violent father, a young baby, a boyfriend and thrice-weekly dialysis sessions with no hope of a kidney transplant in sight. Sue recalled how she had never had an opportunity to say goodbye to her mother and did not have an address at which to contact her. After a few years she claimed to have lost interest in contacting her mother as she felt that her mother had

never listened to her any way. Also, she had little to do with her sisters as she also felt that they had little time for her and seemed to write her off as some sort of cripple since the onset of her renal failure.

However, at the beginning of our session together, it was the patient's relationship with her partner that was the main source of anguish and therefore of primary interest to me. Apart from the fact that he appeared to be the only ongoing source of potential support and constant adult character in the patient's life, it was the manner and context in which she referred to him that had caught my interest. Despite living in one of the worst housing estates in Glasgow, she always referred to him by the comparatively grand and highly implausible name of Edward when talking about him to me, or within the context of interactions between the two of them. In contrast, when she referred to him out of these two contexts he was more plausibly called Ed. This became even more intriguing when one considered that she consistently designated and referred to herself as the more mundane *Sue* when indeed her medical notes indicated that her name was indeed the more ornamented Susannah. The adoption of such a grandiose name appeared to serve to elevate him to a socially more erudite position, not to others, but to herself and to me, her therapist. The following transcript is taken from the end of our first session together, when I drew this matter to her attention.

**Psychotherapist:** *Mmmh. Edward and Sue.*

**Sue:** Big smile. *Yes, that's us!*

**Psychotherapist:** *Almost like he is your prince* (indirect reference to the prince Edward)!

**Sue:** *Oh, yes he is!*

**Psychotherapist's thoughts:** This lady looks like she is in need of a prince, not like a lady who already has a prince.

**Psychotherapist:** *I was wondering what sort of image a prince conjures up to you, in your mind?*

**Sue:** *Edward told me that he is always there for me if I need him* (trailing off) *whatever that means.*

**Psychotherapist:** *What do you think it means?*

**Sue:** Slightly more edgy. *Well, I know when he is there* (in her flat). *He leaves his things lying all over the place, takes up a lot of room and eats like a horse. I know when he is there!*

**Psychotherapist:** *Sounds like you need someone to be there at the moment.*

**Psychotherapist's thoughts:** Whether it is Edward or not in the long term, seems up for negotiation.



**Sue:** *Yes. Became silent for a few minutes and appeared to be deep in thought. Thing is, he never really seems to settle at the apartment. You know they are always calling him to do this and that. I am never really sure whether I should ask him to do things for us. Like, I am taking up his time.*

**Psychotherapist:** *Who are them?*

**Sue:** *Oh, his mother and sisters! They call him all the time. His sister calls every week on a Thursday at 4.00 P.M. to be collected from the supermarket. If I answer she doesn't say hello or anything. Just (assuming an affected accent) "ready." I ask you, (assuming a distorted face and an affected accent) "ready." He doesn't make me feel as though I could ask him to pick me up from the supermarket; it feels like I would be imposing.*

**Psychotherapist:** *Looking toward Sue for confirmation. You became very angry earlier when you spoke about the way in which your sisters did not appear to take you very seriously.*

**Sue:** *Yes, I know what you are going to say. That Edward and his family don't seem to take me very seriously either. The thing is you see, he leads me on.*

**Psychotherapist:** *Leads you on?*

**Sue:** *Well, for example he says all the right things. Like take money from my account if you need it. But when I did he went crazy. Ranted for weeks. So now I just get on with it myself. (Looking directly at me). I am not very sure of him, am I?*

**Psychotherapist's thoughts:** *I don't want to answer directly so as to lead the patient and I don't want to become a princess in the face of a flaky prince. Also, I am very wary of dethroning Edward as her prince when there is no apparent successor. At this point, I am very mindful of a maxim of an old tutor of mine in New York, don't pull something apart if you can't replace it, or put it back together again.*

**Psychotherapist:** *It sounds as though, that after all this time together (I use the words loosely), that you are still courting him.*

**Sue:** *As she was to do on many future occasions, she appeared not to hear some interventions and abruptly change the subject. Mmmh. How am I doing for time? (reference to her remaining session time).*

**Psychotherapist's thoughts:** *One intervention too far I suspect!*

There appeared to be indications from the beginning of our sessions that any eating disorder might well be a symptom of wider social and emotional issues in Sue's life. Therefore, I used this session to try to determine her perception of reality (social and relational situation) and any disparity between the reality that she puts forward in sessions and vignettes that took place in between sessions and that are subsequently recalled within it and maladaptive patterns of eating. The reader may have noticed a number of contradictions and distortions evident in Sue's life. While it was blatantly obvious to me that she was not overweight, she did have a very real intermittent experience of being overweight (defined in terms of her puffed-up face as a result of excess fluid) in



between our weekly sessions and shortly before each dialysis session was due. The “puffed-up” Sue seemed to trigger in her mind a resemblance of her overweight sisters whom she had spent most of her life being afraid of becoming. It was almost as though she had a sneak preview each week of would she could potentially become (her sister) and this acted as a deterrent against becoming obese herself.

However, dialysis also ensured that she remained in the poverty trap as no vocational skills, ill health and little in the way of child-care facilities combined to keep her on a limited income. Having been unable to complete her training as beautician, it seemed that she had some measure of social, economic, and emotional dependency upon her boyfriend, Ed. Despite his shortcomings, for the majority of the time, Sue needed to believe in what they pretended to have: namely a mutually supported, committed relationship. However, the first of many references to discrepancies between what he said and what he meant (illustrated above by virtue of access to his bank account, coupled with his living arrangements between two households) indicated that the relationship had boundaries, or rather limitations, which Sue learned not to push too hard.

### **Progress of Psychotherapy**

Over the following year that Sue attended therapy, it became apparent to both of us that the onset of anorexia served to legitimize her position of being ill and helped her to retain a childlike appearance. Ed did not seem to consider renal failure and dialysis as an illness, as it was not an illness that is always visibly apparent or appreciated by the outside observer. However, the purpose that it did serve was to ensure that he needed to come to the apartment three nights a week, to mind the children, thereby keeping him close to her. Any attempt to explore the possibility of daytime dialysis and hence ending the need to sleep during the day, thereby freeing up time while the children were at school, was met with a flat dismissal. The anorexia ensured that she retained a childlike appearance and hence provokes in Ed an obligation to take care of her. However, this presentation was somewhat convoluted, contradictory and by no means static in time, as she also hankered after larger breasts as a means to appear more attractive and womanly to him. As time passed, I also came to realize that her eating disorder also served to ensure that she remained in psychotherapy, hence further legitimizing her illness position and retaining my attention.

It was about 6 months into therapy that there began to be a shift in her behavior. The patient started to eat, albeit a restricted diet (fast food)

within a limited time frame (she would not eat before 4:00 P.M. each day) without the need to vomit. Once this pattern of eating started, the focus of treatment shifted accordingly. While we were both aware that a restricted diet and time frame were her way of eating on her terms, under her control, we started to consider what might be so magical about 4:00 P.M. Certainly, dialyzing during the night and sleeping during the day meant that she was essentially working within a jet-lag time frame. However, this did not hold up so well when you considered that she awoke and started her daily routine at midday. It soon emerged that there was a need to earn the right to and be deserving of food.

As we started to work toward building her self-esteem and her right to food, Sue began to introduce a little flexibility in her 4:00 P.M. meal-time. She also developed a craving for iced buns. However, these cravings coincided with a more relaxed, even playful attitude toward food, which was often enacted during our sessions.

**Sue:** *Well, I am able to eat at 1:30 P.M. now, it's getting better.*

**Psychotherapist's thoughts:** Who is she trying to convince, herself or me? I don't want to fall into the approval scenario, but at the same time I want to share in her obvious delight.

**Psychotherapist:** *So, how does it feel to have a more flexible eating pattern?*

**Sue:** *Hunched her shoulders and looked mischievous. It feels good. I am into iced buns at the moment. Once I wake up, I go down to the bakers and buy an iced bun. Then I bring it home and put it on one of my best plates and place it in the center of the table. Then I go about my chores around the apartment and keep peeking at the bun. I am going to have you, I say. Then I eat it about an hour later. The best bit is that I eat it and keep it down.*

**Psychotherapist's thoughts:** An iced bun for breakfast? Diet has not necessarily improved, but she is eating and seems to be refraining from being sick. Also, food seems to have become more precious, treated with respect (indicated by the use of a best plate, in the center of the table) and she appears to have some control over food (*I am going to have you*), as opposed to food controlling her.

**Psychotherapist:** *It seems like food has become less of an ordeal, more fun and enjoyable.*

The iced bun era was closely followed by a fancy for cheeseburgers. She began to describe the same routine each treatment session whereby she would drive to her local burger bar each day at 1:00 P.M. and order the same meal. Far from being irritated by her daily custom, staff at the burger bar were quite amused and began referring to her on first-name terms. I had just started to contemplate weaning her off her penchant for

cheeseburgers onto a more varied diet, when it became apparent that all was not as it had first appeared. The patient arrived for a session accompanied by the manager of the local burger bar that she had been frequenting. However, it soon became apparent, as she started dragging in a chair from the corridor adjacent to my office, that he was not destined to wait outside, but was going to be actively taking part in our session. Some psychotherapists might argue that I should have taken control and excluded him on the basis that he had not been in from the start. However, their determined and purposeful manner tended to indicate that his visit was meaningful and in itself not without purpose. Also, contrary to popular opinion, therapists are only human and my curiosity got the better of me. It was almost immediately obvious that Sue and the manager of the local burger bar, Fred, had not only developed a romantic attachment but had eloped to Gretna Green and gotten married the previous weekend. In effect, Sue was bringing her new husband to me for approval. He was, she claimed her “knight in shining armor.”

It also seemed that this visit was also by way of a “goodbye” to me, her therapist, as they had great plans and she would no longer have time to attend her sessions. However, over the next year she kept in touch by phone and it seemed that things were finally working out for her. She maintained her ideal weight although I remain concerned that she might well be bulimic but she refused any further input. Also Fred gave up his job as manager of the local burger bar and brought a garden center, where they now both work. Her increasing confidence was apparent when she telephoned to tell me that she has a plan to open a little coffee shop within the garden center selling tea and buns. The irony was not lost on either of us. The key to the apparent success and stability of this relationship and Sue’s subsequent improved emotional, social and economic state was determined by the fact that the relationship between Sue and Fred had flexible boundaries that might stand the test of living with the reality of her illness. However, I could not help contemplating that the key to this relationship lay in the difference between a “knight” being an honor that is earned and a “prince” being someone born in the right place at the right time, to the right people—a title that does not necessarily have to be earned. Sue continues to wait for her second transplant 4 years after returning to dialysis.

## CONCLUSION

We have seen above how both anorexia and bulimia nervosa are triggered and maintained by a heightened sensitivity to body weight and

shape. In previous chapters, we saw how renal patients (most notably dialysis patients on fluid restrictions and early posttransplant patients taking steroids) describe their body shape expanding and contracting from day to day. In all of this, all too often, physicians who place emphasis upon body weight (particularly during dialysis) are out of step with their patients who tend to place emphasis upon body shape. Further, the fluctuating body shape or distortions that are synonymous with renal disease, serves to alienate these patients from a society that is preoccupied with ideal body weight and image. Therefore, it is hardly surprising that adult renal patients, with no previous history of eating disorders, are at risk of developing anorexia and bulimia and maintaining of ideal weight through maladaptive eating, as a means to retain the little social standing remaining to them.

We suggest that the reasoning behind the treatment of eating disorders in renal patients is at variance with that of the general population, while a better understanding of the manifestation and maintenance of eating disorders among this patient group might lie in the experience of living with a chronic illness. That is, living in a world that is uncertain, unpredictable, dependent upon their own survival (in face of death of their fellow patients), differentiated (by virtue of their illness) from peers and subjected to an ongoing relentless regime of dialysis and medication over which they have little power. A more enlightening perspective of the manifestation of eating disorders among renal patients, might be to consider not only the effect of maladaptive eating patterns on themselves (empowerment in the face of a disempowerment, but life-sustaining treatment regime), but also on others (fellow patients, medical staff, family, and friends). Our experience of working with this patient group suggests that ongoing eating problems serve not only to empower the patient, but to differentiate them from other patients, while keeping medical staff, family and friends attentive or in close emotional and physical proximity, even if such attention manifests negatively as disapproval.

Therefore, any treatment regime needs to reflect the social, emotional, and relational degenerative effect of chronic illness and the fact that any mental health professional is working with such patients within the confines of an uncertain and restricted reality and not just with patients from the general population. In short, there is only so much potential for change while the patient remains on dialysis. Unyielding treatment regimes that have as their sole focus the consumption of food and weight gain and do not explore the emotional issues are likely to fail and leave already vulnerable patients not only estranged from their therapist, but from renal staff as well.

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## **Chapter 9**

# **ALCOHOL ABUSE AMONG DIALYSIS AND TRANSPLANT PATIENTS**

Alcohol abuse, a maladaptive pattern of alcohol use, is incorporated under the DSM-IV Classification of Substance Related Disorders. In contrast to alcohol dependence, abuse is not concerned with tolerance, withdrawal, compulsive, and repetitive behavior. Rather, emphasis is on irresponsible behavior, unreliability, legal, social, and interpersonal problems. Patients with alcohol dependency are more likely to be referred to the psychiatrist for a more multifaceted program of detoxification and pharmacological intervention, with or without psychological therapies, which is beyond the scope of this book. Psychotherapists however, are likely to be finding themselves regularly asked to treat renal patients who are abusing alcohol as an emotional prop or to reduce anxiety, both during dialysis and after a successful transplant.

Traditionally, alcohol problems among transplant patients have been considered in terms of liver failure (Lucey et al. 1994). However, alcohol abuse has also been associated with medical and psychosocial complications across most fields of chronic illness. There has been a relationship established between pancreatic cancer and ongoing use of alcohol, a situation that is further compounded by smoking (Lagergren et al. 2002). There have also been attempts to incorporate the management of addiction into palliative care among this patient group (Passick & Theobald 2000). Ongoing alcohol abuse not only complicates the progression of cardiovascular disease, but is seen as contraindicated to heart transplantation. However, the indications are that those patients, who do man-



age to abstain from alcohol for a period of time before transplantation, can receive a successful heart transplant (Hanrahan et al. 2001).

Despite alcohol consumption being a significant problem among patients with chronic illness, there has been little documented evidence as to the best means to support or rehabilitate these patients. While there are no statistics pertaining to the incidence of alcohol abuse among the renal population, in our experience, it is a significant problem among renal patients, which often goes undetected and untreated, particularly among those who have lost hope of ever receiving a transplant. Moreover, for those patients who do develop a pattern of alcohol abuse during dialysis and who go on to receive a successful transplant, undetected alcohol abuse can jeopardize the newly acquired kidney. Possibly, for this very reason, we receive more self-referrals from patients after a successful transplant requesting help with alcohol abuse, than any other. Generally, alcohol, which has been used as a means to dull depression and the anxiety that they might never receive a transplant, is utilized posttransplant to lessen any depression and anxiety that they might lose the transplant.

This has led public and professional debate centered upon the morality and justice of allocating scarce organs to patients who have brought about their own illness and who might stand less chance of postoperative survival (Ubel 1997).

The absence of existing data as to the cause, manifestation, and treatment of these patients with alcohol abuse has led us to compile our own program based upon the experiences and progress of patients in psychotherapy. This forms the basis of this chapter. We provide a brief overview of the causes and manifestation of alcohol abuse in the general population and then discuss the manner in which this traditional understanding of alcohol abuse interacts with the adverse psychosocial consequences of renal disease, described throughout this book.

## **ALCOHOL ABUSE**

The DSM IV criteria for alcohol abuse requires that an individual suffer one or more of the below mentioned criteria over a twelve-month period:

1. Recurrent use of alcohol to the point whereby major life roles are disrupted (alcohol-related absences from work, school, home, poor performance at these activities and neglect of self, children, and home).

2. Recurrent substance abuse in physically hazardous situations (driving a car or operating a machine).
3. Recurrent substance-related legal problems.
4. Continued substance use despite suffering from the above-mentioned problems.

Medical complications, which therapists need to be aware of, include cerebral atrophy, cerebellar degeneration, epilepsy, peripheral neuropathy, cardiomyopathy, myopathy, alcohol hepatitis, cirrhosis, gastritis, pancreatitis, peptic ulcer, and nutritional deficiencies.

In the United Kingdom, additional Department of Health guidelines have been drawn up for sensible alcohol use. These stipulate that women drink less than 14 units of alcohol and men less than 21 units per week. It is often more helpful to patients to discuss this in terms of daily units (women 2–3 and men 3–4 units per day), lest they consume a weekly allowance in one session. It should be remembered that these are general guidelines and that for at-risk groups, such as the elderly, pregnant, patients suffering chronic illness, or those on medication, the effects of alcohol are likely to be greater. The Department of Health Omnibus Survey (2000) found that on average young people (16–24 years of age) drink much more than their older counterparts. Men were found to be drinking 15.5 units of alcohol per week and women 7.9 units. The generational difference was particularly marked among women aged 16–24, compared with women of 65 years and over, who only consumed 3.4 units. Further sociological analysis suggested that individuals from the manual classes were more likely than those from the non-manual classes not to drink at all.

In the United States Health Survey (2001) [<http://www.cdc.gov/nchs/fastats/alcohol.htm>] based upon household interviews of the civilian population, 48.4% of the population considered themselves to be “regular” drinkers in contrast to 14.5% who were “irregular” drinkers. The 25–44 year-old age group represented the highest percentage (71.5%) of drinkers. This was particularly so among the white, non-Hispanic population in the same age groups (76.7%). In line with the trend in the United Kingdom, individuals over 65 years of age had the lowest rates of incidence of drinking among all racial groups (Meltzer et al. 2000).

It is especially important that alcohol abuse does not go undiagnosed and untreated among patients on dialysis and after a kidney transplant. The secondary effects of such abuse, such as relationship problems, work- and college-related difficulties, health and legal complications, render an already vulnerable patient group liable to further complica-

tions. As with the general population, it is likely the sedative effect of alcohol and the short-term relief from anxiety, depression and insomnia that makes renal patients prone to abuse. However, over the long term, alcohol may actually cause anxiety, depression and insomnia, as tolerance to alcohol increases. The patients may then find themselves needing increasingly larger amounts of alcohol to achieve the desired effect. This deterioration can lead to alcohol dependence. Over time, it becomes difficult to determine whether alcohol is having a sedative or causative affect upon the patients, depression, anxiety, and insomnia.

## **CAUSES OF ALCOHOL ABUSE AMONG THE GENERAL POPULATION**

There is little consensus among those who treat and research the issues of both substance addiction and abuse as to the causative factor. Suffice to say that is generally considered that it is usually the presence of more than one of a number of variables in a patient's life. These variables as to the cause and susceptibility to developing and tolerance of alcohol are both numerous and complex and such an in-depth discussion is beyond the scope of this book. Therefore, we have limited ourselves to a brief overview of current thinking described briefly below.

### **Individual Differences**

This tends to imply that the patient who is an alcoholic has a characteristic component part that differentiates him or her from the rest of the population; this may be a psychiatric illness, an alcoholic personality, or an allergy. The psychiatric-illness perspective is aligned with the disease or medicalization of alcohol-related disorders, which in turn has been criticized for leading to the disempowering of patients in the face of their illness. In an attempt to further clarify and promote understanding of alcohol-related disorders, the World Health Organization (1977) [Velleman 2001] suggested that alcohol problems be referred to as "alcoholism" or "alcohol-dependence syndrome." Both of these concepts are further characterized by the need to determine the following: the extent to which the individual's drinking behavior is abnormal; whether or not they perceive their drinking as a problem; and tolerance of and withdrawal from alcohol.

### **The Alcoholic Personality**

Theories put forward to either prove or disprove the alcoholic-personality perspective have tended to be centered upon cause and effect.

That is to say, an individual develops problems with alcohol because he or she possesses particular personality traits, or that a particular type of personality emerges following long periods of alcohol use. However, real advancement of this theory has been plagued by the absence of valid personality measures. The classified personality thought to be particularly vulnerable to alcohol problems is that of antisocial personality.

### **Allergy**

The allergy perspective has developed upon the belief that when some individuals are exposed to alcohol, they develop an allergic reaction, or craving for more alcohol. It has also been considered that individuals who have problems with alcohol are somehow deficient, or lack some component part in comparison to their general-population counterparts. Further, it has been suggested that alcoholics have some blood-regulating deficiency, that prevents them from experiencing or observing physiological cues associated with high blood alcohol levels, such as feelings of dizziness, nausea, or hangovers.

### **Parental Behavior**

This is considered one of the foremost determining factors on adult drinking behavior. The parental variable is thought to have its basis in the belief that the key to being an independent and healthy adult is having one's dependency needs met as a child (Wolin et al. 1979). However, children of alcoholics are thought often to be victims of inadequate parenting or emotional neglect. This scenario is often further compounded by the need to adopt prematurely adult roles as a way to fill the gaps in parenting. Also parental values, beliefs, and attitudes toward alcohol may or may not be passed from parent to child depending on the intensity of the attachment, or identification with the adult drinker. Further, children of alcoholics who do not become alcohol dependent as adults may still resort to alcohol as a coping mechanism during times of stress when they themselves reach adulthood. Al-Anon is a self-help group that recognizes the effects of alcohol on the family and aims to support those beset by and promote understanding of this dilemma. However, some children of alcoholics live their whole adult life without alcohol problems, a phenomenon that has never been fully explained.

### **Genetic Vulnerability**

Although there is very little conclusive data, it is generally considered that there may well be some genetic component that renders some pa-

tients more vulnerable to developing problems with alcohol than others. What the genetic component quite is that is transmitted from one generation to the next and how it might be differentiated from familial role models and attachment patterns are unclear. However, one theory put forward has been that children of alcoholics might be more vulnerable to developing the disease because of their decreased reaction to ethanol doses, resulting in them having less awareness of their intoxication.

### **Gender Vulnerability**

The social, emotional, and physiological consequences of drinking are thought to differ for men and women. The onset of physical illnesses secondary to alcoholism (e.g., esophageal varices) is thought to be more common among women. In recent years there have been increases in the number of women suffering from alcoholism, particularly young and single working women. Comparison between men and women needs to take into account, but the tendency is toward women to seek out health care and therefore, have their problems recorded. There is also the matter of society being less tolerant of women alcoholics, who attract more stigma and shame.

### **Organ and Neurological Degeneration**

Ethanol tolerance has been linked to an enzyme deficiency and may account for the differences between one individual and another regarding vulnerability to organ and neurological deterioration. Neurological deterioration, such as Wernicke-Korsakoff's, is characterized by cognitive impairment and is often present in patients with a history of heavy alcohol drinking.

### **The Home Environment**

Alcohol abuse seems to run in families, with children of alcoholic parents likely to abuse alcohol as adults, even when they are raised apart from their biological parents. This familial scenario is thought to be particularly evident among sons of alcoholic fathers. Also, parental conflict, instability, and prolonged absence of or inconsistencies in parenting are likely to contribute to the onset of adult drinking. However, the influence of the family is thought to diminish during adolescence as individual begins to model themselves on their peers. This is also the time

when the peer group will influence the development of attitudes and behavior toward many issues, including alcohol.

### **Cultural Influences**

There have been shown to be specific ethnic and cultural differences in susceptibility to alcohol and its effects. Acute toxic reactions to alcohol have been found in Asians, such as intoxication, flushing, dizziness, and headaches after small intake of alcohol. Also, the distribution of alcohol disorders among different religious groups has been noted. For example, Jews, practicing Protestants, and Asians have lower rates of alcohol dependence, while Native Americans, Eskimos, African Americans, and Hispanic men show a higher incidence of alcohol dependency. The etiology of these trends has largely been attributed to genetic inheritance. Societal influence has been considered in terms of social class or more specifically social deprivation. Also, the historic and religious nature of drinking within specific cultures is thought to influence the individual family unit's attitude to and use of alcohol (Ablon 1986). The wide availability of alcohol in the Western world is often thought to contribute to the problem. Availability to alcohol has also been considered in terms of restricted access, that is to say, in countries like the United Kingdom where access to alcohol in restricted use over short periods of time will give greater effect. Meanwhile the media, in particular the film industry, has been criticized for glamorizing the use of alcohol.

In the absence of conclusive evidence that promotes one causative element over another, those who work with alcoholics tend to work on the basis that any number of the above-mentioned variables can interact to bring about the onset of alcohol abuse or dependence. Rather than consider only the amount of alcohol consumption, we look for evidence of any of the above social, environmental, or genetic factors that might have contributed to the onset of the patient's problems.

### **MODALITIES OF TREATMENT FOR ALCOHOL ABUSE**

The numerous causes of alcoholism along with the various social, economic, and legal problems with which this patient group tend to present, have led to a multifaceted treatment approach that attempts to match the individual needs of the patient to the most cost, and clinically effective treatment package. This generally entails psychopharmacology, at-

tendance at Alcoholics Anonymous (AA) or Al-Anon, and psychotherapy. Psychotherapy as it relates to alcohol abuse and dependence has received a great deal of attention in recent years. Most facilities tend to follow an integrated approach based upon any number of behavioral, psychodynamic, psychoanalytic psychotherapy, delivered in an individual, group of family setting. We will use this section to provide the reader with a brief overview of recent findings with special emphasis on the most statistically powerful and largest evidenced-based study to date—a study that will probably provide the template for future research—the Matching Alcoholism Treatments to Client Heterogeneity treatment (MATCH) from the United States.

### **Cognitive Behavioral Therapy, Motivational Enhancement Therapy, and Twelve-Step Facilitation Therapy**

MATCH utilized three forms of therapy: CBT, Motivational Enhancement Therapy (MET), and Twelve-Step Facilitation Therapy (TSF). MATCH suggested that treatment outcomes could be greatly improved by matching individual characteristics to specific therapeutic approaches. CBT, a behavioral approach aimed at modification of maladaptive behavioral patterns was described in chapters one and eight. However, MET and TSF warrant further explanation.

MET adopts a client-centered approach in an attempt to bring about behavior change, by targeting ambivalence about engaging in treatment and abstinence. This is a highly focused approach generally consisting of up to five sessions in total, including the initial assessment. Information gained during the initial assessment is utilized to form motivational statements, the identification of high-risks situations associated with relapse, and the formulation of coping strategies. Emphasis is on change and sustained abstinence. TSF is considered as preemptive and supportive program parallel to AA. TSF places emphasis upon peer support and mutual acceptance and sharing. The key to AA's success is that it provides mutual support and acceptance in keeping with human needs, factors often absent in the life of the long-term alcoholic. AA aims to dispel the belief in individual self-sufficiency, in favor of surrendering to a power greater than himself or herself. The higher power is not necessarily God, but any power greater than themselves that is meaningful to the member. Progression through the twelve steps entails addressing problematic personality traits associated with drinking, guilt and past misdemeanors.

In the MATCH trial, 1,726 respondents (952 outpatients and 774 aftercare patients) were randomized to twelve sessions of one of the three treatment programs listed above. Patients attended on average two-thirds of their treatment sessions. Drinking behavior was monitored through blood tests, interviews with relatives, and patient self-report. The results indicated significant improvement in drinking behavior, with patients moving from an average of 25 drinking days per month to 6 days per month at the termination of treatment. There were also reports of significant improvement in levels of depression, liver function, alcohol-related problems, and use of other drugs. These findings have also been upheld over time. At one-year follow-up, patients were still averaging 25 alcohol-free days per month (comment, *Addiction* 1999).

However, returning to the main aim of MATCH, namely that of considering whether specific patient characteristics determine outcome, only patients with insignificant psychological symptoms had more abstinent days than others during the first year, when randomized to TSF. Over this time period 87% of patients remained abstinent compared to 73% receiving CBT. In contrast, patients who expressed heightened anger at the outset of treatment and who were randomized to MET had better posttreatment outcomes than patients randomized to CBT, while patients who had entered into the project from after-care programs tended to fair better when randomized to TSF. As predicted, previously low dependence respondents did better in CBT.

### **Group Psychotherapy**

The foremost benefit of using groups among alcoholics is thought to be because they offer a unique opportunity to share experiences and identify with others going through similar experiences; in addition, there is the matter of peer pressure as a means to confront individual patient defenses against abstinence and problem behavior and attitudes. Peer pressure can in addition provide the necessary motivation to attend treatment that can also be an issue for alcoholics. It is also widely considered that group psychotherapy offers patients an opportunity to improve their communication skills. Moreover, many patients will come to group therapy with a negative attitude or experience of their family group and may doubt their ability to function in such a situation again. Acceptance within a group can provide a positive supportive environment from which to build their confidence.

However, there are also disadvantages to group work with patients who are not suitable or for whom it is inappropriate. These include pa-



tients who adamantly resist belonging to the group, those who have a distorted view of reality, or those who tend to be suspicious of other people.

We described the process or mechanics of group psychotherapy in chapter one. Suffice to say, each group takes on a life of its own to some extent by virtue of the group leader's own style, theoretical orientation, and the characteristics of the group members. However, common to the aims of all groups that are conducted to support alcoholics, most are committed to abstinence as a condition of membership. This concept is influenced to a greater or lesser extent by the work of Yalom (1974) who believed in the group as a fundamental agent of change within the present or here-and-now structured time frame. Yalom viewed the group as a social microcosm within which to develop and analyze member's attachments and interactions with each other, as opposed to their relationships outside of the group. Yalom aimed to facilitate such interaction, within a present—as opposed to past and future—time frame, by placing less emphasis upon any inhibition required by usual social etiquette and encouraging frank and honest discussion and confrontation. Yalom also made particular reference to the dilemma of trust facing the group leader in working with alcoholic patients. On the one hand most alcoholics have some level of mistrust of any nonalcoholic and on the other, they can easily allocate trust to the leader, to the point of transferring their dependency for alcohol into social and relational dependency upon the leader.

Other professionals working with alcoholics in both group and individual treatment have pointed to other issues that might characterize the relationship between the group leader and its members. These have included countertransference issues (the emotional response of the therapist to the client) and frustration associated with relapse and the need for assertiveness and social-skills training. Countertransference dilemmas that arise in psychotherapy groups with alcoholics have been considered in terms of the therapist's own feelings of inadequacy in the event of a group member's relapse—a dilemma to which therapists with their own or family history of alcohol abuse were thought to be more vulnerable (Vannicelli 2001). However, Velleman (2001) placed emphasis on practical skills being incorporated into the group structure. This form of training is based upon the assumption that alcoholics have either never been socialized with the adequate social skills for successful living, or have lost confidence in their own ability to conduct themselves in a socially acceptable manner. Valleman analyzed patients' social skills in the group, which he further contemplated in light of the individual atti-

tudes and behavior. He viewed these skills as "micro-skills" or a series of motor skills that included, brief, or prolonged eye contact, respect for person space, pressure of speech, and posture (fists and pointing). All these factors he addressed by introducing an educational component to the group. Many of the skills acquired during social-skills training could be utilized in the assertiveness component of the group. For these purposes assertion was concerned with the adoption of appropriate expression of both positive and negative feelings. Specific exercises described include "feeling talk" (practice expressing any type of feeling), "facial talk" (matching expressions to emotions), "disagreeing" (expression of contradictory opinions in nonaggressive manner), "owning" (speaking in the first person), "self-positives" (the deliverance of positive self-statements), and "accepting compliments" (accept them, hold them, and don't undermine them). The acquisition of appropriate social and assertiveness skills is thought to alleviate or defuse tension and frustration, as well as provide a means to express gratitude and warmth.

Many alcoholics attending group therapy may also be attending AA simultaneously or alternatively will come to group therapy with AA as their sole experience of being in a group. The reader should be aware that simultaneous group membership, of any therapy group, in many areas of mental health is strictly discouraged, on the groups of conflict of interest. However, most professionals who work with alcoholics actually encourage simultaneous membership as a result of the effectiveness of AA and membership in one group might not necessarily adequately address the complex nature of the problem. However, Vannicelli (1986) pointed to the need for group members to distinguish between group psychotherapy and AA from the outset. This means that psychotherapy groups require that members attend every week, and notify the group of their absence and of any intention to discontinue their membership. There is also the matter of the process of the psychotherapy group, or the commitment to examine both past and present experiences, with a view to a better understanding and integration of such into their concept of self. Some patients may find the less-structured nature of psychotherapy groups conflicts with AA or generally find it difficult to combine the two modalities.

### **Family Therapy**

The shift in emphasis on treatment from alcoholic marriage to the family coincided with the trend in utilizing family therapy among alcoholics. In the context of family therapy the individual is viewed as part

of a dynamic system (the family), which is fluid and highly interactive, both inside and outside of the family. Particular emphasis is placed on the assessment of the family, particularly its mechanisms for survival. These mechanisms include the interaction patterns of family members, alliances, allegiances, and particular estrangements and rules (both spoken and unspoken) that serve to maintain equilibrium or not as the case may be.

The primary aim of family therapy is to attempt to correct any maladaptive behaviors and patterns of interaction within the family, which might be facilitating or preventing recovery from alcoholism. One of the key maladaptive roles assumed by family members was identified some time ago, namely that of the "enabler" or the person who protects the alcoholic from the consequences of his or her behavior (Black 1982). Black suggested that "enablers" might present with repressed anger, worry, overt or covert anger, and dependency upon the alcoholic. Specific mechanisms they might employ and to which the family therapist should be alert, include denying, avoiding or rationalizing the problem, as well as protecting the alcoholic from the consequences of drinking or alternatively exerting control over individuals or manipulating situations as a means to limit the amount of alcohol consumed.

Many alcoholics present for treatment convinced that their children are not aware of their drinking behavior. However, when working with family groups that include children, it often becomes clear that the children are only too aware. Similarly, in working with these children in different settings, professionals need to make themselves familiar with possible presentations which might include low self-esteem, aggressive or bullying behavior, withdrawal, generally disturbed behavior, and a deterioration in school activities and work. Psychotherapists can help these children both during and outside of sessions by identifying a supportive attachment figure, whether it is a teacher or a relative.

In contrast to engaging relatives in treatment alongside the alcoholic, members of the patient's social networks have been recruited as a means to engage and maintain the alcoholic in individual psychotherapy. Galanter (1993) developed Social Network Therapy as an outpatient treatment for alcoholics. This entails regular meetings (as opposed to treatment sessions) with the mental health professional, patient and his or her identified social network members. The approach emphasizes the social cohesion of the social network in helping the patient to overcome any denial, illusions of social drinking, and maintaining sobriety. One of our concerns with this approach is that the relatives end up effectively policing the alcoholic, which in turn might cause resentment

on both sides. Also, the approach is very patient-focused and does not take into consideration any part that the social network might inadvertently play in facilitating alcoholism, or indeed whether they are alcoholics themselves. Similarly, the social network is often considered as static, rather than a dynamic entity that does not really evolve as treatment progresses. Therefore, we would caution health professionals using this approach, to be alert to the alcoholic being used as a scapegoat. Similarly, the uncertainty of sobriety shifts in social roles and unfamiliar coping strategies can cause instability, or imbalance within the family. Therefore, there is often an ongoing need for the continuance of psychotherapy after sobriety in order that the family system can be stabilized and supported through uncharted coping mechanisms and ways of interacting.

## **OBSTACLES TO ASSESSING AND TREATING ALCOHOLICS**

As the reader would have probably noticed by this time, psychotherapists are not generally overly concerned with assessments in the orthodox sense of systematic information gathering. As discussed in chapter one, we tend to utilize the initial session to determine suitability for therapy, compatibility of patient and psychotherapist, number of sessions planned, and to establish some level of rapport with our patients. In short, we are happy to let the situation, or the world as the patient sees it, unfold, evolve, be negotiated, contemplated, adapted, and changed as and when the patient is willing to do so. However, psychotherapeutic intervention among alcoholics is one context in which a number of factors need to be determined at the outset. These can be summarized briefly as follows:

### **Determining Extent of the Problem**

The psychotherapist needs to determine the quantity of alcohol being consumed and the effect that it is having upon the patient's life.

### **Insight Into Drinking Behavior**

It will be almost impossible to work with a patient who does not have some level of insight and acceptance that there is a problem with alcohol. A more complex situation might be a patient who flip-flops between acceptance and denial. In such situations the patient will need to be confronted with any inconsistencies or contradictions in his recollection

of events, behavior, and cognitive effects. In such cases the main role of the psychotherapist is to clarify and reiterate the pivotal role of alcohol in the presenting problems.

### **Ambivalence of the Psychotherapist and Other Health Professionals**

Many of us have been indoctrinated with the fact that we should never believe the alcoholic's estimation of how much alcohol is regularly consumed. However, such distortion may come about as a result of a fear of being judged, or that alcoholics are just unable to admit the full extent of the problem to themselves, for fear of being overwhelmed or losing control. We have found that this is a good place to start, as long as patients have some insight into the problems that have developed in their life as a result of drinking and are willing to attend treatment sessions then.

### **Alcoholics' Difficulties with Lifestyle Change**

The extent of the social, economic, and relational disruption caused by ongoing heavy drinking is often so extensive that major lifestyle changes are needed. Patients will need support in building their self-esteem if they are to recognize the need for and implement changes in their lives at a time when they are feeling most vulnerable.

### **Dealing with Relapse**

Psychotherapists who work with alcoholics will need to come to terms very quickly with the reality of relapse in this patient group. Alcoholics presenting to a psychotherapist after relapse need to be nonjudgmental and refrain from seeing it as their own personal and professional failure. Rather the recently relapsed alcoholic is likely to be distressed and needs an opportunity to explore and identify the events leading up to the relapse. While the patient needs to accept responsibility for the relapse, he or she also needs to believe that he or she can learn from the experience and construct coping strategies, and thereby avoid relapse in the future.

## **ALCOHOL ABUSE AMONG RENAL PATIENTS**

Alcoholics and patients suffering from renal disease, before and after transplant, are socially, emotionally, and economically vulnerable. This vulnerability is greatly increased when an alcoholic goes into renal fail-

ure, or a patient with renal disease becomes an alcoholic. It is also not difficult to image how a renal patient might become vulnerable to alcohol abuse. One or more of the deterioratory characteristic variables of alcoholics listed by the project MATCH might easily apply to some renal patients who have endured prolonged periods of dialysis or suffered one or repeatedly failed transplants. Therefore, it might be argued given the positive outcome of the MATCH project that CBT, MET or TSF might well be the treatment of choice for renal patients who are also abusing alcohol. However, while both alcoholic and renal patients live in a world that is unpredictable, unstable and dependent upon their own survival, in working with renal patients they are not necessarily able to manipulate or renegotiate their reality as and when they feel able to so. For example, alcoholics with no history of renal failure who enter into any of the treatments described above open themselves to the potential of recovery from alcoholism and a better quality of life. However, renal patients who are abusing alcohol (often as a means to cope with the uncertainty of dialysis and transplant) may well reach sobriety but a better quality of life may still be unobtainable. Therefore, the emphasis placed upon change in lifestyle, attitudes, and emotions in the above treatments is not always realistic for renal patients, as the abuse often runs parallel with their illness. Our experience of working with renal patients who are abusing alcohol has focused more upon remolding lifestyle, attitudes, and emotions within the confines of the reality of their illness.

Therapists working with renal patients with or without alcohol abuse face many of the obstacles to treatment mentioned above. However, we have discussed previously renal patients' tendency to isolate themselves from other patients on an ongoing basis and to become quite insular—a scenario that many transplant patients equate with survival. Therefore, we have tended to have the best results among this patient group when they are treated individually and when treatment acts as a prelude to AA or runs concurrently with attendance at meetings of that group or some other supportive or collective treatment. The tendency toward premature termination of treatment or relapse among these patients is something to which most mental health professionals have become accustomed. However, it is a state of affairs that is not well tolerated in the medical environment. Such patients are liable to find their physicians unwilling to consider such patients suitable for transplant. Therefore these patients are arguably more vulnerable than the average alcoholic without organ damage and have more riding on a successful outcome to therapy, and a more limited time frame within which to achieve sobriety. Therefore, when working with such patients, we find that they respond to a slightly

more structured frame of intervention than originally acquainted with Systemic Integrative Psychotherapy described in chapter one.

In part, the causative nature of alcohol abuse lies in the patient's experience of living with an ongoing chronic illness, a theme that runs throughout the course of the book. However, we have found that the pivotal factor to expediting insight into alcohol abuse and subsequent sobriety lies in the ability of patients to comprehend the nature of relationships with significant individuals over time and their effect on both their mood and behavior. Many people retain attachments with other individuals out of habit as the years pass and are often unaware of the destructive nature of some of these relationships. Similarly, other social network members that have been deemed problematic or redundant can sometimes have been misperceived or represented by patients. Therefore, the pivotal factor in expediting insight into alcohol abuse is to gain insight into the patient's interactions with members of his or her social networks and to identify maladaptive and manipulative patterns of interactions that serve to collude or antagonize the patient's drinking habits. This may manifest in social network analysis terms as alliances, allegiances, exclusion, collusion, and feelings of difference or inferiority in relationship to other members.

This is in contrast to network therapy described above by Galanter (1993) in which members of patient's social networks are actively called into sessions in a monitoring role to bring about sobriety. We have based our work on social network analysis (Moreno 1934) that does not involve the physical attendance, or even awareness of the patient's social networks. Rather, we seek the compilation of simple social network graphs at strategic points in therapy (apparent contradictions, inconsistencies, or implausibility presented by the patient) to determine how their interaction patterns contributed to the perception of their illness and the onset and maintenance of alcohol abuse. Moreno called such graphs sociograms and used them as a means to chart social configurations. Individuals are represented as nodes and their interactions as interconnecting lines. He placed emphasis upon the position of the node and the relationship between one node in relationship to another, as opposed to the size of the node. Sociograms facilitate the visualization of the channels through which information could flow from one person to another and thereby expedite insight into problematic relationships. Within the social network graph the patient is the primary point of analysis.

Therefore, the patient's social network members enter in the session metaphorically speaking through the patient's perceptive lens and it is



up to the psychotherapist to draw the patient's attention to any apparent contradictions or misconceptions as to presentation and effect. This is a much more gracious manner in which to address alcohol abuse among renal patients who are already very compromised within the family. We have found that any attempt at family therapy results in the patient being credited with being the source of all the family's problems. This puts patients on the defensive and makes them less open to contemplate the effect of specific interactions positive or negative upon their life. We try to keep what little dignity and self-esteem they have intact, while gently but determinedly remolding their perception of the world around them.

## CASE STUDY

### Background Information

Jamie is a 42-year-old single man who arrived at our hospital for a transplant after ten years of hemodialysis at a satellite unit. A few weeks prior to his call for a transplant the physicians had told him that they were having trouble with access and had needed to put in a neckline. Having received a positive cross-match the patient consented to the transplant. However, a little later the patient became very flustered and asked for more time to decide whether to proceed with the transplant. The kidney had already been on ice for some fifteen hours and we were in danger of losing our slot in the operating room, so time was of the essence. It was at this time that the psychotherapist was called to help the patient reach a decision.

The patient was in a 4-bed ward where the curtain was drawn around the bed. The patient was lying in bed with the covers pulled up to his chin and was wearing a white sun hat and a large pair of glasses that seemed to cover most of his face. Jamie had huge brown eyes which remained fixed on the ceiling for most of our conversation. At meaningful points during our initial meeting he would quickly swivel his eyes in a swift half-circular movement, to look first downwards and then toward me on his left side, before returning to the ceiling. The whole image that this scene conjured up for me at first glance was one of physical and emotional entrenchment.

**Jamie:** Staring at the ceiling. *Have you come to tell me whether I should have the transplant or not?*

**Psychotherapist:** His rigid body posture did not indicate that this was to be a bed-perching moment. The patient had quite literally tucked himself away from the world.



To the point whereby he could see the world, but he was mostly obscured from the world by his hat and glasses. Lowering myself onto a minuscule, exceedingly low and decidedly rickety-looking footstool to the point whereby my chin was almost resting on the side of the bed I tried to think of something to say. *Not really.*

**Jamie:** Looking a bit nonplussed followed by his sudden half-circular head movement.

**Psychotherapist:** Very well aware that we had a limited time to decide what to do and that a transplant was his best chance of staying alive. *I was wondering if we could look together* (trying to indicate that this is a joint venture and therefore less frightening) *at what it is that is standing between you and a transplant, right here, right now* (in other words, we can wonder down memory lane post-transplant, but we don't have that luxury in the here and now).

**Jamie:** *I am a drinker?*

**Psychotherapist:** *Can you elaborate?*

**Jamie:** *Truth?*

**Psychotherapist:** *It's the only language we have right now* (a reference to the fortuitous and timely nature of our meeting).

**Jamie:** *I can't sleep and I get really panicky, anxious you know sometimes. Lately I have been getting very panicky because they have been running out of access, this line in my neck is a nightmare. I have been drinking three or four glasses of wine a night just to get off to sleep.*

**Psychotherapist:** *Mmmh.*

**Jamie:** *I used to drink a bit before, you know when I was depressed or anxious it seemed to me in a better frame of mind.*

**Psychotherapist:** *A bit?*

**Jamie:** *A couple of glasses of wine before bed. Once things calmed down a bit, I could stop. But now I'm in debt and in trouble with the housing, you know the rent and stuff. I hate myself for it because all my family are drinkers and I vowed that I would never drink.* Patient became very tearful. *It has only been going on for a couple of months, but I am afraid that I have started on a slippery slope and am going to end up a drunken slob like my father.*

**Psychotherapist's thoughts:** This patient should have been referred when the problem of his drinking first arose. He does not have a significant history of fluid excess, so I do not think that we are looking at alcohol dependence. This is a difficult situation to be in for both the patient and myself. However, we are in this predicament and we need to find some answers and quickly.

**Psychotherapist:** *We have social workers here that can help and advise you with rent arrears. Is this the reason that you are hesitating about the transplant?*

**Jamie:** *Not really, I was about to go to the social and try to sort it out.* Patient stared at the ceiling apparently in deep thought for about five minutes. I was aware of a head peeping through the curtain (probably the operating room technician getting twitchy) I

decided to screen him out and just focus on the patient. He was obviously having some sort of meaningful dialogue with himself and would speak when he was ready.

**Jamie:** Apparently unaware of the tension building up the other side of the curtain. *Thing is, that's how it all starts isn't it?*

**Psychotherapist:** *How and what all starts?*

**Jamie:** *You know the alcohol and stuff. Next thing you know, they are dragging you out off the sidewalk. Like my father and mother for that matter!*

**Psychotherapist:** *It must have been difficult growing up with an alcoholic father (pause to allow patient to acknowledge this to himself), but you are not your father. If you were to come into therapy, with or without a transplant (psychotherapy must not be seen to be conditional to transplant) we could look at differentiating you from your father and try to come to terms with what it must have been like to have a father who was not always the father that you wanted, or the father that he necessarily wanted to be (I always like to give parents a little latitude otherwise there is no room for renegotiation of childhood experiences).*

**Jamie:** *I am scared that I will mess up my life and mess up the transplant.*

**Psychotherapist:** *But you still came to the hospital today!*

**Jamie:** Patient swung round to face the psychotherapist for the first time. He moved so quickly that his hat started to slip over his head and down his face. He immediately tucked in down again. *So?*

**Psychotherapist:** *Trying to look unperturbed. So maybe you have more faith in yourself than you realize.*

**Jamie:** *I don't have very much support either; I live alone.*

At this point we both became aware of a commotion from the other side of the curtain. The curtain stopped short of reaching the ground by about 20 centimeters and the porters feet could be seen pacing up and down, waiting to take the patient to the operating room, or not as the case may be. We were running out of time. But this patient has a checklist and he is going to work his way through it. Directing a nonchalant expression toward the direction of the commotion and then returning to look at the patient.

**Psychotherapist:** *It sounds as though it is as frightening to go forward (to transplant) as it is to stay put (refuse the transplant and stay on dialysis with uncertain access). Whatever you decide to do, I will support you.*

**Jamie:** Very matter of fact but determined. *I might as well go forward then.* Whipping off his hat and glasses with a determined grin. *Hey you're a c-o-o-l lady.*

**Psychotherapist:** Allowing a smile. Upon reflection I am not sure whether this was a to express relief that an informed decision had been made by the patient, or pride that

psychotherapist do indeed feel for their patients when they responsibly contemplate difficult times in their lives, often in impossible circumstances.

**Psychotherapist:** Attempting to stand up from her near crouching position on the footstool and gain some vertical composure in a ladylike manner. *I will take that as a compliment.*

No sooner had I pulled the curtain back than the porters were transferring him onto the trolley to transport him to the operating. As he was be pushed out of the ward and what some might consider in decent speed. Jamie called out to me.

**Jamie:** *Am I ready?*

**Psychotherapist:** *We are ready.* An indirect reference to the fact that we could work together.

**Psychotherapist's thoughts:** We are as ready as we will ever be on the wrong side of a transplant, running out of access.

Jamie received a successful transplant and we started our sessions directly following his discharge. As a condition of treatment, Jamie underwent regular screenings for alcohol during the first 3 months of treatment all of which were negative.

*First Session 3 Weeks Posttransplant:* The patient arrived promptly for his session in a long dark coat that reached his feet and beyond. Indeed it dragged along the ground and from him and at a conservative estimate was about three sizes too big for him.

In the same way that the white sun hat and glasses had obscured most of his face during our first meeting, the coat obscured most of his body. The reader would have realized by now that Jamie overly accessorized and clothed himself as a means to obscure his bodily perimeter from the outside world. As in the instance of the hat and overly large glasses, it was difficult for others to really see his face. This was a strategy that he used particularly when he felt very vulnerable. However, an indication of his growing ease with others was determined when he removed the item of clothing, as in the transcript above. However, during this first session it has become apparent that Jamie has significant feelings of inadequacy. The psychotherapist began to hypothesize that clothes and accessories might also be used as a means to extend his bodily perimeters to the point whereby he appeared to be bigger, taller, and more interesting than he felt himself to be. However, he would always draw attention to his perceived shortfalls maybe as a means to preempt other people drawing attention to them.

**Jamie:** As he sat down his feet did not reach the floor and he looked at me and grinned. *I am a bit short; my feet don't reach the floor.*

**Psychotherapist:** *No.*

**Psychotherapist's thoughts:** Get a grip, what is "no" supposed to mean? "No" your feet don't reach the floor, or "no" you are not too short? However, while I was busy berating myself the patient appeared to have moved on.

**Jamie:** *My kidney is doing really well and I am feeling a bit tired and not able to get about as well as I had hoped, but they say it takes time. We are doing OK.*

Note this early reference to the ownership ("my kidney") of the kidney, but they are not quite fully integrated or as one yet).

**Psychotherapist:** *Sounds good.*

**Jamie:** Looking a bit doubtful. *I haven't been drinking any more but that whole side of my life is a mess—I mean my people are from the lolly farm.*

**Psychotherapist:** *"Lolly farm."*

**Jamie:** *You know it's a whole mess. It's so crazy you couldn't make it up.*

**Psychotherapist:** *It sounds quite a daunting task for you. I mean juggling your medical problems without any apparent support.*

**Jamie:** *You can say that again. Still when you came to see me on the ward, you said that we could meet once weekly for three months and then see how we go.*

**Psychotherapist:** *Of course!*

*Patient stood up and removed his coat.*

During the three months that followed Jamie reflected on a complex past characterized by loss, stress, and seclusion. As the youngest of 3 children with alcoholic parents, he had grown up with the chaos and unpredictability that alcoholism creates within family life. He recalled his father as being quite violent during the last two years of his life (patient was between 10 and 8 years old at the time) and how at one point his older sister and himself had locked themselves into their respective bedrooms for 2 or 3 weeks at a time, not going to school and only venturing out when their mother or elder brother left them food outside on a tray. Jamie recalled how his elder brother had become what he called the "favored son" and had started drinking with his parents at the age of 13. When drunk, his brother would also become violent and often became aggressive toward Jamie. Jamie had lived in a notorious area for drug dealing and high crime. At the age of 16 he had become involved with a street gang at a time of his life that he was never able to recall in any detail during our sessions together. Suffice to say that he

had been sent to prison for 10 years at age nineteen for his part in the murder of a member of a rival street gang.

During his prison sentence, he had spent much of his time in his own cell before being transferred to an open prison where he had learned to use the computer and studied English Literature. At first he had become very claustrophobic in prison but later had come to relish in the solitude. Once he had been discharged from prison he had moved to a different part of the country and had been homeless for a while and lived in hostels. After discharge he had become quite agoraphobic but with support from the same organization had overcome this difficulty. With the help of a support group for ex-offenders he had managed to secure an apartment in a good neighborhood, near to the local park. He had struck up a friendship with his neighbor and they had started to go to antique fairs together on his motor bike. However, within a few years of leaving prison Jamie had developed renal failure and had needed to attend hospital dialysis three times weekly.

**Jamie:** *Thing is it was like going from one prison to another. The routine of prison quite suited me, you know, no time to get into any trouble. I think that I became a bit institutionalized and found it difficult to manage with blank spaces, you know nothing mapped out.*

**Psychotherapist:** *It seems that during periods of your life when you have felt vulnerable you have become quite reclusive, but there have also been quite active times in your life as well.*

**Jamie:** *Yes.*

**Psychotherapist:** *I am wondering which of these experiences, reclusion or active is associated with alcohol abuse.*

**Jamie:** *Active. Yes, definitely active.*

**Psychotherapist:** *It seems like we need to balance routine with spontaneity if we are going to bring some harmony to your life.*

**Jamie:** *I have created a routine for myself. You know what with attending for outpatients follow-up after the transplant and going for walks. I have created my own little world, really. I have got every thing I need in my flat, TV, radio and I am comfortable. I try not to get involved with anyone too much. But they all keep trying to come in; you know Jamie and my sister and now my brother has turned up. But so far I am holding out.*

**Psychotherapist:** *It seems that you have created a sort of prison, outside of prison.*

**Jamie:** *The thing is, whether to let anyone in.*

**Psychotherapist:** *Certainly while you are volatile you might want to be cautious.*

**Jamie:** *Yes, cautious, that's it.*

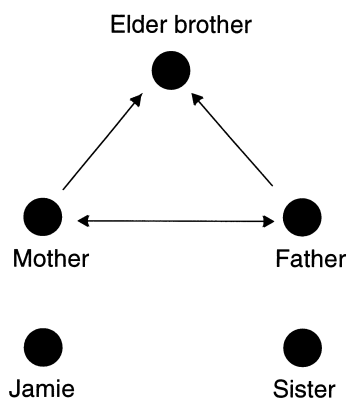
Jamie found it very difficult to come to terms with his turbulent past, particularly his childhood experiences of living with an alcoholic parent.

He seemed to be both afraid and contemptuous of his mother and elder brother and went to great lengths to avoid them. During the time that we met, both his mother and brother had made repeated attempts to contact him and each time he avoided them but he would arrive at the subsequent session in a highly agitated state. On one occasion he had called me from his apartment at the time he was due for his session to inform me that he would be unable to attend as his brother had been hanging around the entrance to his building all day. He sounded quite frightened to leave in case that his brother saw him.

In the following session, prompted by me, Jamie contemplated what might happen if he had left his building and ran into his brother. While this might sound like an obvious question to the reader it appeared to have the effect of pulling the patient up short. The aggressive and bullying persona that Jamie accredited to his brother did not equate with the pathetic figure that he described during our sessions. I suggested while his brother may well have been aggressive in the past (during Jamie's childhood) the erosive effects of alcohol and his poverty-stricken life style may well have taken its toll on his health. I volunteered that both his mother and his brother sounded quite apathetic and so persistent that it might be worth just hearing what he had to say. Jamie's initial reaction to the suggestion of listening to his brother was quite dismissive, he had convinced himself that his brother wanted money and that the family always either "*used*" or "*abused*" him. He retained his perception of his childhood memories of family dynamics, which placed his sister and himself as estranged from his mother and brother (Figure 9.1). As

**Figure 9.1**

**A Sociogram to Demonstrate Dynamics in the Family Home during Jamie's Childhood. An indication that his brother also felt isolated lies in the one way flow of interaction, from the parents to the brother.**



he felt that such a meeting might jeopardize his sobriety we decided to postpone it until he felt more confident. Also, the sister with whom he claimed to be close had never really featured in his recollections.

However, over the following weeks he missed a number of sessions and did not keep his screening or outpatient appointments. After he had missed a second session the psychotherapist had contacted him at home. After his initial defensiveness had subsided he told the psychotherapist that he had not left his flat since the last time that we had met, that he had been drinking and lying on the couch. When asked to sum up his current feelings he said that he felt "*paralyzed*" he knew that he "*had to*" meet with his brother, but he couldn't summons up the courage. I replied that she thought that one of the advantages of being sober and enjoying better health (virtue of a transplant) was so that he could make choices, and not have rhetorical choices forced upon him. Once he realized that he did have a choice, he chose to become much more receptive to the idea until a meeting was arranged.

One of the most remarkable outcomes of the meeting with his brother from the patient's perspective was that his brother also resented his parents. In the past, Jamie had always considered his brother aligned with them and against his sister and himself. His memory of them all downstairs while he was locked away in his bedroom was suggestive of a line of demarcation drawn between the two factions of the family. However, his brother had also been afraid of his parents and being a few years older had been less able to avoid them and therefore had joined them. Indeed he had envied Jamie and his sister for being able to lock themselves away in their rooms. Jamie's brother had been in recovery for some years and was a regular attendee of AA. He had heard that Jamie had had a kidney transplant and had wanted him to go to AA with him. Ironically, he had not contacted Jamie previously because he had also been frightened of letting other people into his life. Jamie had cast his brother in the past and it took some weeks before he was able to contact his brother again. He came to realize that he was not so alone in the world and that he had an elder brother whom he could be proud of, someone to help him through his present tenuous sobriety and someone with whom to build a future. The same intense analysis was turned upon his relationship with his mother who was suffering ill health as a result of drinking.

It was at this point that the patient's sister started to be mentioned during our sessions. However, far from being aligned with Jamie against their brother and mother, the context in which she was placed during his recollections was that of alignment against all of the family. She often featured in a needy or demanding context and the patient seemed to feel

overly responsible or indebted to her. When the psychotherapist brought this to the patient's attention he initially denied it. However, some weeks later he appeared for a session once again in a highly agitated state having had a fight with his sister over her drinking. Jamie recalled that he had not actually seen his sister for many years and their conversations took place by telephone, despite the fact that they both lived quite close to each other. The nature of the interactions usually centered around money, his sister demanding money for alcohol and Jamie trying to be as forthcoming as he was able, on a limited budget. Jamie came to realize that there were two problems with this relationship. First, the mode of the interaction, for example, the telephone, it was almost as though they were both still in their bedrooms at home communicating through the bedroom wall waiting for the commotion to settle downstairs. Second, she appeared to be an alcoholic herself and was not really in a position to offer the support that Jamie felt would be forthcoming if he was able to meet her financial demands. Alcohol had served to alienate all of the siblings in adulthood (present time). Any alliance that had existed in the past had been cultivated by virtue of shared experiences. Indeed, the patient's sister who was herself a heavy drinker and had no intention of stopping in the near future was indeed a risk to his own sobriety and subsequently his newly acquired kidney.

At our 6-month review, Jamie remained sober and had started attending AA meetings with his brother. We came to view our work together as preemptive to AA which was able to offer the ongoing support, structure, and comradeship that Jamie had denied himself for so much of his life, but that he found that he enjoyed. Of course, he had reflected that this was the "*right sort of company*," other alcoholics who had experienced the same problems as himself. We decided to finish our sessions in order that Jamie could devote more of his time to AA, with the understanding that he could return if he wished. Three years after our first meeting, Jamie remains sober and his transplant remains stable. He never physically returned to psychotherapy but I still receive postcards from time to time, keeping me abreast of his AA progress and his studies. Also, I have it on good authority that nowadays he keeps his overcoat for cold days only.

## CONCLUSION

It is our belief that to expose a highly structured therapeutic regime such as CBT upon Jamie and others like him would have both reinforced his sense of institutionalization and further suppressed his spontaneity.



Having spent years living under a harsh prison regime, followed by 10 years on dialysis, arguably another repressive regime, he may never have had the opportunity to gain his confidence at his own pace.

We have seen in previous chapters how transplant patients often find it difficult to regain their confidence and need an opportunity to come to terms with experiences of illness and near death that are not necessarily accommodated by more focused short-term approaches. There is also matter of the uncertainty of the transplant. Any recovery from alcohol among transplant patients needs to be strong enough to withstand graft failure and a return to dialysis. Similarly, any relapse could jeopardize a renal patient's life or the graft. Therefore, in working with such patients, mental health professionals need to be able to intervene in a nonjudgmental and informed manner at short notice, within a psychotherapeutic framework that is responsive to the needs of the patient at a particular point in time.

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