
Psychosocial Aspects of the Organ Transplant Experience: What Has Been Established and What We Need for the Future



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This article briefly describes the current status and limitations of the organ transplant process that has now become a routine medical procedure. The article discusses how transplantation is not a cure for end-stage organ disease but an alternative form of treatment with both potential medical and psychosocial problems. Both transplant candidates and recipients encounter psychosocial problems. The article examines how these psychosocial problems affect transplant patients prior to transplant, immediately following surgery, and posttransplant. The psychosocial problems include psychiatric diagnoses, individual and family adjustment and relationship problems, sexual dysfunction, return-to-work (RTW) difficulties, and compliance problems and variables related to noncompliance. The article also reviews the special problems of pediatric and adolescent transplant recipients. The need for empirically supported interventions is noted in each of the problem areas. The author outlines problems with previous research studies that hamper solid interpretations of the data, and discusses literature suggesting that the psychosocial problems of transplant candidates and recipients are likely to be underreported. The article concludes with recommendations about the need to switch research efforts toward intervention studies in the problem areas already solidly identified by the literature. © 2001 John Wiley & Sons, Inc. *J Clin Psychol* 57: 521-549, 2001

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Close to 22,000 solid organ transplants are performed each year, while another 68,000 patients with end-stage organ disease have been approved for transplantation and are waiting for a suitable organ to become available (United Network for Organ Sharing, 2000b). This article outlines the medical ramifications of end-stage organ disease and the successes and limits of the transplantation process. Transplantation is not considered a cure but an alternative form of treatment presenting the patient with ongoing medical and psychosocial challenges. Although overall quality of life of the transplant patient greatly improves, there are several serious psychosocial problems confronting the patient both before and after transplant. This article reviews the literature on the psychosocial aspects of the patient's experience that shift as the patient undergoes evaluation, the wait for a suitable organ, early posttransplant recovery and the later posttransplant period. Psychological diagnoses in transplant patients range from transient Adjustment Disorders to Major Depression and Post Traumatic Stress Disorder. Depression and anxiety are most prevalent. Psychosocial problems include struggles with family roles and relationships, sexual dysfunction, return to work, compliance to a necessary but challenging medical regimen, and the ongoing possibility of organ rejection. Adolescents face additional challenges such as feeling so different from peers because of body changes that they may risk quitting immunosuppressive drugs that cause the weight gain or other problems. The author discusses evidence suggesting that the presence of psychosocial problems of transplant recipients are under reported. Finally, this article also brings attention to the paucity of empirical data necessary to guide intervention efforts of mental health providers.

Transplant Success and Limits

Efforts to transplant human organs began in the first decade of the last century. These early transplants did not succeed because of a failure to understand the roles that blood type, tissue matching, and immunosuppression played in avoiding rapid organ rejection. Once these problems were understood and resolved, transplantation efforts grew rapidly in the second half of this century, resulting in many milestones in the field of organ transplantation (United Network for Organ Sharing [UNOS], 2000a).

Broad Conclusions from Meta-analyses

Since the 1980s, newer medications have continued to become available and have succeeded in fostering an increase in both the number and successes of organ transplant surgery. Hundreds of studies assessed organ transplant outcomes and the Quality of Life (QOL) of the transplant recipients as well as two meta-analyses (Bravata, Olkin, Barnato, Keeffe, & Owens, 1999; Dew et al., 1997). The Dew analysis included 218 well-designed studies covering almost 15,000 heart, lung, kidney, pancreas, heart/lung, kidney/pancreas, and bone marrow transplants. The Bravata analysis included 49 studies covering more than 3,500 liver transplants. This meta-analysis concluded that the quality of life for transplant recipients is statistically improved for physical functioning and daily activities, social functioning, but not consistently for psychological health. The majority of studies in the Dew meta-analysis found improvements in physical functioning and in overall quality of life. However, some types of transplants have better physical and psychological outcomes. For example, kidney transplant patients have better overall outcome than heart transplant patients. A majority of studies comparing transplant recipients to similarly ill comparison groups (most often those awaiting transplantation) did not show gains in the domain of psychological health. These two meta-analyses offer con-

vincing evidence that the quality of life in organ transplant recipients is greatly improved, but many psychosocial problems remain for certain patients.

Many of the studies in the meta-analyses or Dew and Bravata are found in medical rather than psychological literature, and that distinction reflects some difference in meaning and focus. Medical QOL studies are often focused on the functional abilities of the patient, that is, how well can they perform the tasks involved in daily living, the ability to return to work, and so on. Psychological QOL studies attend more to mood disorders and emotional states (anxiety, depression, stress), and the subjective experience of the patient. Recently there has been a growing discussion in the medical literature that argues for a broadening of the medical understanding of QOL. Some wish to revise the conceptual basis of QOL to include the legitimacy of the patients' subjective perspective as valid (Leplege & Hunt, 1997).

Organ Shortages and Psychosocial Implications

Approximately 22,000 heart, liver, lung, kidney, pancreas, and intestine transplants are performed each year.¹ However, a persistent problem, universally stated in the transplant literature, is a severe shortage of donor organs. Every 16 minutes another person is listed for transplantation and, every day, 13 patients die while waiting for a transplant, for a total of over 4,000 each year (Donor Network of Arizona, 1999). This shortage of available organs contributes strongly to the development of psychological problems for those awaiting a transplant. The recipient is caught in a situation where the technology, improved immunosuppression, and improved survival rates are available, but the certainty of staying alive until an organ is available is unknown.

Efforts to Close the Gap

National and local efforts continue to raise awareness of this shortage, and to promote an increase in voluntary organ donations. People in the transplantation field are generating a number of ways to improve the donor pool. Some proposals suggest strategies to improve the rate of human organ donation. (Abauna, 1997; Dunstan, 1997; First, 1997; Lewis & Valerius, 1999; Write & Cohen, 1997). Others continue to pursue the complex solution of Xenotransplantation (the grafting of organs from one species to another). Xenotransplantation has great potential for increasing available organs, as organs could be grown on demand. However, a major stumbling block, with which the world has no experience, is the possibility of transmitting a disease from the animal species to the human species, with an uncertain chance of a pandemic. (Bloom, Moulton, McCoy, Chapman, & Patterson, 1999; Plat, 1999; Robson, Schulte am Esch, & Bach, 1999; Sim, Marinov, & Levy, 1999). Another alternative is in initial stages of development. The isolation of embryonic stem cells creates the possibility that laboratories may produce perfectly matched tissues for transplantation (Mooney & Milkos, 1999; Pedersen, 1999). Finally, a growing emphasis on living donation is developing in many transplant centers as a way to bridge the gap between supply and demand. Living kidney donorship has been available since the beginning of kidney transplantation, but is receiving a renewed emphasis. One center estimates that kidney transplantation may increase by 20% with the encouragement of the broad application of living donor nephrectomy (Peters et al., 1999). Recently, living

¹In addition to solid organ transplantation, cornea, bone, and tissue transplants affect the lives of approximately 500,000 recipients each year. The present article, however, will restrict the focus to psychosocial problems of solid organ transplant recipients, excluding cornea, bone, tissue, and bone marrow recipients.

liver, lung, and pancreas donations have begun to occur. Here, single lobes of lungs or sections of the liver or pancreas are removed from donors and placed in recipients. Cadaveric livers can also be split, with the larger section going to an adult and the smaller section to a child. Efforts to close the gap between patient need and available organs will continue.

The Patient Experience

Patient Problems

Transplantation does not offer a cure. Transplant patients still face many challenges related to physical functioning, mental health/psychological well-being, and social functioning. This article will emphasize the latter two categories. The two meta-analyses noted above give strong support for consistently positive *physical functioning* and improved overall quality of life. This article will attend to the psychosocial problems of transplant recipients, where the picture is not as bright.

Pretransplant Psychosocial Problems

Chronic illness or an acute episode of disease or trauma may lead to organ failure. Any of these experiences leads to a major disorganization in the world of the patient and his or her family (Goodheart & Lansing, 1996). The family is forced to make many adjustments, including changing roles for family members, fears and anxiety about the future, dealing with losses of body integrity, comfort, independence, autonomy, privacy, and control. There are also interruptions to a family's future goals and plans. Chronic illness often strains relationships with family, friends, and colleagues. All this may be accompanied by loss of income and severe threats to economic well-being. Although these threats and losses hold true for most chronic conditions, there are threats and concerns specific to those facing transplantation. For example, those awaiting transplant do not know when it will happen or if they will survive until an organ becomes available. Immunosuppression increases the risks of serious infections and certain cancers.

This article focuses primarily on the effects of end-stage disease on the psychosocial experience of the patient. The field of psychoneuroimmunology (PNI), however, alerts us to the complexities of the relationship between psychological variables and disease, which are important to keep in mind. PNI provides evidence that the interrelationship between disease and psychological variables is bi-directional. In some conditions, a psychological characteristic or state elicits CNS innervation or hormonal responses that result in immune changes and disease susceptibility (Cohen & Herbert, 1996). Some psychological states can also result in behavioral changes such as poor health practices (e.g., poor diet or smoking) that may have immunosuppressive effects (Cohen & Williamson, 1988; Kiecolt-Glasser & Glasser, 1988). Therefore, we must keep in mind that the interrelationship between disease and psychosocial variables is bi-directional.

Preevaluation

Before transplantation, the patient faces evaluation for suitability as a transplant candidate. This evaluation often brings with it a great deal of psychosocial stress. Patients become very worried about whether or not they will "pass" the evaluation and receive approval for a transplant. Kelly, Bart, and Craven (1992), writing about candidates for lung transplantation, note that patients feel a sense of relief when the evaluation is com-

pleted and they are accepted for transplant. The very act of evaluation for transplant makes the seriousness of the illness very real, undermining any denial used by the patient as a coping strategy. Patients may fear doctors will find them too ill for the procedure, or that some previously undetected organic problem will rule them out. As a result, patients are stressed by performance anxiety regarding the evaluation process.

Postevaluation/Preoperative

Once accepted for transplant, the stress does not disappear. Lung transplants, for example, will need to be near the transplant center for periods ranging from 9 to 24 months (Kelly et al., 1992). If patients live outside the transplant center area, the burden of relocation falls on them and their families. During the wait, hospitalizations are common for pulmonary insufficiency and infections, and anxiety arises about the ability to live until a transplant can happen. The risk of death before transplantation increases as the candidate's wait increases. Those awaiting other organ transplants (e.g., heart and liver) may have to relocate because these organs must be transplanted in a relatively short time. Patients must be able to get to the hospital quickly. Kidneys have a longer viability once harvested, and patients have a somewhat larger window of opportunity to prepare for surgery.

Anxiety disorders were found in 21% of those waiting for a lung transplant (Kelly et al., 1992). Another study (Chacko, Harper, Gotto, & Young, 1996) found heart, kidney, liver, and lung transplant candidates ($N = 311$) to have a high incidence of DSM-III-R diagnoses (American Psychiatric Association, 1987). Sixty percent met criteria for an Axis I diagnoses, 32% met criteria for an Axis II diagnosis, and 25% met the criteria for both Axis I and Axis II diagnoses. This last subgroup had the poorest coping skills and the lowest degree of marital harmony, putting them at high risk for problematic outcome. Note that many studies that cite percentages of diagnostic disorders often do not compare them to normative data or to the rates in the general population. Therefore, it is sometimes unclear whether these rates are average, high or low.

Some patients, awaiting lung transplantation, exhibit extreme anxiety. The anxiety may result from psychosocial factors such as the experience of hopelessness, loss of control or physical confinement due to progressive disability. However, with end-stage lung disease patients, what sometimes appears to be high levels of anxiety may also be the result of the biological presence of PCO_2 , a measure of carbon dioxide in the blood and in the lungs (Kelly et al., 1992).

The patient's life style changes dramatically as the severity of the illness increases. The medical regimen is difficult. Transplant patients also know that someone has to die in order for them to receive a cadaver organ. Sometimes they may even wish an accident to happen, and then experience guilt that they have such thoughts (Kelly et al., 1992). One article has referred to this period of waiting for a transplant organ to become available as the "dance with death" (Kuhn, Davis, & Lippmann, 1988).

In a study of heart patients awaiting transplant, Jalowiec, Grady, and White-Williams (1994) identified 39 preoperative stressors. Among the worst stressors was the fact of having end-stage heart disease and knowing it to be fatal without a transplant. Family worry and uncertainty about the future, loss of control and dependency on others also contribute greatly to distress. While the patient waits he or she is faced with the illness symptoms, the lack of energy for leisure activity, and the constant fatigue. Examining physical complaints, quality of life, and depression in 66 patients waiting for a heart transplant, Zipfel et al. (1998) found statistically significant changes in these patients in

just four months. There were significant increases in depression, subjective physical symptoms, and significant changes in impairment in social activities and everyday life. These rapid changes demonstrate the need for psychotherapy interventions for these patients awaiting heart transplantation. Serrano-Ikkos, Lask & Whitehead (1997) examined 51 children considered suitable for transplantation. Of those examined, 25% had a psychiatric disorder and 60% had a degree of impairment in psychosocial functioning.

Surman (1992) writes about liver candidates waiting for transplant. All patients evaluated for liver transplant were seriously ill, with life expectancy of less than one year. Because medical urgency primarily determines the position on the waiting list for liver transplant, patients often become sicker before their surgery. It is surprising that only 4.5% of these patients exhibited Major Depressive Disorder, while 19.8% had an Adjustment Disorder. Another study, however, found that anxiety in those awaiting transplant was highly likely to be present (Trzepacz, Brenner, & Van Thiel, 1989).

Kidney patients with end-stage renal disease (ESRD) are subject to the strong effects of uremia. With uremia, toxic products in the blood stream affect both the brain and the central nervous system (Lipkin & Cohen, 1998). The symptoms produced by uremia could be confused with symptoms associated with some psychiatric disorders. For example, uremic patients can ramble, have an impaired ability to concentrate, and a poor attention span. They are often lethargic, sleepy, and confused. In addition to these symptoms, the dialysis patient faces physical limitations, dependency, the prospect of never having a full recovery, and often an intense nausea. Many are forced to make social and economic adjustments. As they become more limited, the roles of family members and household often have to change dramatically. They are anxious about the future, worrying about day-to-day living and about the patient's acceptance for transplant, and the uncertain wait for a suitable organ to be available. Patients sometimes worry that their illness makes them a burden on the family or has thwarted important family plans.

Living Donation

If the patient with ESRD can find a living related or unrelated donor, the process becomes more certain, but the quest for a donor poses its own set of psychosocial problems. Lipkin & Cohen (1998) suggest that patients may avoid asking for a living donation for fear of a negative response. They also suggest that relatives sometimes avoid the patient, afraid of being asked to be a donor, and fearing that they will feel guilty if they refuse. Some possible donors may still see the donation as palliative rather than curative, and therefore, not worth the risk. Caregivers sometimes feel guilty or useless if they cannot or will not donate the needed kidney (Lipkin & Cohen, 1998).

Bridges to Transplant

Those awaiting kidney transplant are able to sustain life with either peritoneal dialysis or hemodialysis, and therefore, are at some advantage over end-stage lung, liver, or heart disease. Dialysis patients have a life sustaining procedure, but the literature is clear that they are still in a state of chronic illness with all the medical and psychosocial problems that accompany chronic illness. Some end-stage heart disease patients are bridged to transplant with the aid of left ventricular assist devices (Kormos, Murali, Dew, & Armitage, 1994). Under investigation are liver support systems that will function in somewhat the same way as hemodialysis machines. In this system blood is drawn from the patient

and plasma is pumped through a chamber filled with living liver cells (hepatocytes) obtained from pigs (Lysaght & Aebischer, 1999). Medical improvements continue to raise hope about losing fewer patients before transplant, but the gap between organ availability and need continues to widen.

Psychosocial Evaluation

Many transplant centers have collected data about the emotional and psychological state of potential candidates. Centers hope that the data may reveal variables predictive of good posttransplant medical outcome. The transplant team is challenged, because of the extreme shortage of organs, to decide which candidates are best suited for transplant. However, the predictive use of this data is mixed. For example, some studies found attempts to predict organ rejection based on psychological factors were largely unsuccessful (Canning, Dew, & Davidson, 1996; Steinberg, Levy, & Radvilla, 1981). Although the predictive value of these studies may be limited, knowledge of psychological states is important in informing professionals about the need to stabilize a patient psychologically before and after transplant (Freeman, Westphal, Davis, & Libb, 1995).

Range of Findings

A sample of findings from studies that measured psychological problems will demonstrate the range of psychosocial problems experienced by transplant patients. The nature of these problems ranges from transient Adjustment Disorders (Fricchione, 1989) to more persistent and serious disorders such as Major Depressive Disorder and Post Traumatic Stress Disorder (Dew et al., 1996b). Some believe that unrealistic quality of life expectations on the part of transplant patients was associated with the posttransplant depressive symptoms (Dubovsky & Penn, 1980; Levenson & Olbrisch, 1993).

Kalman, Wilson, and Kalman (1983) used the General Health Questionnaire (Goldberg, 1978) to compare 57 kidney transplant recipients (5+ years postsurgery) with 44 dialysis patients. They found psychiatric morbidity in 46% of the transplant group and 48% in the dialysis group. They found that psychiatric morbidity is high in patients with end-stage renal disease, and that psychiatric morbidity rates are unrelated to the type of treatment (dialysis vs. transplant). Petrie (1989), using the same questionnaire, found that 27% of renal transplant patients had psychiatric morbidity, a rate lower than the 43% found among dialysis patients.

A heart study of 44 Ss showed that at six months posttransplant the patients significantly improved in emotional, domestic, sexual, social, and vocational functioning. However, 25% demonstrated deterioration in psychosocial adjustment, and 11% had increased levels of mood disturbance (Bohachick et al., 1992). Studying heart and heart/lung transplants, Stillely, Dew, Stukas, and Switzer (1999) examined depression, anxiety, and anger-hostility levels. Only the subjects' mean anxiety symptoms were substantially elevated over normative levels. However, nearly half of the Ss showed clinically significant distress in one or more of the three symptom areas. Dew and colleagues (1996b) found the following in 154 heart transplant patients: Major Depressive Disorder, 17.3%; PTSD, 13.7%; and Adjustment Disorder, 10.

Not all studies found troubling psychological problems for transplant patients. For example, Strauss et al. (1992) found "no specifically high incidence of psychopathology." Mai, McKenzie, and Kostuk (1990) found that, overall, the transplant patients ($N = 24$) displayed substantial improvement in psychosocial adjustment and quality of

life in the 12 months following transplant. Fourteen of those Ss had a psychiatric diagnosis pretransplant, and only 5 had such a diagnosis at one year posttransplant. Those with no pretransplant diagnosis did not develop one in the year following surgery.

Simmons, Kamstra-Hennen, and Thompson (1981) found mild depression scores for 71% of the transplant patients, and mild anxiety for 45%. In 1993, Mai reviewed heart transplant patients and found both pretransplant and posttransplant anxiety and depression. The substantial majority in her study were found to have a positive physical and psychological outcome. A minority manifested problems with family conflict and sexual dysfunction.

A posttransplant liver study found that psychological adjustment improved significantly in vocational and domestic environments and in the domain of sexual relationships (Payne et al., 1996). Another liver study found that transplant returns patients to normal or near normal in measures of cognitive capacity, emotional well-being and social, vocational, and behavioral competency (Tarter, Erb, Biuller, Switala, & Van Thiel, 1988).

There is clearly a wide variance in the findings of these studies, possibly reflecting different sample sizes, different measurement instruments (some nonstandardized), and differences in the time of the assessment. These factors make it difficult to distinguish clear patterns of psychological diagnoses or social problems, necessitating a careful assessment of each individual entering the transplant process.

Predictors of Psychosocial Outcome

Some have sought to determine if pretransplant psychosocial states predict posttransplant psychosocial problems. Dew, Roth, Thompson, Kormos, and Griffith (1996a) found overall sample improvement ($N = 72$). However, a relatively large portion, about one-third, showed high distress levels at all time points. Predictors of a diagnosis of depression and anxiety were a history of psychiatric disorder, lower caregiver support, and lower sense of mastery in the initial two months posttransplant. Predictors of anxiety included the three just mentioned, with the addition of younger age, exposure to a major life event involving a loss at the time of transplant, poor self-esteem, and use of avoidance coping strategies. Predictors of depression were close to those of anxiety except that a major life event at the time of transplant was an even stronger predictor, while age and coping strategy did not influence depression.

Canning, Dew, and Davidson (1996) found that employment status and caregiver's health were predictive of posttransplant distress. Psychological history was not predictive. Interpersonal and social support resources in the early transplant phase were associated with distress in both the short term and long term.

Bunzel and Wollenek (1994) attempted to establish predictors of posttransplant outcome in heart patients. They identified a number of variables that had no predictive value, including schooling, occupation, social status, length of stay in ICU or hospital, and the extent of preoperative anxiety or depression. Support by the partner was the most significant variable influencing the clinical success of heart transplantation. Bremer, Haffly, Foxx, and Weaver (1995) assessed patients for health locus of control. Results indicated that control over life dimensions, which includes control over illness, is a significant factor in psychological adjustment in kidney transplants. Others find that locus of control, positive self-esteem, and perceived social support and dispositional optimism are highly related to quality of life (Burckhardt, 1985; Scheier, Matthews, Owens, Magovern, Lefebvre, & Abbott, 1989). One of the most consistent findings across studies is that family and social support is predictive of positive psychosocial outcome.

Posttransplant Psychological Problems

Anxiety at Discharge

Frierson, Tabler, and Spears (1992) and Surman (1992) observed that anxiety often increases when the transplant patient is discharged from the hospital. This increase may result from loss of security provided by intense hospital care and by the daunting adjustment to the posttransplant medical regimen. Kelly et al. (1992) noted that lung transplant patients are also leaving close relationships formed with other transplant patients. Unacknowledged anxiety on leaving the safety of the hospital may manifest in somatic complaints, problems in assuming independence and overinvolvement in the transplant associated community. Patients may also experience some estrangement from the community and family if relatives and others assume that the transplant has returned the patient to a completely "normal" life.

Family Adjustment to Wellness

It was noted previously that the onset of end-stage disease disrupts family life and dramatically alters family roles. When the transplanted patient returns home, a second adjustment in family roles and responsibilities must happen. This transition is not always smooth. Rauch and Kneen (1989) observed that occasionally the spouse attaches to roles he or she assumed during the time of caregiving and is quite reluctant to give them up. Other caregivers find themselves burdened and tired of the caregiving role, and relinquish that role before the patient is able to be self-reliant after transplant (Kelly et al., 1992). In the extreme, the caregiver uses the recovery from end-stage disease as the time to leave the relationship. Some transplanted patients have been in the sick role for a long period of time and find it difficult to give up that role, accept renewed responsibility and become more active in the family (Christopherson, 1987).

Michel and Murdaugh (1987) observed that family members had to adjust to posttransplant expectations, and to modify their expectations to meet the challenge of living with continuing unpredictability. They noted that there is a theme to posttransplant adjustment that couples make, which they refer to a "redesigning the dream." This adjustment moves through stages of *immersion*, *passage*, and *negotiation*, which these authors believe parallel the states of *waiting for transplant*, *hospitalization*, and *recovery*. Rauch and Kneen (1989) spoke of adaptive tasks of heart transplant patients including the grief associated with the loss of the old heart; psychic integration of a new heart, the fear of physiological rejection of the new heart, and continuing possibility of death. Some recipients emphasize spiritual concerns related to the theme of rebirth into new life.

Spousal stress does not resolve with the transplant. Frazier, Davis-Ali, and Dahl (1995) studied 121 transplant patients and spouses and found that, overall, patients were more distressed than spouses, but spouses were equally or more stressed on some issues. Patients and spouses did not differ in terms of marital satisfaction. Patients reported significantly more depression than the spouses. Lower marital satisfaction resulted in higher overall stress and depression for both parties. A less-stressed spouse offered more beneficial posttransplant support.

Intervention in Psychosocial Problems

There is an almost total absence of empirical data to inform the mental health practitioners who work with transplant patients. The need for this data is critical. Many papers cited

have identified the prevalent psychosocial problems in transplant patients, and often conclude that identification of psychosocial factors will be valuable to health psychologists and others in their work with transplant patients. Some literature proposes specific interventions (Abbey & Farrow, 1998; Gier, Lewick & Blanzina, 1988; Juneau, 1995; Littlefield, 1995).

Bright, Craven, and Kelly (1990) suggest that informal social support networks decrease psychosocial stress in lung transplant candidates. They believe that results are even better if complemented with formal interventions. Stewart, Kelly, Robinson, and Callender (1995) describe one transplant center's success with support groups, but argues for the need of empirical validation of such groups. Delmur-McClure (1985) Kirchenbaum (1991), and Littlefield (1995) all recommend the use of cognitive behavioral interventions with different types of transplant patients.

Soos (1992) believes that transplant patients do not require any new type of psychotherapy to deal with stress or other psychosocial issues. That may be true, but it still leaves us with the question of which existing psychotherapy interventions are best suited to the transplant population. Certainly, those providing psychotherapy treatment to chronically ill patients need to be aware of the intrapsychic and interpersonal issues that are likely to arise because of any chronic illness including end-stage organ disease (Goodheart & Lansing, 1996; Soos, 1992). Presently, those treating transplant patients left to rely on clinical experience or to borrow from empirically supported interventions in other situations (e.g., other disease populations) without knowing if the intervention effects will hold true in the transplant population.

Empirical Studies

Bibliotherapy for transplant patients may hold some promise. Hodges, Craven, and Littlefield (1995) provided 11 double lung transplant recipients and 9 support people a self-help book designed to alleviate psychosocial distress and foster adaptive coping. Although the study is uncontrolled and small, it found significant changes in coping strategies.

Cohen, Littlefield, Kelley, Mauer, and Abbey (1998) propose that pretransplant stress management interventions may be productive. They refer to the bibliotherapy study cited above and to studies of presurgical stress management with nontransplant populations (Johnson, 1984; Ludwick-Rosenthal & Newfeld, 1988). These studies found lower stress and arousal levels by providing sensory and procedural information and coping skills or stress management training.

One controlled intervention study for patients awaiting a lung transplant (Napolitano, 1999) used a telephone-based strategy consisting of emotional support and cognitive behavioral techniques. There were significant group effects for general well-being, general quality of life, and disease-specific quality of life. Social support also improved for the treatment group, suggesting that people who have a better sense of well-being may attract better social support.

May (1998) used a control and treatment group with renal transplant candidates. The treatment group was taught cognitive behavioral interventions. Both groups changed significantly over time, with the treatment group showing a larger decrease in state anxiety than the control group.

The literature reflects many references to the value of support groups for both transplant candidates and recipients. Konstam (1995) conducted an intervention study with heart transplant patients and their families. The short-term psychoeducational group dealt

with transitions from health to illness and to the posttransplant state. The group also explored life plans, support systems, and coping strategies. Assessment of mood states identified a significant decrease in anger levels within group members. However, the study suffers from lack of a control group.

McAleer, Copeland, Fuller, and Copeland (1985) identified problem areas in post-transplant heart patients and established support groups designed specifically to address those issues. The authors make it clear that they were operating on subjective investigational methods.

It is common practice for transplant centers to offer some form of support group to transplant candidates and/or recipients. The assumption is that such groups are beneficial to patients. However, there is no research base to validate the presumed value of such groups for transplant candidates and recipients. Support groups for cancer patients have been researched, and this may inform us regarding their possible benefits and limitations for the transplant population. Helgeson and Cohen (1996) reviewed the intervention research of support groups for cancer patients. Cancer patients most strongly desire emotional support (vs. educational or instrumental support), but evidence for the effectiveness of peer discussion groups designed to provide such emotional support is less than convincing. Educational groups did as well if not better than the support groups. They caution, given the importance of emotional support to patients, against discarding the possibility of beneficial effects of such groups. The authors call for evaluations of such groups that are more methodologically sound than those conducted to date.

In follow-up work, Helgeson, Cohen, Schulz, and Yasko (1999, 2000) endeavored to discover which patients benefited from the peer discussion groups and informational groups. In their 1999 study, education-based groups demonstrated benefits for women with early-stage breast cancer. No evidence was found for positive effects of peer-discussion groups, and there was some evidence of adverse effects on vitality and negative affect. The educational-based interventions increased psychological and physical functioning largely by enhancing self-esteem, instilling positive body image and reducing disturbing intrusive thoughts. In their 2000 study, educational groups showed greater benefit on the physical function of women who started the study with less support and fewer personal resources. Peer discussion groups were helpful for women who lacked support from their partners or physicians, but these groups were harmful for women who had high levels of support.

It is uncertain whether this information holds true for transplant candidates, recipients, and caregivers. Given the fact that support groups, informational groups or a combination of the two have become standard practice in most transplant centers, we need to establish which groups have beneficial outcomes for which patients and caregivers.

Posttransplant Sexual Problems

Prevalence of Sexual Problems

Chronic illness in general often induces a loss of sexual libido and activity. Those awaiting transplantation and those transplanted are no exception. Many who study pretransplant and posttransplant quality of life problems point to difficulties with sexual function as a common problem (Littlefield et al., 1996; Mai, 1993; Mulligan, Sheehan, & Hanrahan, 1991; Tabler & Frierson, 1990; Taylor, 1999). As many as 30% of transplanted patients are estimated to experience a sexual dysfunction (Mordkin, 1999). Taylor, although not writing directly about heart transplant patients, finds that sexual problems plague a large portion of cardiac patients. After a cardiac event, many do not return to normal

sexual activity. In a small study of 16 patients transplanted with a new heart and 4 patients awaiting transplant, Tabler and Frierson (1990), found that sexual problems included erectile dysfunction, ejaculation problems, and altered libido.

Body Image and Sexuality

Body image often influences sexual dysfunction. One study indicates that there are sexual fears associated with body image changes (Beer, 1995). Immunosuppressant medications usually are not a direct cause of sexual dysfunction (Raval, 1999), but may have an indirect effect because of unwanted side effects. For example, immunosuppressant regimens include the steroid prednisone, a medication that greatly increases appetite and fluid retention, leading to a puffy moon-like face and often a sizeable weight gain. These physical changes can cause transplant patients to perceive their bodies negatively, and to feel sexually unattractive. Cyclosporine, a standard immunosuppressant, may cause unusual hair growth. Women may have to treat facial hair growth, and many experience hair growth on chests, backs, arms, hands, and legs. Hair growth can also affect body image, leading to changes in perceived sexual desirability.

Medication Side Effects

Many medications play a direct role in a decrease in libido or other sexual problems on the part of transplant patients (McWaine & Procci, 1988). Antihypertensive agents, often necessary for transplant patients, can cause a range of sexual problems (Raval, 1999; Roche Laboratories, 1998). Central-acting hypertensives may cause erectile dysfunction, while beta-blockers have a high incidence of erectile dysfunction and decreased libido. Diuretics have a high incidence of decreased libido, vaginal dryness, and gynecomastia. There are lower rates of sexual dysfunction in other classes of antihypertensives (ACE-inhibitors, alpha-adrenergic blockers, selective beta-blockers, loop diuretics, and calcium channel blockers).

Several medications are given to transplant patients prophylactically, especially right after transplant. Some of these medications may also have a direct bearing on sexual function. Antifungals can cause erectile dysfunction and reduced libido. Although post-transplant depression has a dampening effect on sexual desire and function, care has to be taken regarding the selection of appropriate antidepressant medications if the aim is to restore sexual function. Tricyclic antidepressants (TCAs) are more likely to cause erectile dysfunction, problems with ejaculation, and decreased libido, while selective serotonin reuptake inhibitors (SSRIs) are more commonly associated with delayed ejaculation, inability to ejaculate, and absent or delayed orgasm (Raval, 1999).

Other Sexual Concerns

Some transplant recipients come to perceive their bodies as fragile (Roche Laboratories, 1998), and fear that sexual activity may dislodge organs or stitches, despite information from transplant units that normal sexual activity may resume at a specified time following surgery. Others fear a heart attack or death during sexual activity (Roche Laboratories, 1998; Tabler & Frierson, 1990). Taylor (1999) states that few patients have specific cardiac reasons for limiting sexual activity and believes that there is opportunity here for the transplant team to intervene with support and information (Roche Laboratories, 1998).

Anxiety and fear may also intrude on a couple's intimacy. Patients considered for transplant have an end-stage disease, meaning that the transplant is the only alternative to inevitable death, and the only hope for a return to somewhat normal health. A spouse may detach emotionally from the gravely ill person, preparing for the possibility of death. This possibility is very real, because of the shortage of transplant organs and the fact that over 4,000 patients die annually before receiving a transplant. A transplant candidate may also have witnessed the death of another candidate, bringing the issue very close to home. Once a successful transplant happens, the spouse may have a difficult time reestablishing pre-illness levels of attachment, and this struggle may manifest in a strained marital and sexual relationship.

Effects of Disease on Sexual Function

The end-stage diseases necessitating transplantation also cripple sexual behavior. Glass, Fielding, Evans, and Ashcroft (1987) compared dialysis patients with kidney transplant patients and found that those on dialysis were less able to gain and maintain erections than those who had been transplanted. They also found that those on dialysis had intercourse less frequently than those transplanted. Mordkin (1999) believes that nearly half of all renal transplant patients experience erectile dysfunction.

Discussing Sexual Problems

Patients often do not bring up sexual problems (Frierson et al., 1992; Raval, 1999), and doctors do not facilitate those discussions (Raval, 1999; Roche Laboratories, 1998; Tabler & Frierson, 1990). Tabler and Frierson (1990) propose several recommendations to the transplant team that would facilitate a better response to the extensive sexual problems of transplant patients and spouses. These recommendations apply equally as well to therapists, counselors, and social workers. Obtain a routine sexual history of both pretransplant and posttransplant patients and maintain a heightened awareness about the increased probability that these patients may have sexual problems. Be aware that this population of patients is often depressed (Dubovsky & Penn, 1980; Rodin & Abbey, 1992), and aggressively treat depression's dampening effect on libido. Attend to the needs of the spouse as well as the patient, referring them to appropriate peer support groups or psychotherapy. Supply appropriate didactic material on illness and sexuality to both the patient and the spouse. Explore the possibility of adjusting medications where that is possible, and finally, address one's own level of comfort in discussing sexual problems.

Intervention Studies

Searches of both the medical and psychological data bases fail to reveal any controlled intervention studies designed to improve sexual dysfunction or to improve coping with sexual problems in either transplant candidates or recipients.

Return to Work

Difficulties in Returning to Work

The goal in performing organ transplantation is to return the patient, as closely as possible, to normal functioning in terms of physical health, mental and emotional well-being,

and social functioning. Social functioning includes a return to productive employment. Winsett (1998) found that patients who had an identifiable support person, no other chronic illness or who were employed all showed significantly better ($p < .05$) adjustment scores than their counterparts.

Studies have gathered data on rates of return to work (RTW), and have attempted to understand factors influencing those rates (Adams, Ghent, Grant, & Wall, 1995; Craven, Bright, & Dear, 1990; Evans, 1995; Fisher, Lake, Reutzler, & Emery, 1995; Hunt, Tart, Dowdy, Batte, Williams, & Clavien, 1996; Kavanagh, Yacomb, Kennedy, & Austin, 1999; Littlefield et al., 1996; Manninen, Evans, & Dugan, 1991; Matas et al., 1996; Meister, McAleer, Meister, & Riley, 1986; Newton, 1999a, 1999b; Paris et al., 1992, 1993, 1998; Thomas, 1996). A look at return-to-work rates (RTW) found in most of these studies reveals that posttransplant employment falls far short of optimal levels. Paris and colleagues (1992, 1993, 1998) studied RTW rates in both heart and lung transplant patients. The return-to-work rate for those medically able to work was 37% in a lung study and 55% in a heart study. In the lung study, 38% were medically able to work, but were unemployed, and in the heart study, 36% were in that category. Twenty-nine percent of the lung transplant patients qualified as disabled, while a lesser 13% of the heart transplant patients were. Retirees accounted for 10% of the lung transplants and 6% of the heart transplants.

Botsford (1995) reviewed the literature on heart transplant recipients RTW and found that the rates ranged from 21 to 87%. Large ranges are also found in other types of transplant patients. Botsford outlined several possible causes of such wide ranges. Some studies measure those who have returned to work against those who were working prior to transplant, while other studies measure those who have returned to work against the total number of recipients. Higher RTW rates will result if the number of those working before transplant is used. Different centers use different selection criteria for acceptance for transplant, and these differences may be reflected in RTW rates (Olbrisch & Levenson, 1991). Botsford found that sample sizes varied widely, ranging from 11 to 250. Finally, there is a wide variation in the time of date collection, which Botsford found ranged from two months to 14 years.

Variables Associated with Return to Work

Return to work is an important issue. The ability to be gainfully employed is associated with a person's psychological well-being. For example, in a study of transplant patients comparing those working, those not working, those disabled and those retired, Duitsman and Cychosz (1994) found that those not working had significantly higher rates of psychosocial problems than those working, retired, or disabled.

Several researchers have been interested in determining variables predictive of the transplant patient's return to work. Paris and colleagues (1993) found several factors influencing the return to work. These factors included self reports of being physically able to work, no loss of health insurance, longer length of time after transplantation, educational level of more than 12 years, no loss of disability income, and shorter length of disability before heart transplantation. This information could accurately profile 91% of the patients employed. A 1992 study, also by Paris and colleagues, found similar results in heart patients. Meister and colleagues (1986) examined heart transplant patients' return to work. Their analysis identified four major variables predictive of work status: age, length of disability before transplantation, control over working conditions including redefinition/discrimination, and type of health insurance including cost of medica-

tion. Those unable to return to work because of loss of insurance coverage are termed by Meister as "insurance disabled." Thomas (1996) supports the conclusion that many do not return to work because of the possibility of losing insurance benefits or health benefits. This finding is also supported by Markell and colleagues (1997). They found that 57% of renal transplant patients ($N = 58$) were not working. In both the employed and unemployed groups 80 to 90% were insured by Medicare, with the second greatest number insured by Medicaid. Of those insured by Medicaid, 67% reported that their decision not to work related to fear of losing their Medicaid benefits because they could not afford the immunosuppressant medications without it. These studies make a case that transplant patients often do not return to the work force because they cannot risk the loss of insurance benefits provided by disability.²

Some studies have found that pretransplant employment was a strong predictor of posttransplant RTW (Hunt et al., 1996; Paris et al., 1998). The Hunt study found that employed and unemployed liver transplant patients showed no significant difference in age, education, gender, marital status, race, family coping skills, or cause of liver disease, socioeconomic status, or spouse's employment. This same study is interesting in that 80% of those not returning to work cited "problems with their health" as the reason, although objective medical evidence found their health to be good to excellent. The employed patients' health perception had marked differences from that of the unemployed group. Health perception was also important in another study (Paris et al., 1998). In this study of lung transplants, self-reports of being physically able to return to work were predictive of actual return.

Newton (1999a), while finding that only 63% of the sample had returned to work, established that higher levels of "hardiness" and a higher "sense of coherence" related to those working. A Canadian study by Adams and colleagues (1995) found that 43% of liver transplants were unemployed. The reasons given for unemployment were: not well enough to work (18%), early retirement (8%), return to school (3%), family reasons, (3%), no work available, and chose not to work (3%). Loss of insurance coverage or loss of disability are noticeably absent as reasons given in the Canadian study. There also appears to be another subgroup composed of patients needing retraining and often lacking information as to how to make that happen in their lives (Winsett, 1998).

Intervention to Improve Return to Work

Literature searches found no interventions studies designed to improve return to work rates in transplant patients. Winsett (1998) summarized the efforts of the Vanderbilt transplant program to identify major problems of transplant recipients. They proposed to design intervention studies to address these problems, including return to work rates. The results of these efforts have not been published. The existing literature has been able to profile those who are most at risk for not returning to work. For the present, social workers and others must rely on clinical experience or on intervention studies with other populations of patients.

²Medicare has paid 80% of the cost of the immunosuppressant medications for the first 36 months following the date of transplant. It does not pay for other medications. The 1999 Congress passed legislation extending payment for immunosuppressant medications to 44 months, still far short of the average life of an organ transplant. The 1999 Congress also passed legislation allowing those on disability to buy into the coverage extended to patients on disability, thus making it possible for many to consider a return to work. States must still opt to participate in the Medicaid portion of this program.

Organ Rejection and Compliance Problems

Immunosuppression

Immunosuppression and organ rejection have psychosocial implications for transplant patients. Transplanted organs, whether they are cadaveric or from living donors, are always "borrowed." That is, the immune system will always see these organs as foreign tissue and will do its best to reject that foreign tissue. Therefore, immunosuppression is necessary for the entire life of the organ graft. Sometime organ rejection is explainable because of noncompliance to the medical regimen while other organ rejection is unexplainable (First & Singer, 1996). There are cases where the patient is compliant, where the blood levels of the immunosuppressant medications are on target, where there has been no medical event to explain the rejection, and yet the body rejects the transplanted organ.

There are three kinds of rejection episodes: hyperacute, acute, and chronic. Hyperacute rejection is very rare, and happens either during surgery or in the first few hours after surgery. It results in the immediate and complete failure of the transplant organ. Careful donor to recipient matching, newer immunosuppressant medications, and good preparation of the donor organ before surgery make chances of this type of rejection minimal. Acute rejection, a more common form, is most likely to happen during the first few months posttransplant with the risk decreasing over the course of the first year. A year free of rejection episodes generally bodes well for the future, but does not eliminate the rejection possibility. Acute rejection episodes are treatable, sometimes requiring hospitalization. Chronic rejection usually occurs after the first year, and can extend for months or years. The cause is often unknown and difficult, if not impossible, to treat.

The implications of a rejection episode are enormous. If a rejection episode ends in the shut-down of the graft, the patient returns to an end-stage disease and faces the possibility of death. End-stage renal disease patients can return to dialysis and can begin the wait for another suitable organ. Other organ transplant patients (liver, heart, lung) can also be relisted for transplant, and second and third transplants do happen. However, these patients do not have the same life-bridge afforded by dialysis.³

The patient's role in preventing rejection is extremely important. Patients have the responsibility of taking their immunosuppressant medications very consistently. No one knows the exact number of missed or late doses needed to activate a rejection episode (Coffey, 1999). Transplant patients also have the responsibility to keep lab appointments to allow proper monitoring of medications and detection of any rejection problems.

Medication and Medical Regimen Compliance

Researchers have examined compliance rates among transplant patients, and have attempted to identify factors that contribute to medication compliance. Poor medical compliance is indicated in a large proportion of deaths occurring subsequent to initial recovery (Dew, Dormos, Roth, Murali, & DiMartini, 1999). These researchers found that noncompliant recipients were at risk for an acute graft rejection at a rate of 4.17 times greater than those who were compliant. The risk of cardiac allograft disease (CAD) was elevated by persistent depression, persistent anger/hostility, or medication noncompliance. The risk of

³Retransplantation occurs across types of transplantation. The latest data is from 1998, and provides information about the percent of all transplants that are retransplants. This information is provided by UNOS (personal communication): heart/lung, 2.7%; heart, 2.8%; kidney, 12.2%; liver, 11.6%; lung, 3.1

mortality was elevated in those who experienced Post Traumatic Stress Disorder related to the transplant. A retrospective study of kidney transplant patients found a startling 91% of those found to be noncompliant with medication or medical regimen either lost their grafts or died (Schweizer, Rovelli, Palmeri, Vossler, Hull, & Bartus, 1990).

Raiz, Kilty, Henry, and Ferguson (1999) and colleagues examined posttransplant kidney patients and found that older patients and those who perceived less pain were more likely to forget to take medications. This study found evidence that the patient's *subjective experience* played a large role in either forgetting medications or failing to take them as prescribed. If some part of the transplant experience was negative, they were more likely to be noncompliant. Positive feelings regarding their physicians and the transplant experience increased compliance. Others also found *subjective reactions* to the transplant experience predictive of compliance (Dew et al. 1996a; Rovelli, Palmeri, Vossler, Bartus, Hull, & Schweizer, 1989). Dew also found the quality of family relationships and the patient's style of coping to be important to compliance. Rovelli and colleagues (1989) suggested that compliance to dialysis may be the best predictor of renal transplant compliance. According to Dew, pretransplant screening and demographic variables had limited utility in predicting compliance (Dew et al., 1996a). Mai and colleagues (1990) on the other hand, found that a pretransplant psychological diagnosis was highly correlated with posttransplant compliance to the medical regimen.

Deshields, McDonough, Mannen, and Miller (1996) express concern about using pretransplant psychological diagnoses to predict those who will be noncompliant. While acknowledging that some studies show a relationship between psychological symptoms and compliance, they make the point that the pretransplant experience is extremely stressful and patients will likely manifest psychological symptoms during that time. These authors believe that candidates could be ruled out because of temporary symptoms due to the situation rather than to an enduring psychological state. Kugler et al. (1994) lends support to this concern by finding that posttransplant emotional adjustment is predicted by pretransplant ratings of locus of control rather than presurgical emotional adjustment.

Didlake, Dreyfus, Kerman, Van Buren, and Kahan (1988), followed 531 kidney transplant patients. Major noncompliance leading to graft loss happened in 2.8% of the sample, while minor noncompliance contributed to rejection episodes in 1.9% of the sample. One study found that males were more noncompliant about medication, while females were more noncompliant about diet (Kiley, Lam, & Pollak, 1993). These authors also report that noncompliance was positively associated with several variables including the number of prescribed medications, depression, Black race, external locus of control, unemployment, and lack of social and family support. Frazier and colleagues (1994) found greater medication noncompliance in younger, female, unmarried, retransplanted or lower income patients.

Littlefield et al., in 1996, received an 82% return rate of surveys of 55 heart, 149 liver, and 59 lung transplant patients. The heart patients reported greater intrusiveness of their illness in their daily lives and greater difficulty with compliance with the lifestyle regimen. Dew et al. (1996a) followed heart patients for the first year, and found the following persistent noncompliance rates: exercise, 37%; blood pressure monitoring, 34%; medications, 20%; smoking, 19%; diet, 18%; having blood work completed, 15%; clinic attendance, 9%; and heavy drinking 6%. Frazier and colleagues (1994) found that half of their sample had compliance problems with some area of the total medical regimen. Those having the most difficulties with medical compliance were patients who were unmarried, had low income, were not insulin dependent, or had survived a longer time since the transplant. Noncompliance with both medication and the medical regimen man-

ifested in those who reported higher stress and more depression, who coped with stress with avoidant strategies, and who believed that health outcomes are beyond their control. In this study, stress level was the strongest predictor of noncompliance.

In a study of renal transplant patients, Douglas, Blixen, and Bartucci (1996) found that somewhere between 5 to 18% of the patients do not comply with posttransplant medical protocols. Following 126 subjects over three years, they found that 61% of those identified as noncompliant before transplant lost their graft or died after transplant.

Intervention with Compliance Problems

There are few posttransplant studies designed to increase compliance in the transplant patient. Kober, Kachler, Broelsch, Kremer, and Henre-Bruns (1990) conducted a study following transplant patients for 36 months. They found that a support program did increase the patients' compliance.

Multivariate research does clarify some factors involved in patient compliance in general. (DiMatteo, 1993). First, the patient must believe in the usefulness (effectiveness and benefits to exceed cost). Second, a patient's ability to carry out the regimen depends upon its difficulty and on availability of support to assist the patient.

In 1998, DiMatteo and Lepper review noncompliance problems associated with provider-patient communication. DiMatteo, Ritter, and Gambone (1994) propose a structured system designed to improve the communication and thus influence the decision-making process between the physician and patient. They review research stressing the collaborative relationship necessary at the time a medical regimen is established and throughout its course. Factors lying outside the patient also influence compliance.

Although not working directly with the transplant population, the work of Christensen (1996) and his colleagues (Christensen, Benotsch, & Smith, 1997; Christensen, Smith, Turner, & Cundick, 1994) may hold value for those working to improve compliance with transplant patients. Their assertion is that adherence can be better understood by considering patient individual differences with treatment and disease-related factors. We do not know if this holds true for transplant patients, or if, for example, there are differences across types of transplant.

Steinberg, Diercks, and Millsbaugh (1996) demonstrated that usual individualized discharge education, and usual education plus a videotape were equally able to teach patients necessary transplant information. The importance of compliance motivated the study. However, we do not know if differences in teaching methods actually influences compliance after discharge.

In summary, there is no clear data by which to determine what interventions have a positive influence on compliance in transplant candidates and recipients.

Problems of Transplanted Adolescents

There is a large body of literature on psychosocial problems of chronically ill pediatric and adolescent patients. Comments will be restricted here to problems facing *transplanted* children and adolescents. Authors who have examined posttransplant psychosocial problems find that compliance is often a major concern with adolescents across all types of organ transplant. Uzark and colleagues (Uzark et al., 1992) remind us that transplanted school-age children and adolescents perceive more differences between themselves and their peer group, and are, therefore, more likely to feel alienated or to fear rejection by their peers. Concerns about acceptance may be so strong as to precipitate a

life-threatening decision to discontinue drug therapy (Dew et al., 1999). Uzark found that when family members can openly express feelings and concerns and can support one another, the heart transplant recipient is better able to cope with stresses and to adapt to the situation. There is other research support for the benefits of the expression rather than suppression of emotions related to chronic disease (Spiegel, 1999).

Psychosocial problems in transplanted children and adolescents often need attention. In one-year postliver transplants, Bradford (1991) observed that children typically show continuing developmental delays. Bradford also reports that many families continue to experience problems in normalizing their interactions within and outside their families. Reynolds, Garralda, Postlethwaite, and Goh (1991) also noted the impact on the family. While physical health, behavioral, and family functioning improved with transplant, parents required continued psychological and social support. They need assistance in coping with minor psychological problems posttransplant. A study in England (Brownbridge & Fielding, 1991) compared children with a renal transplant to those on either hemodialysis or peritoneal dialysis. Children with a transplant suffered less functional impairment and less social impairment than those on dialysis. However, both the transplant and dialysis groups reported psychological stress associated with treatment, stress on the marital relationship, heightened levels of anxiety and depression in both parents and children, and behavioral disturbances in the children.

A group of pediatric and heart transplants ($N = 23$) had very positive psychological functioning (78%), but those who had psychological difficulties before transplant had more hospitalizations posttransplant (DeMaso, Twente, Spratt, & O'Brien, 1995). The patient's pretransplant emotional functioning and family functioning were more highly correlated to posttransplant psychological functioning than to medical side effect severity. A recent case study (Hanton, 1998) reported a number of concerns on the part of the adolescent and family, including feelings of isolation, depression, boredom, hopelessness, helplessness, exhaustion, lack of privacy, financial burden, role strain, and family disruption. Rodin and Abbey (1992) found that children and adolescents were more non-compliant, had lower self-esteem, and exhibited more problems with body image. The recipients manifested delayed psychosocial and psychosexual development and problems in family relationships. Urzak et al. (1992) did not find self-esteem or anxiety differences from peers.

One study has examined adults transplanted as children to determine their long-term psychosocial well-being. In this study, Reynolds, Morton, Garralda, Postlethwaite, and Goh (1993) found the overall quality of life to be substantially positive. However, an early start of illness and a state of current health problems were associated with poorer social outcome. The transplanted patients had more stress in developing a close relationship with the opposite sex than controls, and had more difficulty in forming close relationships outside the family. Compared to controls, these patients were less socially mature, lived more often with their parents, had fewer school qualifications, and were more often unemployed.

Bear in mind that, while there are concerns, transplantation results in a greatly improved quality of life for pediatric and adolescent patients. For example, a study of 41 pediatric liver transplants, more than four years past surgery, used a chronically ill control group and a well-child control group. The transplanted group was comparable to the control groups on many measures. Mild social and scholastic difficulties were experienced by 6- to 21-year-olds, and males were more vulnerable to social competence difficulties. Parents of the transplanted Ss reported a less negative impact on the family than parents of the chronically ill control group (DeBolt, Steward, Kennard, Petrik, & Andrews, 1995).

Psychosocial Treatment Interventions

In 1992, Uzark called for empirical research to identify methods of providing psychosocial interventions beneficial to pediatric transplant patients. Shaben (1993) noted, in a review article of psychosocial intervention with kidney-transplanted children and adolescents, that the literature was largely descriptive. With only a couple of exceptions, the situation is unchanged.

In 1995, Folkes-Jamison conducted a controlled study with treatment containing both an educational and behavioral component. Fourteen children and families were in the treatment group, while 15 children and families were controls. The treatment group was able to display more knowledge about transplantation and demonstrated greater medication compliance. However, the two groups did not differ in their medication compliance to prednisone at follow-up periods. Meade (1999) designed a study to provide social support, information about medications and instruction, and opportunities to practice self-management skills in transplanted adolescents. Although results show some promise, the study suffers from a small sample (9), descriptive statistics and lack of a control group.

Harper (1999) describes his work using clinical hypnosis with chronically and terminally ill adolescents including those with end-stage renal disease or organ transplant. His stated goal is to increase the patient's perception of control, and he illustrates his work with case examples.

Conclusions

Are Psychosocial Problems Underreported?

Several authors have suggested that the number of transplant patients exhibiting psychosocial problems is likely to be conservative and under reported. Dew and colleagues (1994, 1997) argue that it is difficult to get a good baseline of psychosocial problems pretransplant because patients may not want to jeopardize their acceptance for transplant. They may fear that the disclosure of any such problems may lead to disqualification from the transplant list (Kelly et al., 1992). This underreporting may also happen posttransplant. They propose that recipients may feel compelled to report high quality of life satisfaction to the transplant team because of gratitude toward the transplant team and because they continue to need follow-up care from that team. Others believe that recipients may manage posttransplant vulnerability by minimizing their own awareness of psychological difficulties (Snyder, 1998).

There is a second possible reason that findings may understate the extent of psychosocial problems in transplant patients. Several authors believe this to be due to the focus of the evaluation and mode of assessment. Their argument is essentially that there is a strong *subjective* component to the experience of quality of life and psychosocial well being, and this component is missing from much of the current assessment. Leplege and Hunt (1997) and Hyland (1998) argue the following points. First, the emphasis of evaluation has been on the ability to perform everyday tasks and on the fulfillment of occupational and social roles. The assessment of functional capacity may well miss the mark. Functional capacity may not be the predominate issue for the individual being assessed (Winsett, 1998). The transplant team may be concerned much more with functional capacity and return to activities of daily living than with the subjective experience of the patient. Although physicians focus on a return to normal clinical values, the patient attends to such things as felt distress, fatigue, or loss of former valued activities. These authors

suggest that the medical concept of the quality of life is equivalent to the absence of medical complaints. Freeman and colleagues (1995) wrote about the future of transplant psychiatry, and argued for a need to understand the *subjective* as well as the objective aspects of compliance and quality of life for transplant recipients. They suggest a need to turn attention to psychosocial problems, not as predictors of graft life, compliance, or posttransplant complications, but as important in themselves. Such an effort would clarify the transplant patients' psychosocial experience, and create an understanding of patient problems calling for intervention (Desheids et al., 1996). These authors also believe that patients are more likely to reveal serious psychosocial problems where there is a perception that the transplant team exhibits a real interest.

Are There Psychosocial Differences in Different Types of Transplants?

There are no definitive answers to this interesting question. The meta-analysis by Dew and associates (1997) examined the quality of life in different types of transplants. This is an important major study that is complex and comprehensive. Authors took studies that examined at least one of the four domains of physical function, mental health status, social functioning, or the overall quality of life. In each of those domains they examined studies by transplant type (kidney, heart, etc.). The meta-analysis also divided studies into those that examined (1) quality of life (QOL) pretransplant to post transplant, (2) QOL in transplant patients compared with similarly ill comparison groups (usually those awaiting transplantation), and (3) QOL in transplant patients compared to healthy samples.

The analysis demonstrates variability across types of transplant, and the authors conclude that this reflects true differences across diseases and type of transplant. However, they also caution that interpretation of the data is somewhat difficult for several reasons. There was a wide range in the QOL measures used in the study making comparisons difficult. Some QOL measures were standardized, and some were not. Time of assessment varied widely, invoking the possibility that QOL assessments at six months posttransplant may be different from those taken several years after transplant. Differences in findings across studies may have been amplified by demographic and psychosocial differences in the samples studied. Finally, the era in which the study was conducted may have a strong bearing on QOL outcome. Cyclosporine was introduced in 1983, and FK 506 in 1994. The newer immunosuppressants may have a strong influence on QOL because they have fewer side effects and allow dramatic reductions in the amount of steroids given to patients.

Needs for the Future

Those involved in transplant research need to shift their focus away from analyses of the psychosocial traits and states of transplant candidates. Hundreds of studies have established a large empirical understanding of those issues. A large number of predictive studies have also identified those who are at higher risk for posttransplant psychosocial problems. Future quality of life research must be more methodologically sound, and must consider the validity of the subjective experience of the client. However, research must now focus on *intervention studies* in several areas.

Noncompliance is a wide-spread problem among those who receive different forms of medical treatment. However, for transplant recipients, noncompliance can have serious and sometimes fatal consequences. Therefore, we must begin intervention research to establish empirically how to create better regimen compliance in this population. Chil-

dren and adolescents are at especially high risk, and therefore, highlight the need for methodologically sound research studies.

Return-to-work rates are lower than expected for transplant recipients. Some have not returned to work because they would lose insurance or disability coverage. However, a large segment of those unemployed are physically able to work. We need intervention programs designed to increase the return to work rates.

Support groups, educational groups, and psychoeducational groups are a standard practice at many transplant centers. However, there is no empirical basis to determine which transplant candidates, recipients, and spouses may benefit from such groups and which may not. We also do not know if peer support groups have more or less benefit than educational groups. We can no longer presume that what is typically being done is working.

Sexual dysfunction affects a large percentage of transplant candidates and recipients. Both physicians and patients find hard to deal openly with this issue. Better intervention is needed to educate both patients and physicians about the sexual issues and options so that patients and spouses are better served.

Finally, there is established evidence that caregivers of transplant candidates and recipients are at risk for high levels of stress. Now we need intervention studies that will help us better serve this sometimes forgotten population.

In summary, we have established the overall benefits of transplantation, and have identified psychosocial problem areas and those at higher risk for psychosocial problems. Now we need to turn research efforts in the direction of intervention.

References

- Abauna, G.M. (1997). Marginal donors: A viable solution for organ shortage. *Transplantation Proceedings*, 29, 2759–2764.
- Abbey, S., & Farrow, S. (1998). Group therapy and organ transplantation. *International Journal of Group Psychotherapy*, 48, 163–185.
- Adams, P.C., Ghent, C.N., Grant, D.R., & Wall, W.J. (1995). Employment after liver transplantation. *Hepatology*, 21(1), 140–144.
- American Psychiatric Association. (1987). *Diagnostic and statistical manual of mental disorders* (3rd ed., revised). Washington, DC: Author.
- Beer, J. (1995). Body image of patients with ESRD and following transplantation. *British Journal of Nursing*, 4(10), 591–598.
- Bloom, E.T., Moulton, A.D., McCoy, J., Chapman, L.E., & Patterson, A.P. (1999). Xenotransplantation: The potential and the challenge. *Critical Care Nurse*, 19(2), 76–83.
- Bohachick, P., Anton, B.B., Wooldridge, P.J., Kormos, R.L., Armitage, J.M., Hardesty, R.L., & Griffith, B.P. (1992). Psychosocial outcome six months after heart transplant surgery: A preliminary report. *Research in Nursing and Health*, 15(3), 165–173.
- Botsford, A.L. (1995). Review of literature on heart transplant recipients' return to work: Predictors and outcomes. *Social Work in Health Care*, 21(2), 87–89.
- Bradford, R. (1991). Children's psychological health status—The impact of liver transplantation: A review. *Journal of the Royal Society of Medicine*, 84(9), 550–553.
- Bravata, D.M., Olkin, I., Barnato, A.E., Keeffe, E.B., & Owens, D.K. (1999). Health-related quality of life after liver transplantation: A meta-analysis. *Liver Transplant Surgery*, 5(4), 318–331.
- Bremer, B.A., Haffly, D., Foxx, R.M., & Weaver, A. (1995). Patients' perceived control over their health care: An outcome assessment of the psychological adjustment to renal failure. *American Journal of Medical Quality*, 10(3), 149–154.

- Bright, M.J., Craven, J.L., & Kelly, P.J. (1990). Assessment and management of psychosocial stress in lung transplant candidates. *Health and Social Work, 15*, 125–132.
- Brownbridge, G., & Fielding, D.M. (1991). Psychosocial adjustment to end-stage renal failure: Comparing haemodialysis, continuous ambulatory peritoneal dialysis and transplantation. *Pediatric Nephrology, 5*(5), 612–616.
- Bunzel, B., & Wollenek, G. (1994). Heart transplantation: Are there psychosocial predictors for clinical success of surgery? *Thoracic and Cardiovascular Surgeon, 42*(2), 103–107.
- Burckhardt, C.S. (1985). The impact of arthritis on quality of life. *Nursing Research, 34*, 11–16.
- Canning, R.D., Dew, M.A., & Davidson, S. (1996). Psychological distress among caregivers to heart transplant recipients. *Social Science and Medicine, 42*(4), 599–608.
- Chacko, R.C., Harper, R.G., Gotto, J., & Young, J. (1996). Psychiatric interview and psychometric predictors of cardiac transplant survival. *American Journal of Psychiatry, 153*(12), 1627–1628.
- Christensen, A.J. (1996). Patient adjustment and adherence in renal dialysis: A person by treatment interactive approach. *Dissertation Abstracts International: Section B: The Sciences & Engineering, 56* (11-B).
- Christensen, A.J., Benotsch, E.G., & Smith, T.W. (1997). Determinants of regimen adherence in renal dialysis. In: D.S. Gochman (Ed.), *Handbook of health behavior research II: Provider determinants* (pp. 231–244). New York: Plenum Press.
- Christensen, A.J., Smith, T., Turner, C.W., & Cundick, K.E. (1994). Patient adherence and adjustment in renal dialysis: A person * treatment interactive approach. *Journal of Behavioral Medicine, 17*, 549–566.
- Christopherson, L.K. (1987). Cardiac transplantation: A psychological perspective. *Circulation, 75*, 57–62.
- Coffey, J. (1999). Pharmacists respond. *LifeTimes, (4)*, 12.
- Cohen, S., & Herbert, T.B. (1996). Health psychology: Psychological factors and physical disease from the perspective of human psychoneuroimmunology. *Annual Review of Psychology, 47*, 113–142.
- Cohen, S., & Williamson, G.M. (1988). Perceived stress in a probability sample of the United States. In: S. Spacapan & S. Oskamp (Eds.), *Social psychology of health* (pp. 31–67). Newbury, CA: Sage.
- Cohen, L., Littlefield, C., Kelly, P., Mauer, J., & Abbey, S. (1998). Predictors of quality of life and adjustment to lung transplantation. *Chest, 113*, 633–644.
- Craven, J.L., Bright, J., & Dear, C.L. (1990). Psychiatric, psychosocial and rehabilitative aspects of lung transplantation. *Clinics in Chest Medicine, 11*(2), 247–257.
- DeBolt, A.J., Steward, S.M., Kennard, B.D., Petrik, K., & Andrews, W.S. (1995). A survey of psychosocial adaptation in long-term survivors of pediatric liver transplants. *Children's Health Care, 24*(2), 79–96.
- Delmar-McClure, N. (1985). When organs match and health beliefs don't: Bioethical challenges. *Journal of Adolescent Health, 6*, 233–237.
- DeMaso, D.R., Twente, A.W., Spratt, E.G., & O'Brien, P. (1995). Impact of psychologic functioning, medical severity, and family functioning in pediatric heart transplantation. *Journal of Heart and Lung Transplantation, 14*(6 Pt 1), 1102–1108.
- Deshields, T.L., McDonough, E.M., Mannen, R.K., & Miller, L.W. (1996). Psychological and cognitive status before and after heart transplantation. *General Hospital Psychiatry, 18*, 62S–69S.
- Dew, M.A., Dormos, R.L., Roth, L.H., Murali, S., & DiMartini, A. (1999). Early post-transplant medical compliance and mental health predict physical morbidity and mortality one to three years after heart transplantation. *Journal of Heart and Lung Transplantation, 18*(6), 549–562.
- Dew, M.A., Roth, L.H., Thompson, M.E., Kormos, R.L., & Griffith, B.P. (1996a). Medical com-

- pliance and its predictors in the first year after heart transplantation. *Journal of Heart and Lung Transplantation*, 15(6), 631–645.
- Dew, M.A., Roth, L.H., Schulberg, H.C., Simmons, R.G., Kormos, R.L., Trzepacz, P.T., & Griffith, B.P. (1996b). Prevalence and predictors of depression and anxiety-related disorders during the year after heart transplantation. *General Hospital Psychiatry*, 18(6 Suppl), 48S–61S.
- Dew, M.A., Simmons, R.G., Roth, L.H., Schulberg, H.C., Thompson, M.E., Armitage, J.M., & Griffith, B.P. (1994). Psychosocial predictors of vulnerability to distress in the year following heart transplantation. *Psychological Medicine*, 24(4), 929–945.
- Dew, M.A., Switzer, G.A., Goycoolea, J.M., Allen, A.S., DiMartini, A., Kormos, R.L., & Griffith, B.P. (1997). Does transplantation produce quality of life benefits. *Transplantation*, 64(9), 1261–1273.
- Didlake, R.H., Dreyfus, K., Kerman, R.H., Van Buren, C.T., & Kahan, B.D. (1988). Patient non-compliance: A major cause of late graft failure in cyclosporine-treated renal transplants. *Transplantation Proceedings*, 20(Suppl 3), 63–69.
- DiMatteo, M.R. (1993). Expectations in the physician-patient relationship: Implications for patient adherence to medical treatment recommendations. In: P.D. Blanck (Ed.). *Interpersonal expectations: Theory, research and applications* (pp. 296–315). New York: Cambridge University Press.
- DiMatteo, M.R., & Lepper, H.S. (1998). Promoting adherence to courses of treatment: Mutual collaboration in the physician-patient relationship. In: L.D. Jackson, B.K. Duffy, et al. (Eds.), *Health communication research: A guide to developments and directions* (pp. 75–86). Westport, CT: Greenwood Press/Greenwood Publishing Group, Inc.
- DiMatteo, M.R., Reiter, R.C., & Gambone, J.C. (1994). Enhancing medication adherence through communication and informed collaborative choice. *Health Communication*, 6(4), 253–265.
- Donor Network of Arizona. (1999). Facts and figures about organ and tissue donation. Updated in 1999. At: <http://www.dnaz.org/news/factsfigures/html>.
- Douglas, S., Blixen, C., & Bartucci, M.R. (1996). Relationship between pretransplant noncompliance and posttransplant outcomes in renal transplant patients. *Journal of Transplant Coordination*, 6(2), 53–58.
- Dubovsky, S.L., & Penn, I. (1980). Psychiatric considerations in renal transplant surgery. *Psychosomatics*, 21, 481–491.
- Duitsman, D.M., & Cychosz, C.M. (1994). Psychosocial similarities and differences among employed and unemployed heart transplant recipients. *Journal of Heart and Lung Transplantation*, 13(Pt 1), 108–115.
- Dunstan, G.R. (1997). The ethics of organ donation. *British Medical Bulletin*, 53(4), 921–939.
- Evans, R.W. (1995). Socioeconomic aspects of heart transplantation. *Current Opinion in Cardiology*, 10(2), 169–179.
- First, M.R. (1997). Expanding the donor pool. *Seminars in Nephrology*, 17(4), 373–380.
- First, R., & Singer, G. (1996). Chronic renal allograft failure: A summary of current thinking. *Kidney Transplant Forum*, 1(2), p. 3.
- Fisher, D.C., Lake, K.D., Reutzel, T.J., & Emery, R.W. (1995). Changes in health-related quality of life and depression in heart transplant recipients. *Journal of Heart and Lung Transplantation*, 14(2), 373–381.
- Fourkes-Jamison, L.-M.A. (1995). Family-based program to promote medication compliance in renal-transplanted children. *Dissertation Abstracts International: Section B: The Sciences & Engineering*, 55(9-B), 4118.
- Frazier, P.A., Davis-Ali, S.H., & Dahl, K.E. (1994). Correlates of noncompliance among renal transplant recipients. *Clinical Transplantation*, 8(6), 550–557.
- Frazier, P.A., Davis-Ali, S.H., & Dahl, K.E. (1995). Stressors, social support, and adjustment in kidney transplant patients and their spouses. *Social Work in Health Care*, 21(2), 93–108.

- Freeman, A.M., Westphal, J.R., Davis, L.L., & Libb, J.W. (1995). The future of organ transplant psychiatry. *Psychosomatics*, 36(5), 429–437.
- Fricchione, G.L. (1989). Psychiatric aspects of renal transplantation. *Australian and New Zealand Journal of Psychiatry*, 23(3), 407–417.
- Frierson, R., Tabler, J., & Spears, R. (1992). Heart transplantation. In J. Craven & G.M. Rodin (Eds.), *Psychiatric aspects of organ transplantation* (pp. 164–176). New York: Oxford University Press.
- Gier, M.D., Levick, M.D., & Blazina, P.A. (1988). Stress reduction with heart transplant patients and their families: A multidisciplinary approach. *Journal of Heart Transplantation*, 7, 342–347.
- Glass, C.A., Fielding, D.M., Evans, C., & Ashcroft, J.B. (1987). Factors related to sexual functioning in male patients undergoing hemodialysis and with kidney transplant. *Archives of Sexual Behavior*, 16(3), 189–207.
- Goldberg, D. (1978). *Manual of the General Health Questionnaire*. Windsor: NFER–Nelson.
- Goodheart, C.D., & Lansing, M.H. (1996). *Treating people with chronic disease: A psychological guide*. Washington, DC: American Psychological Association.
- Hanton, L.B. (1998). Caring for children awaiting heart transplantation: Psychosocial implications. *Pediatric Nursing*, 24, 214–218.
- Harper, G.W. (1999). A developmentally sensitive approach to clinical hypnosis for chronically and terminally ill adolescents. *American Journal of Clinical Hypnosis*, 42, 50–60.
- Helgeson, V.S., & Cohen, S. (1996). Social support and adjustment to cancer: Reconciling descriptive, correlational and intervention research. *Health Psychology*, 15, 135–148.
- Helgeson, V.S., Cohen, S., Schultz, R., & Yasko, J. (1999). Education and peer discussion group interventions and adjustment to breast cancer. *Archives of General Psychiatry*, 56, 340–347.
- Helgeson, V.S., Cohen, S., Schultz, R., & Yasko, J. (2000). *Health Psychology*, 19, 107–114.
- Hodges, B., Craven, J., & Littlefield, C. (1995). Bibliotherapy for psychosocial distress in lung transplant patients and their families. *Psychosomatics*, 36(4), 360–368.
- Hunt, C.M., Tart, J.S., Dowdy, E., Bute, B.P., Williams, D.M., & Clavien, P.A. (1996). Effects of orthotopic liver transplantation on employment and health status. *Liver Transplant Surgery*, 2(2), 148–153.
- Hyland, M.E. (1998). The problem of quality of life in medicine. [Letter to the editor]. *JAMA*, 279(6), 30.
- Jalowiec, A., Grady, K.L. & White-Williams, C. (1994). Stressors in patients awaiting a heart transplant. *Behavioral Medicine*, 19(4), 145–154.
- Johnson, J. (1984). Psychological interventions and coping with surgery. In: A. Baum, S.E. Taylor, & J.E. Singer (Eds.), *Handbook of psychology and health* (Vol. IV, pp. 167–188). Hillsdale, N.J.: Erlbaum.
- Juneau, B. (1995). Psychologic and psychosocial aspects of renal transplantation. *Critical Care Nursing Quarterly*, 17, 62–66.
- Kalman, T.P., Wilson, P.G., & Kalman, C.M. (1983). Psychiatric morbidity in long-term renal transplant recipients and patients undergoing hemodialysis: A comparative study. *JAMA*, 250(1), 55–58.
- Kavanagh, T., Yacomb, M.H., Kennedy, J., & Austin, P.C. (1999). Return to work after heart transplantation: 12-year follow-up. *Journal of Heart and Lung Transplantation*, 18(9), 846–851.
- Kelly, P., Bart, C., & Craven, J. (1992). Lung transplantation. In J. Craven & G.M. Rodin (Eds.), *Psychiatric aspects of organ transplantation* (pp. 205–223). New York: Oxford University Press.
- Kiecolt-Glaser, J.K., & Glaser, R. (1988). Methodological issues in behavioral immunology research with humans. *Brain, Behavior and Immunology*, 2, 67–68.
- Kiley, D.J., Lam, C.S., & Pollak, R. (1993). A study of treatment compliance following kidney transplantation. *Transplantation*, 55(1), 51–56.

- Kirchenbaum, D.S. (1991). Integration of clinical psychology into hemodialysis programs. In J.J. Sweet, R.H. Rozensky et al. (Eds.), *Handbook of clinical psychology in medical settings* (pp. 567–586). New York: Plenum Press.
- Kober, B., Kuchler, T, Broelsch, C., Kremer, B., & Henne-Bruns, D. (1990). A psychological support concept and quality of life research in a liver transplant program: An interdisciplinary multicenter study. *Psychotherapy and Psychosomatics*, 54(2–3), 117–131.
- Konstam, V. (1995). Anger: A neglected group treatment issue with cardiac transplantation recipients and their families. *Journal for Specialists in Group Work*, 20, 189–194.
- Kormos, R.L., Murali, S., Dew, M.A., & Armitage, J.M. (1994). Chronic mechanical circulatory support: Rehabilitation, low morbidity, and superior survival. *Annals of Thoracic Surgery*, 57(1), 51–57; discussion 57–58.
- Kugler, J., Tenderich, G., Stahlhut, P., Posival, H., Korner, M.M., Korfer, R., & Kruskemper, G.M. (1994). Emotional adjustment and perceived locus of control in hear transplant patients. *Journal of Psychosomatic Research*, 38(5), 403–408.
- Kuhn, W.F., Davis, M.H., & Lippmann, S.B. (1988). Emotional adjustment to cardiac transplantation. *General Hospital Psychiatry*, 10, 108–113.
- Leplege, A., & Hunt, S. (1997). The problem of quality of life in medicine. *JAMA*, 278(1), 47–50.
- Levenson, J.L., & Olbrisch, M.E. (1993). Psychosocial evaluation of organ transplant candidates: A comparative survey of process, criteria and outcomes in heart, liver, and kidney transplantation. *Psychosomatics*, 34(4), 314–323.
- Lewis, D.D., & Valerius, W. (1999). Organs from non-heart-beating donors: An answer to the organ shortage. *Critical Care Nurse*, 19(2), 70–74.
- Lipkin, G.B., & Cohen, R.G. (1998). *Effective approaches to patients' behavior: A guide book for health care professionals, patients and their caregivers* (5th ed.). New York: Springer Publications.
- Littlefield, C. (1995). Psychological treatment of patients with end-stage pulmonary disease. *Monaldi Archives of Chest Disease*, 50, 58–61.
- Littlefield, C., Abbey, S., Fiducia, D., Cardella, C., Greig, P. Levy, G., Maurer, J. & Winton, T. (1996). Quality of life following transplantation of the heart, liver, and lungs. *General Hospital Psychiatry*, 18(6 Suppl.), 36S–47S.
- Ludwick-Rosenthal, R., & Newfeld, W.J. (1988). Stress management during noxious medical procedures: An evaluation review of outcome studies. *Psychological Bulletin*, 104, 326–342.
- Lysaght, M.J., & Aebischer, P. (1999). Encapsulated cells as therapy. *Scientific American*, 280(4), 76–84.
- Mai, F.M. (1993). Psychiatric aspects of heart transplantation. *British Journal of Psychiatry*, 163, 285–292.
- Mai, F.M., McKenzie, F.N., & Kostuk, W.J. (1990). Psychosocial adjustment and quality of life following heart transplantation. *Canadian Journal of Psychiatry*, 35(3), 223–227.
- Manninen, D.L., Evans, R.W., & Dugan, M.K. (1991). Work disability, functional limitations, and the health status of kidney transplantation recipients posttransplant. *Clinical Transplantation*, 5, 193–203.
- Markell, M.S., DiBenedetto, A., Maursky, V., Samrani, N., Hong, J.H., Distant, D.A., Miles, A.M., Sommer, B.G., & Friedman, E.A. (1997). Unemployment in inner-city renal transplant recipients: Predictive and sociodemographic factors. *American Journal of Kidney Diseases*, 29(6), 881–887.
- Matas, A.J., Lawson, W., McHugh, L., Gillingham, K., Payne, W. D., Dunn, D.L., Gruessner, R.W., Sutherland, D.E., & Najarian, J.S. (1996). Employment patterns after successful kidney transplantation. *Transplantation*, 61(5), 729–733.
- May, T.E. (1998). The effects of psychotherapy on state anxiety in the renal transplant candidate population. *Dissertation Abstracts International: Section B: The Sciences & Engineering*, 56(10-B), 5650.

- McAleer, M.J., Copeland, J., Fuller, J., & Copeland, J.G. (1985). Psychological aspects of heart transplantation. *Journal of Heart Transplantation*, 4, 232–233.
- McWaine, D.E., & Procci, W.R. (1988). Drug-induced sexual dysfunction. *Medical Toxicology and Adverse Drug Experience*, 3(4), 289–306.
- Meade, M.A. (1999). The development, implementation and evaluation of a self-management program for adolescents and children with renal transplants. *Dissertation Abstracts International: Section B: The Sciences and Engineering*, 59(8-B), 4474.
- Meister, N.D., McAleer, M.J., Meister, J.S., & Riley, J.E. (1986). Returning to work after heart transplantation. *Journal of Heart Transplantation*, 5(2), 154–161.
- Michel, M.H., & Murdaugh, C.L. (1987). Family adjustment to heart transplantation. *Circulation*, 36, 332–338.
- Mordkin, R.M. (1999). Sexual dysfunction following transplantation. *LifeTimes*, 2, 15–18.
- Mooney, D.J., & Milkos, A.G. (1999). Growing new organs. *Scientific American*, 280(4), 60–65.
- Mulligan, T., Sheehan, H., & Hanrahan, J. (1991). Sexual function after heart transplantation. *Journal of Heart and Lung Transplantation*, 10(Pt 1), 125–128.
- Napolitano, M.A. (1999). Telephone-based psychosocial intervention for patients awaiting lung transplantation. *Dissertation Abstracts International: Section B: The Sciences & Engineering*, 60(1-B), 0371.
- Newton, S.E. (1999a). Relationship of hardiness and sense of coherence to post-liver transplant return to work. *Holistic Nursing Practice*, 13(3), 71–79.
- Newton, S.E. (1999b). Renal transplant recipients' and their physicians' expectations regarding return to work posttransplant. *ANNA Journal*, 26(2), 227–232.
- Olbrisch, M.E., & Levonson, J.L. (1991). Psychosocial evaluation of heart transplant candidates: An international survey of provider criteria and outcomes. *Journal of Heart and Lung Transplantation*, 10, 948–955.
- Paris, W., Diercks, M., Bright, J., Zamora, M., Kesten, S., Scavuzzo, M., & Paradis, I. (1998). Return to work after lung transplantation. *Journal of Heart and Lung Transplantation*, 17(4), 430–436.
- Paris, W., Woodbury, A., Thompson, S., Levick, M., Nothegger, S., Hutkin-Slade, L., Arbuckle, P., & Cooper, D.K. (1992). Social rehabilitation and return to work after cardiac transplantation: A multicenter survey. *Transplantation*, 53(2), 433–438.
- Paris, W., Woodbury, A., Thompson, S., Levick, M., Nothegger, S., Hutkin-Slade, L., Arbuckle, P., & Cooper, D.K. (1993). Returning to work after heart transplantation. *Journal of Heart and Lung Transplantation*, 12(1 Pt 1), 46–53, discussion 53–54.
- Payne, J.L., McCarty, K.R., Drougas, J.G., Chapman, W.C., Wright, J.K., Pinson, N.Y., Beliles, K.E., Newsom, V.L., Hunter, E.B., Raiford, D.S., Awad, J.A., Burk, R.F., Donovan, K.L., Van Buren, D.H., & Pinson, C. W. (1996). Outcomes analysis for 50 liver transplant recipients: The Vanderbilt experience. *American Surgeon*, 64(4), 320–325.
- Peters, T.G., Jones, K.W., Walker, G.W., Charlton, R. K., Antonucci, L. E., Repper, S.M., & Hunter, R.D., Sr. (1999). Living-related kidney donation: A single-center experience. *Clinical Transplantation*, 13(1 Pt 2), 108–112.
- Pedersen, R.A. (1999). Embryonic stem cells for medicine. *Scientific American*, 280(4), 68–73.
- Petrie, K. (1989). Psychological well-being and psychiatric disturbance in dialysis and renal transplant patients. *British Journal of Medical Psychology*, 62(Pt 1), 91–96.
- Platt, J.L. (1999). Prospects for xenotransplantation. *Pediatric Transplantation*, 3(3), 193–200.
- Raiz, L.R., Kilty, K.M., Henry, M.L., & Ferguson, F.M. (1999). Medication compliance following renal transplantation. *Transplantation*, 68(1), 51–54.
- Rauch, J.B., & Kneen, K.K. (1989). Accepting the gift of life: Heart transplant recipients' post-operative adaptive tasks. *Social Work in Health Care*, 14(1), 47–59.
- Raval, P. (1999). Medication induced sexual dysfunction in transplant patients. *LifeTimes*, 2, 19–20.

- Reynolds, J.M., Garralda, M.E., Postlethwaite, R.J., & Goh, D. (1991). Changes in psychosocial adjustment after renal transplantation. *Archives of Disease in Childhood*, 66(4), 508–513.
- Reynolds, J.M., Morton, M.J., Garralda, M.E., Postlethwaite, R.J., & Goh, D. (1993). Psychosocial adjustment of adult survivors of a paediatric dialysis and transplant programme. *Archives of Disease in Childhood*, 68, 104–110.
- Robson, S.C., Schulte am Esch, J., 2nd, & Bach, F.H. (1999). Factors in xenograft rejection. *Annals of the New York Academy of Sciences*, 875, 261–276.
- Roche Laboratories. (1998). *Speaking frankly: A guide to sexual issues and transplantation*. Nutley, N.J.: Author.
- Rodin, G., & Abbey, S. (1992). Kidney transplantation. In J. Craven & G.M. Rodin (Eds.), *Psychiatric aspects of organ transplantation* (pp. 145–163). New York: Oxford University Press.
- Rovelli, M., Palmeri, D., Vossler, E., Bartus, S., Hull, D., & Schweizer, R. (1989). Noncompliance in renal transplant recipients: Evaluation by socioeconomic groups. *Transplantation Proceedings*, 21(6), 3979–3981.
- Scheier, M.F., Matthews, K., Owens, J., Magovern, G., Lefebvre, R., Abbott, R. (1989). Dispositional optimism and recovery from coronary artery bypass surgery: The beneficial effects on physical and psychological well-being. *Journal of Personality and Social Psychology*, 57, 1024–1040.
- Schweizer, R.T., Rovelli, M., Palmeri, D., Vossler, E., Hull, D., & Bartus. (1990). Noncompliance in organ transplant recipients. *Transplantation*, 49(2), 374–377.
- Serrano-Ikkos, E., Lask, B., & Whitehead, B. (1997). Psychosocial morbidity in children, and their families, awaiting heart or heart-lung transplantation. *Journal of Psychosomatic Research*, 42(3), 253–260.
- Shaben, T.R. (1993). Psychosocial issues in kidney-transplanted children and adolescents: Literature review. *American Nephrology Nurses Association Journal*, 20, 663–668.
- Sim, K.H., Marinov, A., & Levy, G.A. (1999). Xenotransplantation: a potential solution to the critical organ donor shortage. *Canadian Journal of Gastroenterology*, 13(4), 311–318.
- Simmons, R.G., Kamstra-Hennen, L., & Thompson, C.R. (1981). Psychological adjustment five to nine years posttransplant. *Transplantation Proceedings*, 13, 40–43.
- Snyder, S. (1998). Idealization in the liver transplant setting. *General Hospital Psychiatry*, 20(2), 80–84.
- Soos, J. (1992). Psychotherapy and counseling with transplant patients. In J. Craven & G.M. Rodin (Eds.), *Psychiatric aspects of organ transplantation* (pp. 89–107). New York: Oxford University Press.
- Spiegel, D. (1999). A 43-year-old woman coping with cancer. *JAMA*, 282(4), 371–378.
- Steinberg, J., Levy, N.B., & Radvila, A. (1981). Psychological factors affecting acceptance or rejection of kidney transplantation. In N.B. Levy (Ed.), *Psychonephrology I: Psychological factors in hemodialysis and transplantation* (pp. 185–193). New York: Plenum.
- Steinberg, T.G., Diercks, M.J., & Millsbaugh, J. (1996). An evaluation of the effectiveness of a videotape for discharge teaching of organ transplant recipients. *Journal of Transplant Coordination*, 6, 59–63.
- Stewart, A.M., Kelly, B., Robinson, J.D., & Callender, C. (1995). The Howard University Hospital transplant and dialysis support group. *International Journal of Group Psychotherapy* 45(4), 471–488.
- Stilley, C.S., Dew, M.A., Stukas, A.A., & Switzer, G.E. (1999). Psychological symptom levels and their correlates in lung and heart-lung transplant recipients. *Psychosomatics*, 40(6), 503–509.
- Strauss, B., Thormann, T., Strenge, H., Biernath, E., Foerst, U., Stauch, C., Torp, U., Bernhard, A., & Speidel, H. (1992). Psychosocial, neuropsychological and neurological status in a sample of heart transplant recipients. *Quality of Life Research*, 1(2), 119–128.

- Surman, O. (1992). Liver transplantation. In J. Craven & G.M. Rodin (Eds.), *Psychiatric aspects of organ transplantation* (pp. 177–188). New York: Oxford University Press.
- Tabler, J.B., & Frierson, R.L. (1990). Sexual concerns after heart transplantation. *Journal of Heart Transplantation*, 9(4), 397–403.
- Tarter, R.E., Erb, S., Biller, P.A., Switala, J., Van Thiel, D.H. (1988). The quality of life following liver transplantation: A preliminary report. *Gastroenterology Clinics of North America*, 17(1), 207–217.
- Taylor, H.A., Jr. (1999). Sexual activity and the cardiovascular patient: Guidelines. *American Journal of Cardiology*, 84(5B), 6N–10N.
- Thomas, D.J. (1996). Returning to work after liver transplant: Experiencing the roadblocks. *Journal of Transplant Coordination*, 6(3), 134–138.
- Trzepacz, P.T., Brenner, R., & Van Thiel, D.H. (1989). A psychiatric study of 247 liver transplantation candidates. *Psychosomatics*, 30, 147–153.
- United Network for Organ Sharing. (2000a). Milestones. Site updated 1/5/2000, at http://www.unos.org/Newsroom/critdata_milestones.htm.
- United Network for Organ Sharing. (2000b). Critical data: U.S. facts about transplantation. Site updated 1/13/2001, at http://www.unos.org/Newsroom/critdata_main.htm.
- Uzark, K. (1992). Caring for families of pediatric transplant recipients: psychosocial implications. *Critical Care Nursing Clinics of North America*, 4(2), 255–261.
- Uzark, K.C., Sauer, S.N., Lawrence, K.S., Miller, J., Adonizio, L., & Crowley, D.C. (1992). The psychosocial impact of pediatric heart transplantation. *Journal of Heart and Lung Transplantation*, 11(6), 1160–1167.
- Winsett, R.P. (1998). Posttransplant quality of life: a decade of descriptive studies leading to practice interventions. *Journal of Transplant Coordination*, 8(4), 236–240.
- Wright, C., & Cohen, B. (1997). Organ shortages: Maximising the donor potential. *British Medical Bulletin*, 53(4), 817–828.
- Zipfel, S., Lowe, B., Paschke, T., Immel, B., Lang, R., Zimmermann, R., Herzog, W., & Bergmann, G. (1998). Psychological distress in patients awaiting heart transplantation. *Journal of Psychosomatic Research*, 45(5), 465–470.