

Psychological Assessment and Care of Organ Transplant Patients

Mary Ellen Olbrisch and Sharon M. Benedict
Virginia Commonwealth University

Kristine Ashe
Harvard Medical School

James L. Levenson
Virginia Commonwealth University

Organ transplant has been developed in animal models over the past 100 years. The major limiting factor in transplant medicine is the shortage of donor organs. This shortage creates pressure for fair and efficient allocation of organs, with expectations that those involved in transplantation will strive to achieve optimal outcomes and ensure just access. This article reviews the major types of transplants and the illnesses and behavioral comorbidities that lead to these procedures, the psychological assessment of transplant candidates, the adaptive tasks required of the transplant recipient at various stages of the transplant process, and relevant psychological interventions. Liaison with others on the transplant team and ethical issues of concern to psychologists who work with transplant patients, including living organ donors, are also discussed. Finally, new developments in transplant and suggestions for future psychological research in organ transplant are presented.

Organ transplant has been developed in animal models over the past 100 years. The development of effective immunosuppressive therapies allowed these surgical techniques to move from the laboratory to the arena of routine clinical practice (Starzl, 1996). In the United States, approximately 12,000 kidney transplants, 2,100 heart transplants, 850 lung transplants, and 4,500 liver transplants are performed each year, while the number of patients awaiting transplant surgery grows steadily and more than 15 patients die on the waiting list each day (United Network for Organ Sharing [UNOS], 2001). Most organs come from cadaveric sources, with head trauma and cerebral vascular accidents causing death in 85% of cadaver donors (UNOS, 2001). The major limiting factor in transplant medicine is the shortage of donor organs. This shortage creates pressure for fair and efficient allocation of organs, with expectations that those involved in transplant will strive to achieve optimal outcomes and ensure just access (Ubel & Caplan, 1998; UNOS, 2001).

In the United States, 871 solid organ transplant programs in 259 institutions are recognized by UNOS, a privately operated entity under government supervision created in 1984 in response to the passage of the National Organ Transplant Act (Public Law 98–507). In addition, laws such as the Rehabilitation Act of 1973 and the Americans With Disabilities Act provide input from the public into policies and practices developed by the transplant community

(Orentlicher, 1996). Organ procurement organizations serve as liaisons between transplant centers and donor hospitals. Because transplant centers compete with one another both economically and academically, significant disagreements and even deep divisions related to issues such as organ allocation may develop. The current system for allocation of donor organs, which differs somewhat for each organ, might best be viewed as an evolving compromise that is subject to ongoing criticism and debate.

Mental and behavioral health issues have been recognized as important since the earliest transplant in human patients, when postoperative psychoses and affective disorders began to appear and threaten what were considered to be technically good outcomes. In this article, we review the major types of transplants and the illnesses and behavioral comorbidities that lead to these procedures, the psychological assessment of transplant candidates, the adaptive tasks required of the transplant recipient at various stages of the transplant process, and relevant psychological interventions. In addition, we discuss liaison with others on the transplant team and ethical issues of concern to psychologists who work with transplant patients, including living organ donors, one of the most rapidly expanding areas of transplant technology. Finally, we point to other new developments in transplant and suggest directions for future psychological research.

Types of Transplant Procedures

Kidney and Kidney–Pancreas Transplant

Kidney transplantation is performed for patients with end-stage renal disease. Common disorders leading to renal failure include hypertension, diabetes mellitus, polycystic kidney disease, and use of nephrotoxic drugs. Frequently, patients who reach end-stage renal disease have been disadvantaged by poor access to medical care. Poor compliance with medical regimens may contribute to renal failure, as patients may have difficulty accepting or main-

Mary Ellen Olbrisch, Sharon M. Benedict, and James L. Levenson, Department of Psychiatry, Medical College of Virginia, Virginia Commonwealth University; Kristine Ashe, Cambridge Hospital and Harvard Medical School.

Kristine Ashe is now in clinical practice in San Francisco, California.

Correspondence concerning this article should be addressed to Mary Ellen Olbrisch, Department of Psychiatry, Medical College of Virginia, Virginia Commonwealth University, Box 980268 MCV, Richmond, Virginia 23298-0268. E-mail: molbrisc@hsc.vcu.edu

taining treatment for asymptomatic conditions such as hypertension. Kidney failure results in uremia, a metabolic disturbance that causes impaired cognitive functioning. Patients with renal failure can be treated with dialysis, but this is a time-consuming process that limits freedom and quality of life dramatically. Allocation of kidneys is based on histocompatibility match and time on the waiting list. Living donations are the fastest increasing source of kidneys, in part because of the increased availability of laparoscopic nephrectomy, which results in less pain and faster recovery for donors (Brown, Biehl, Rawlins, & Hefty, 2001; Hawasli, Boutt, Cousins, Schervish, & Oh, 2001). One-year survival of cadaveric kidney grafts is 89.4%; 5-year survival is 64.7%. One-year graft survival from living donors is 94.5%; 5-year survival rate is 78.4% (UNOS, 2001).

Kidney-pancreas transplant is recommended for diabetic patients who experience renal failure and other complications of diabetes. Although pancreas transplant is sometimes performed alone, the combination of pancreas transplant with kidney transplant is usually performed. Diabetes is managed by regimens that include blood sugar monitoring, insulin, diet, and exercise management. Patients requiring kidney-pancreas transplants have been unable to manage their disease and prevent serious complications, due to either compliance difficulties or especially severe disease. Pancreas and kidney-pancreas transplant can both extend patient life and lead to major improvement in quality of life (Gross, Limwattananon, Matthees, Zehrer, & Savik, 2000). One-year graft survival for pancreas and kidney-pancreas transplant is 83.7%; 5-year survival is 67.4% (UNOS, 2001). Pancreas survival is significantly better in the context of kidney-pancreas transplant than for pancreas transplant alone (UNOS, 2001).

Liver Transplant

Liver transplant is performed for a broad range of diseases but most commonly for decompensated cirrhosis secondary to chronic viral hepatitis or alcohol abuse. Pediatric liver transplants are performed for congenital abnormalities such as biliary atresia or alpha-1 antitrypsin deficiency. More recently, early stage hepatic cancers have been successfully treated with liver transplant (Hemming et al., 2001). Toxicity from various medications, especially acetaminophen overdose in suicide attempts, may result in fulminant hepatic failure and the need for emergency transplants (Wiesner, 1996).

Intravenous drug use is a primary risk factor for viral hepatitis B and C. Although cirrhosis is irreversible, treatment of infection and abstinence from alcohol may slow or halt progression in healthy liver tissue (Sanyal, 2000). Patients with end-stage liver disease experience fatigue and may become encephalopathic, with symptoms ranging from mild sleep disturbance to delirium to coma. Ascites can be uncomfortable, and development of esophageal varices may leave patients vulnerable to catastrophic bleeding. Livers are allocated within regions according to medical need and time on the waiting list, although newer systems for liver allocation are currently under investigation (McCaughan & Strasser, 2001; Wiesner et al., 2001). Living-donor liver transplant is increasing but is well established in this country only for pediatric recipients (Cronin, Millis, & Siegler, 2001). One-year survival for liver transplant is 81.4%; 5-year survival is 66.1% (UNOS, 2001).

Heart Transplant

Heart transplant is indicated for patients with New York Heart Association Class IV heart failure (i.e., those who have symptoms even at rest) who do not respond to more conservative medical therapies and cannot be managed with other surgical interventions (e.g., bypass surgery). Conditions that might lead to transplant include familial, ischemic, viral, idiopathic, and postpartum cardiomyopathies. Some congenital cardiac malformations can be treated with heart transplant for pediatric patients. Patients who require heart transplant have limited exercise tolerance, shortness of breath, and fatigue. Poor perfusion may result in impaired cognition. Risk factors for ischemic heart disease include behavioral factors such as tobacco use, high-fat diet, and sedentary lifestyle. Alcohol abuse can cause cardiomyopathy. Hearts are allocated on the basis of medical need, with patients requiring mechanical support or intensive care prioritized over patients able to wait at home. One-year survival for heart transplant is 85.1%; 5-year survival is 68.5% (UNOS, 2001).

Lung and Heart-Lung Transplant

Lung transplant improves quality of life and may extend survival for patients with chronic obstructive pulmonary disease (COPD), idiopathic pulmonary fibrosis, cystic fibrosis, primary pulmonary hypertension, and Eisenmenger's complex (i.e., defect of the interventricular septum causing severe pulmonary hypertension; Arcasoy & Kotloff, 1999). Heart-lung transplant may also be indicated for patients with the latter two conditions, but it is rarely performed because policies favor helping the most patients possible by prioritizing patients awaiting a heart or lung over patients awaiting both. Smoking causes COPD and worsens other lung diseases.

Lung transplant patients frequently suffer from anxiety disorders (Smoller, Pollack, Otto, Rosenbaum, & Kradin, 1996). Many are on oxygen continuously and have extremely limited exercise tolerance. Pulmonary rehabilitation programs can improve quality of life but do not affect the progression of the underlying disease. Lungs are allocated within regions according to time on the waiting list, although there are discussions within the transplant community about developing a priority system based on patient expectancy for survival (R. S. Higgins, personal communication, July 10, 2001). One-year survival for lung transplant is 76.1%; 5-year survival is 42% (UNOS, 2001).

Bone Marrow and Stem Cell Transplant

Technically very different from solid organ transplant, bone marrow and stem cell transplants are not in themselves surgical procedures and in many cases use the patient's own cells (autologous transplantation). Bone marrow otherwise comes from living donors (allogeneic transplantation) who may be family members or immunologically compatible strangers located through national registries. Bone marrow and stem cell transplants permit the use of high-dose radiation and chemotherapies and are most often used in the treatment of leukemias and lymphomas, aplastic anemia, and sometimes other cancers (e.g., multiple myeloma, breast cancer). When allogeneic transplants are performed, immunosuppression is necessary to prevent rejection. A serious potential complication of allogeneic bone marrow transplant is graft versus host disease, in

which the donor cells attack the recipient's body. Bone marrow and stem cell transplant patients are more immunocompromised than solid organ recipients and are very vulnerable to infection, anemia, and bleeding. Although finding a match may be difficult, particularly for minority patients, allocation is not an issue in bone marrow transplant.

Psychological Evaluation of Transplant Candidates

The importance of psychological evaluation of candidates under consideration for transplant is widely endorsed (Debray & Plaisant, 1990; Dew, Switzer, et al., 2000; Dobbels et al., 2001; Levenson & Olbrisch, 1993b; Streisand et al., 1999). Comprehensive screening of potential transplant recipients is best accomplished within the framework of a multidisciplinary team approach (Bryant & Reams, 1998; Levine & Levine, 1991; Strouse, 1996) designed to ensure that patients and their families gain a complete understanding of the transplant process (Freeman, Davis, Libb, & Craven, 1992) and to provide continuity of care (Stevenson, 1996). Goals of the pretransplant psychological evaluation are to identify potential risk factors (i.e., substance abuse, compliance issues, serious psychopathology) that may result in increased risk of postoperative noncompliance and morbidity (Bryant & Reams, 1998; Leigh, Wilson, Burns, & Clark, 1995; Shapiro et al., 1995) and to provide information to inform treatment planning for those individuals identified as high risk (Craven & Rodin, 1992; Dew, Switzer, et al., 2000; Geller & Connolly, 1997).

Psychosocial assessment of transplant candidates also serves other purposes such as promoting fairness and equal access to care (Klapheke, 1999), providing a description of the patient's neuropsychiatric and cognitive functioning, serving as a guide for the clinical management of the patient and addressing the psychological needs of the transplant team with regard to patient care (Strouse, 1996). Although psychosocial evaluations may be used as a means to select or prioritize candidates (Craven & Rodin, 1992; Moss & Siegler, 1991), this is not usual practice (Olbrisch & Levenson, 1995). There is considerable debate about whether psychosocial factors, other than extreme noncompliance, should ever be considered as absolute exclusion criteria (Freeman et al., 1992). Additionally, questions have been raised concerning the ethical responsibility of mental health professionals to inform candidates that the information they provide during the psychosocial evaluation may be used in the selection process (Lowry & Martin, 1992; Olbrisch, 1996; Strouse, 1996), because this may increase the tendency toward socially desirable responses (Carnrike, 1997; Carnrike, McCracken, & Aikens, 1996; Stillely, Miller, Gayowski, & Marino, 1999).

Although it has been argued that transplant evaluations require assessment of psychiatric, psychological, and social factors (Freeman et al., 1992), a great deal of variation exists among transplant programs in the methods and criteria for psychological assessment of candidates; few use formal, written psychosocial criteria for selection (Levenson & Olbrisch, 2000; Olbrisch & Levenson, 1991). The majority of programs use clinical interviews conducted by mental health professionals to gather detailed information about various domains of the patient's background and functioning (Levenson & Olbrisch, 2000). Brief instruments such as the Psychosocial Assessment of Candidates for Transplantation (PACT; Olbrisch, Levenson, & Hamer, 1989) and the Transplant Evaluation Rating Scale (TERS; Twillman, Manetto, Wellisch, & Wolcott,

1993) have been designed to assess the reliability and validity of the selection of transplant candidates and are used as adjunctive tools in the assessment process. As there are several factors that need to be fully assessed in a short period of time, the use of a more directed approach (Strouse, 1996), such as a semistructured interview format, has been suggested by some (Mori, Gallagher, & Milne, 2000; Surman, 1992). A recent study by Hoffman, Szkrumelak, and Sullivan (1999) also demonstrated the utility of a more intensive psychodynamically oriented interview approach for bone marrow transplant candidates.

A supportive environment has been found to be an important factor in favorable outcomes of all types of transplant (Christensen, Turner, Slaughter, & Holman, 1989; Debray & Plaisant, 1990; Molassiotis, van den Akker, & Boughton, 1997; Schlebusch, Pillay, & Louw, 1989; Surman, 1992). Assessment of the quantity and quality of the patient's support system is vital and can be facilitated through the use of collateral family interviews. These interviews provide the transplant team with additional crucial information, particularly when certain factors (i.e., cognitive impairment or substance abuse) render the patient an unreliable historian. Interaction with family members offers an opportunity for the interviewer to assess the nature and quality of the patient's social support system, observe family communication patterns, and facilitate the expression of family members' attitudes, reservations, and fears about the patient's transplant and his or her perceived role in the process (Strouse, 1996).

With substance-abusing patients, collateral information about history, current usage, and corroborated reports of abstinence serve to clarify the nature and extent of the addiction and allow the team to intervene with strategies for treatment or relapse prevention (Beresford, 1992). Patients who present emergently for transplant (e.g., acute hepatic failure) are often unable to undergo a lengthy evaluation process and in some cases may not even be conscious. In this instance, informed consent cannot be obtained, and interviewing family members to determine a patient's eligibility for transplant is critical, particularly if there are concerns about the patient's ability to cope with the responsibilities of becoming a transplant recipient. Every attempt should be made to contact physicians previously responsible for the patient's care and to request and review past medical records that might include information about noncompliance, substance use, and past psychiatric illness (Carlson et al., 2000; Strouse, 1996).

Although formal testing is generally not included as part of the psychological screening process for many organ transplant programs in the United States (Levenson & Olbrisch, 1993b), administration of neuropsychiatric and psychological measures may serve to highlight cognitive and personality factors (Brandwin, Trask, Schwartz, & Clifford, 2000; Carlson et al., 2000; Dobbels, Put, & Vanhaecke, 2000) that may warrant further clinical attention (Greene & Sears, 1994). Most transplant populations have significant potential for cognitive decrements related to the nature of the specific disease process (e.g., hepatic encephalopathy, hypercarbia, hypoxia, uremia). Often, psychosocial assessment of transplant candidates includes a routine, brief screen for cognitive deficits (e.g., mental status exam, trail-making test; Freeman et al., 1992; Strouse, 1996). A more comprehensive neuropsychological evaluation, including tests of intellectual functioning, verbal learning and memory, psychomotor speed, and executive functioning may be recommended following poor performance on a screening

instrument or upon observation of cognitive difficulties during the clinical interview (Farmer, 1994; Tarter & Switala, 2000).

In an effort to provide appropriate comparison groups within organ systems, normative data on commonly used measures of cognitive functioning, affective status, psychosocial adjustment, coping, quality of life, and life satisfaction have recently been published for liver, cardiac, kidney, and bone marrow transplant candidates (Baker, Marcellus, Zabora, Polland, & Jodrey, 1997; DeShields, McDonough, Mannen, & Miller, 1996; Greco, Brickman, & Routh, 1996; Hecker, Norvell, & Hills, 1989; Putzke et al., 1997; Sears, Rodrigue, Sirois, Urizar, & Perri, 1999; Streisand et al., 1999; Trzepacz, Brenner, & Van Thiel, 1989; Triffaux et al., 2001). Although the movement toward establishing normative databases for the assessment of transplant candidates is promising, wide variation exists in the types of instruments used to assess the different domains of functioning in adults (Mori, Klein, & Gallagher, 1999; Riether, Lewison, & Cohen-Cole, 1992) and there is a pressing need to study the differential aspects of pretransplant evaluation in pediatric and adolescent patients (Shaw & Taussig, 1999).

Although the option of living donation is a viable alternative for a small segment of solid organ transplant patients (e.g., kidney, liver), many still remain wait-listed for significant periods of time because of the shortage of available organs. Periodic follow-up assessments to monitor changes in affective status, cognitive functioning, support system, compliance, and, when indicated, abstinence from substance use are desirable (Dew, Switzer, et al., 2000; Rodrigue, Pearman, & Moreb, 1999) but may not be economically or practically feasible. Nevertheless, Stevenson (1996) argues that successful outcomes may well depend on serial assessments and continuity of care throughout the pretransplant process.

Adaptive Challenges for Transplant Patients and Relevant Psychological Interventions

The transplant patient encounters adaptive challenges at each stage of the illness and treatment (i.e., organ failure/chronic illness, pretransplant evaluation, waiting for a donor, surgery, recovery, rehabilitation, permanent maintenance). Psychological interventions are often required to assist patients in these adaptations (U. Koch, 1999; Soos, 1992; Tringali, Arria, & Trzepacz, 1994). Although established treatment approaches are useful, therapists must adapt treatment strategies to address the unique problems encountered by patients throughout the transplant process (Soos, 1992).

Acceptance of and Adjustment to the Patient Role

Accepting the patient role is an important precursor to facilitating the patient's cooperation with medical treatment. Perhaps the most common psychological defense mechanism is denial or avoidance, which, although adaptive in milder forms (Levenson & Olbrisch, 1993a), can greatly interfere with a patient's ability to accept and adjust to the diagnosis of a chronic medical illness. In pediatric heart and lung transplant patients, denial within the family system has particularly damaging effects on the patient's ability to adjust and cope (Parsons, Goodwin, Bickerton, & Lask, 1996). Patients who have had sudden, unexpected onset of organ failure may be particularly vulnerable to acute maladaptive denial, which can result in noncompliance with medical treatment and

disregard of modifiable risk factors (i.e., tobacco use, substance abuse). Avoidant coping can be detrimental (Levenson & Olbrisch, 1993a), and extreme denial is the most common reason for patients to refuse transplant (Frierson, Tabler, & Lippman, 1990).

The role of transplant patient often requires adjustment to losses in various domains (i.e., occupational, physical, and social) and can precipitate unexpected difficulties (e.g., change in financial status). The patient is also confronted with seemingly endless medical sequelae related to the surgical procedure, rigorous medical surveillance and immunosuppression maintenance, which may result in adoption of a perpetual sick role. Studies that have examined coping mechanisms suggest that for patients and significant others, problem solving, optimism, and religious coping are associated with better adjustment in the short and long term (Tix & Frazier, 1998). One longitudinal study of cardiac transplant patients found that even in patients who experienced health setbacks, positive preoperative expectations were associated with good mood, adjustment to the illness, quality of life and medical compliance (Leedham, Meyerowitz, Muirhead, & First, 1992).

Waiting for a Donor

The pretransplant period is often a very anxious time, during which patients face the decision to pursue transplant, the evaluation process, and the inevitable waiting period (Levenson & Olbrisch, 1987; Moran, Christensen, Ehlers, & Bertolatus, 1999). Additionally, candidates may experience fears about the procedure (i.e., anesthesia, pain, bleeding, intubation, "alien" tissue), potential invalidism and mortality (Tringali et al., 1994). Less acutely ill patients are often required to wait longer for an organ, risking serious health deterioration before transplant. The relationship with the medical team may be vulnerable during this period because of patient uncertainty about where they rank on the waiting list (Levenson & Olbrisch, 1987). Patients often inhibit self-advocacy or dissatisfaction with treatment providers, fearing that it may negatively affect their chances of receiving an organ. This in turn accentuates the power differential between patient and provider and may result in suboptimal communication and a maladaptive provider-patient relationship.

Financial Issues

The transplant process is extremely costly (\$100,000–\$300,000), and most individuals cannot afford the procedure without insurance or some form of assistance (Geevarghese et al., 1998). Patients who are candidates for longer periods (i.e., 31–352 days) find paying bills to be more stressful than do emergent patients (Jalowiec, Grady, & White-Williams, 1994), as they have had more time to accrue (and worry about) higher medical costs. The high cost of medications and the need for extended postoperative care make transplantation a long-term financial commitment and hardship for most families, especially when the patient is the primary source of income. These financial difficulties may create pressure for patients to discontinue or reduce their immunosuppressants, placing them at high risk for graft rejection. Patients receiving disability payments are often incentivized to remain unemployed or risk losing their benefits (Levenson & Olbrisch, 1993a; Paris, Tebow, Dahr, & Cooper, 1997). Those who wish to work may find employers reluctant to hire someone at risk for high health care costs.

Family Issues

Family members of transplant patients often face many challenges and adjustments, which may have a significant impact on their relationship with the patient, the patient's coping (Moran et al., 1999), and their own physical and mental health (Dew et al., 1998). In particular, the stress for spouses is significant (Frazier, Davis-Ali, & Dahl, 1995), especially in the early posttransplant period, when difficult decisions are required and adjustment to life changes must be made (Canning, Dew, & Davidson, 1996). For example, it is common for the transplant center to be distant from the patient's home, necessitating difficult choices for spouses or partners (e.g., staying home to care for children, missing work to be with the patient). In some instances, family members may feel pressure to become living donors when there is the option to do so. Should it become necessary, the patient's family often assumes the responsibility for organizing fundraising efforts. Other issues may be more intrapsychic than instrumental in nature, such as fear of losing a loved one or guilt about a familial disease that may have resulted in the need for transplant (e.g., hypertension, breast cancer, cardiac disease). Watching a loved one suffer with a serious medical condition also raises certain questions that may be quite upsetting and difficult to talk about (e.g., balancing acts, change in family roles, coping with uncertainty).

Because of the volume of transplant patients and the scarcity of mental health resources, it is not always possible or realistic for the transplant team to provide all the support that is needed by family members. However, the inclusion of caregivers into medical and psychological visits is generally experienced as a valuable opportunity to provide education and support, monitor family interactions, and, if necessary, provide referrals for mental health care (e.g., support groups) in the family's local area. Participation in psychological support groups by patients and family members has been found to increase compliance, provide validation, offer social support, facilitate the educational process, and increase a sense of control (Kober, Kuchler, Broelsch, Kremer, & Henne-Bruns, 1990; Soos, 1992; Stewart, Kelly, Robinson, & Callender, 1995). Support groups or other forms of interventions such as marital or family therapy can also provide assistance in regaining or renegotiating family roles and a forum for family members to address issues unique to caretakers.

Psychiatric Disorders and Psychological Interventions

Psychiatric disorders are common among transplant patients (see Dew, Switzer, et al., 2000 for a comprehensive review). Although many studies cite a strong influence of psychiatric illness on posttransplant morbidity and mortality (Dew, 1999; Dew, Roth, Schulberg, & Simmons, 1996), the evidence is mixed. For example, a recent investigation of lung transplant patients found that a premorbid psychiatric history did not predict a worse outcome posttransplant (Woodman et al., 1999). Psychological variables also did not predict survival of bone marrow transplant recipients (Broers et al., 1998), although emotional difficulties during recovery were predicted in another bone marrow study (Molassiotis, 1999). Cardiac transplant candidates and recipients who showed high distress on the Millon Behavioral Health Inventory (Millon, Green, & Meagher, 1982) had greater mortality than low-distress patients (Brandwin et al., 2000). In addition, a study of pretransplant candidates across organ systems found Axis I diagnoses to be

associated with poorer psychosocial adjustment and health status and Axis II disorders to be associated with medical compliance problems (Chacko, Harper, Kunik, & Young, 1996).

Preoperatively, adjustment disorders with depression and/or anxiety are highly prevalent in the transplant population. The incidence of major depression ranges from 2% to 16%, and many patients report primary anxiety (approximately 39%; Trzepacz, Levenson, & Tringali, 1991). A study examining 311 candidates for major organ transplants found that 60% of patients met criteria for Axis I disorders and 32% for Axis II disorders. Twenty-five percent of candidates have comorbid Axis I and II disorders, representing a subgroup at special risk for problematic outcomes (Chacko et al., 1996).

Posttransplant, psychological difficulty in adult cardiac transplant patients was found to be increased by pretransplant psychiatric history, poor social supports, the use of avoidant coping strategies and low self-esteem early posttransplant (Dew et al., 1996). Changes in body image are also common (Engel, 2001). Many illness-related psychiatric disorders abate postoperatively (Moore, Burrows, & Hardy, 1997), but medication-induced mood disorders and anxiety are common in the first year posttransplant (Surman, 1994). Major depression was found to be the most prevalent disorder, followed by post-traumatic stress disorder and adjustment disorders in the first year after cardiac transplant (Dew et al., 1996), with episodes developing after the first year less likely to be precipitated by transplant-related stressors (Dew et al., 2001). A Hong Kong study of 101 kidney recipients identified the main stressors posttransplant to be fear of organ rejection and infection, anxiety about medication regimen and side effects, uncertainty about the future, and financial concerns (Kong & Molassiotis, 1999). Coping predicted quality of life outcomes at 1 year after heart transplant (Grady, Jalowiec, & White-Williams, 1999). Reliance on criteria from the *Diagnostic and Statistical Manual of Mental Disorders* (4th ed.; American Psychiatric Association, 1994), however, may lead to underdiagnosis of problems common among medical patients (Grandi et al., 2001). A guilt-related disorder termed *paradoxical psychiatric syndrome* has been identified among a significant number of adult recipients of organs from living donors in Japan (Fukinishi et al., 2001). Although patients typically feel a sense of relief and well-being in the initial posttransplant period, adjustment problems, coping difficulties, or existential issues may develop over time (Soos, 1992).

Because of the likely presence of psychiatric comorbidity in transplant patients, the literature consistently stresses the importance of mental health assessment and intervention (Howard, Williams, & Fahy, 1994; Levenson & Olbrisch, 2000). An integrative model, combining aspects of various approaches to psychotherapy, has been recommended for use throughout the transplant process as an efficacious method of addressing the myriad of problems confronting these patients (Reid, 1990). For example, self-control procedures (i.e., progressive muscle relaxation, systematic desensitization, self-hypnosis, visual imagery) are useful in reducing anxiety during any phase of the process (e.g., undergoing medical procedures). Other skill-building techniques may be incorporated as well (e.g., assertiveness training, anger management, problem solving) to instill or restore a sense of mastery or control in situations where patients often feel powerless (e.g., dealing with managed-care issues). A cognitive-behavioral approach is effective when the patient has unrealistic expectations for him- or herself or others or when irrational thought patterns threaten emo-

tional stability. Patients with high preference for health-related information demonstrated reduced depression following renal transplant, whereas patients with low preference for information tended to demonstrate increased depression (Christensen, Ehlers, Raichle, Bertolatus, & Lawton, 2000). However, it is not clear whether educational interventions are equally effective for patients with different coping styles. Using a psychodynamic approach, Bosnak (1996) found dreamwork to be helpful in aiding transplant patients to adjust to their new organ. Although psychotropic medications have been very useful in treating depressive, cognitive, and anxiety symptoms in transplant candidates (Fukinishi et al., 1998; Plutchik, Snyder, Drooker, Chodoff, & Sheiner, 1998; Shapiro, 1991), careful consideration must be given to changes in pharmacokinetics, drug interactions, and side effects (DiMartini & Trzepacz, 1999). Electroconvulsive therapy may also be indicated to treat depression in some patients (Lee, Jayaran, & Teitelbaum, 2001).

Substance Use and Abuse

Substance abuse among organ transplant candidates, including alcohol, nicotine, and other drugs, presents a challenge for transplant teams. Transplant programs strive to reduce morbidity and mortality, as they bear a social responsibility for using scarce organs wisely and ensuring the best possible outcomes (Levenson & Olbrisch, 2000; Olbrisch & Levenson, 1995). Given that substance abuse can undermine the immediate and long-term success of the surgery, transplant centers would be remiss if they did not have policies and procedures in place to address this issue. The assessment, treatment, and monitoring of these patients, however, require specific expertise (Stowe & Kotz, 2001).

Formerly, alcohol abuse or illicit drug use was viewed as an absolute contraindication for transplantation (Beresford, 1992). However, particularly in the alcoholic liver transplant population, it has been clearly demonstrated that carefully selected recipients do not differ significantly from nonalcoholic recipients in terms of morbidity and mortality (Beresford, 1992). Not surprisingly, methods other than self-report demonstrate higher relapse rates than patients are willing to acknowledge (Fabrega et al., 1998). However, the associations among pretransplant variables, relapse, and survival do not provide clear guidance for development of patient selection criteria (Tringali, Trzepacz, DiMartini, & Dew, 1996). Nevertheless, recent studies of risk factors for recidivism have provided crucial information, which will inform future clinical practice (Dobbels et al., 2001; Gish et al., 2001). Today, selection practices among transplant centers with regard to substance abuse remain variable. Most centers prefer to require rehabilitation or monitoring and tend to avoid outright rejection of applicants on the basis of current or past substance abuse.

Although abstinence from substance use is generally agreed to be an important goal from a behavioral health perspective, there is no consensus on the best method to reach it. Motivational interviewing (Miller & Rollnick, 1991) has been shown to be an effective technique in moving patients to change harmful or unhealthy behaviors that may impede or prevent a transplant or jeopardize a successful outcome. This approach may also be used in combination with other techniques (i.e., behavioral contracting, coping-skills training; Cupples & Steslow, 2001; Nelson, Presberg, Olbrisch, & Levenson, 1995). Group settings such as 12-step programs and relapse prevention groups have also been found to

be effective components of substance abuse treatment programs, both pre- and posttransplant (Tringali et al., 1994; Wagner, Haller, & Olbrisch, 1996).

Smoking is an adverse risk factor for all transplant candidates. This is most evident for heart and lung transplant, but smoking increases perioperative morbidity and mortality (e.g., myocardial infarction, stroke) with all major surgery. Recently, decreased survival in smokers has been shown in cardiac (Nägele, Kalmar, Rödiger, & Stubbe, 1997) and renal transplant patients (Cosio et al., 1999). Although abstinence is generally recommended, most centers do not require patients to quit smoking in order to be listed as candidates except in heart and lung transplant.

Cognitive Impairment

Cognitive impairment is commonly seen in one third of all patients with end-stage organ failure diseases (Burkhalter, Starzl, & Van Thiel, 1994; Guarino et al., 1996) and can present during any phase of the transplant process. In the pretransplant phase, cognitive impairment can be caused by metabolic imbalances such as hepatic encephalopathy and uremia, but these deficits typically reverse after transplant. Postoperative cognitive impairment is also common and can be caused by several factors (e.g., medication, infection). In general, patients demonstrate good cognitive recovery at 1 week posttransplant with only mild evidence of cognitive impairment (DiMartini, Trzepacz, Pajer, Faett, & Fung, 1997; Howard et al., 1994).

Delirium, typically treated with low-dose neuroleptics, is the most prevalent neurocognitive impairment in transplant patients. In the pretransplant phase, delirium ranges in incidence from 3% to 50% (Trzepacz et al., 1991) and is usually secondary to organ failure. Immediate postoperative delirium can be caused by hypoxia, electrolyte disturbance, hepatic insufficiency, renal failure, hyperglycemia, central nervous system embolus, infection, organ rejection, hepatorenal syndrome, and drug toxicity (Trzepacz et al., 1991). Early postoperative delirium is observed frequently and is more likely to occur when there have been preoperative neurological problems. During the maintenance immunosuppressant phase, delirium is usually due to infection or acute rejection. Delirium can present a diagnostic challenge, as it is often misdiagnosed as depression or anxiety (Trzepacz, Maue, & Coffman, 1986). Nevertheless, it is important to detect even mild delirium, as it alters a patient's ability to fully comprehend and comply with medical treatment.

Immunosuppression, Medication Side Effects, and Compliance

Lifelong compliance with immunosuppressant medications is crucial to prevent graft rejection (except autologous bone marrow). A recent review of the literature (Bunzel & Laederach-Hoffmann, 2000) found that noncompliance or poor compliance is responsible for up to 25% of deaths in transplant patients after the initial recovery period. Immunosuppression requires patients to be mindful of infection risk in situations they previously had taken for granted; this may be burdensome for many patients, who understandably are eager to abandon the sick role after surgery. Even after full recovery, health vigilance remains important, as immunosuppression increases vulnerability to infections. Accordingly,

patients must take precautions such as frequent hand washing and minimizing contact with sick individuals.

Immunosuppressant medications are challenging for patients owing primarily to the numerous side effects, including mood swings, sleep disorders, gastrointestinal problems, fever, sexual dysfunction, cognitive dysfunction, decreased coordination, tremors, headaches, and hallucinations (Franke et al., 1999). Immunosuppressant neurotoxicity is common in the early posttransplant period and can mimic serious neuropsychiatric conditions (Strouse et al., 1998). Patients report, however, that most side effects diminish with time, and the advent of newer drugs (e.g., mycophenolate mofetil, sirolimus) has made it possible to reduce side effect burden.

Although there are methodological challenges to obtaining reliable compliance data, noncompliance with immunosuppressant medication has consistently been associated with rejection episodes, graft loss, retransplant, and death (Brickman & Yount, 1996; Bunzel & Laederach-Hoffmann, 2000; Dew et al., 1999; Rudman, Gonzales, & Borgida, 1999; Shapiro, Williams, Gelman, Foray, & Wukich, 1997). In a recent study of heart transplant recipients, Dew (1999) found that psychological distress in the early posttransplant period predicted compliance levels at 2 and 7 months postsurgery. Another finding showed that recent lung transplant recipients demonstrated better compliance than those further along in recovery, suggesting the necessity for patient reeducation in the posttransplant period (Teichman, Burker, Weiner, & Egan, 2000). Compliance with behavioral recommendations is also a factor in morbidity and mortality; Dew, Kormos, et al. (1999) found that obesity was even more important than medication compliance as a risk factor for cardiac allograft disease among heart transplant recipients.

Physical Rehabilitation and Return to Work

Because of protracted convalescence, many transplanted patients often become markedly deconditioned. Prolonged immobility and treatment with corticosteroids cause loss of muscle and bone mass. Consequently, physical rehabilitation can be a long and difficult process. Patients with minimal complications generally rehabilitate at home without medical assistance. Even after physical rehabilitation, however, patients may face functional limitations and medical restrictions in their activities.

Employment is an important aspect of the reestablishment of a transplant recipient's identity, self-esteem, and quality of life (Paris et al., 1997). History of alcoholism has been associated with lower likelihood of return to work in France (Pageaux et al., 1999), but this result has not been replicated in other countries (Stefanini et al., 1997). For those who attempt to reenter the work force, medication and surgery side effects can impede their ability to return to the same type of work. Common difficulties include concentration problems, fatigue, trouble coping with stress, and frequent sick days (Olbrisch et al., 2000). In spite of these challenges, recent studies have demonstrated that most transplant patients are able to resume work within 9–12 months posttransplant (Moore et al., 1997; Olbrisch et al., 2000). The transplant program can influence return to work by explicit expectations and policies against automatically supporting applications for continued disability benefits (Paris et al., 1997).

Graft Failure and Retransplant

Irreversible graft failure can be a life-threatening complication. Kidney transplant recipients who experienced graft failure were more likely to become depressed if they exhibited an internal health locus of control (Christensen, Turner, Smith, Holman, & Gregory, 1991). Retransplant is often the only treatment, depending on organ type, and takes place in approximately 17% of cases (Gallichio, Hudson, Young, Diethelm, & Deierhoi, 1998; Marckmann et al., 1997). In 1999, candidates for retransplant represented 14% of wait-listed patients (UNOS, 2001). Many patients with graft failure do not end up on the wait list for multiple reasons, including patient choice, deteriorated medical condition, and, most commonly, nonreferral despite patient interest (Gallichio et al., 1998).

Retransplant is associated with markedly increased morbidity and mortality and generally inferior outcomes (Gallichio et al., 1998; Marckmann et al., 1997). A number of variables have a significant effect on outcome such as age, interval to retransplant, total number of grafts, and recipient UNOS status. Because donor organs are few in supply and high in demand, some argue that retransplant is too costly and uses organs inefficiently (Marckmann et al., 1997). It is therefore recommended that patient selection remain stringent and guided by available outcome data.

Death and Dying

Despite the success of most transplant surgeries, a significant number of patients die either waiting for a donor or within the first year after transplant. The death of a recipient is obviously the most devastating outcome of transplant, although there are other losses throughout the process that may engender feelings of grief in patients, donors, and family members. For example, recipients may grieve the loss of their diseased organ or may face the loss or threatened loss of a graft (Fertziger, 1991; Rauch & Kneen, 1989). Living donors can have complicated reactions to graft failure, as they struggle to accept the loss of not only their donation but possibly their loved one (Switzer et al., 1998). Survivor guilt may be complicated by caregivers' feelings that sufficient attention may not have been given to signs of rejection or infection. These issues, if unresolved or poorly handled, may result in a difficult bereavement process for those close to the recipient, including transplant team members.

Liaison Issues

Typically, a transplant team includes specialists from surgery, internal medicine, nursing, psychology or psychiatry, and social work. Representatives from other medical specialties and disciplines may be included as well (e.g., anesthesiology, financial services, occupational or physical therapy, nutrition, chaplain). The effectiveness of a multidisciplinary team is influenced by several factors, including the promotion of a clear understanding of members' specific duties and responsibilities (Youngson-Reilly, Tobin, & Fielder, 1995) and maintenance of healthy team dynamics. For example, it is imperative for team members to engage in a cooperative, integrated effort to present a consistent message to patients, particularly when educating them about the transplant process and their responsibilities as transplant recipients. Further, positive interdisciplinary collaboration and communication serve

to foster a supportive team environment in which the quality of the services provided to patients and their families is optimized.

Despite collaborative efforts, the issue of competing agendas inevitably emerges whenever different disciplines are involved in the care of patients and, ideally, should be acknowledged and openly addressed. Genuine attempts must be made by team members to recognize the different arenas in which other professionals work and to respect differing values concerning outcomes of care. For example, the transplant surgeon may consider patient and graft survival to be the primary determinants of positive outcome, whereas members of the psychosocial team may hold a more contextual, holistic view of success. Harmonizing various goals and methods is challenging and requires a focus on patient needs and respect for various viewpoints and contributions to patient care.

The compassionate care of transplant patients requires dedication and empathy on the part of caregivers. For members of the transplant team, this level of commitment often results in prolonged job stress, which places individuals at high risk for developing burnout, a syndrome in which the individual experiences a depletion of physical and emotional strength (Felton, 1998). Transplant psychologists, therefore, must be sensitive to symptoms of burnout in themselves and others. Contributing factors include long work days, frequent on-call time, emergent situations requiring immediate coordination of services, life-and-death decisions, and the emotional distress that accompanies the loss of a patient. Recent literature stresses the importance of early recognition and intervention for burnout in health care professionals in order to avoid disruption in the provider-patient relationship (Felton, 1998; Molassiotis & Haberman, 1996).

Psychologists may also find themselves serving as patient and family advocates. Frequently, the rescue mentality of transplant physicians exhibits itself in a "full court press" to do everything possible for a failing patient, even long after the family has become exhausted and given up hope. The simple act of arranging a family meeting where information can be shared, misunderstandings resolved, and concerns expressed can do much to prevent negative feelings and bring the patient, family, and health care providers into agreement.

Another role that might emerge for the transplant psychologist is that of "therapist" to the team. Although it is appropriate and necessary to educate the team about boundary issues they may confront in caring for transplant patients (e.g., emotional attachment to patients, participation in fundraising activities, attending funerals), the psychologist must also recognize the limitations of interventions with team members (i.e., potential dual relationships) and maintain an awareness of their relevant role as team member and colleague.

Ethical Issues

The scarcity of donor organs and the high cost of transplant create a unique set of circumstances that raise ethical concerns. These concerns include questions about the application of transplantation in special populations, the duties of transplant professionals to their own patients and to patients other than those under their care, and the use of healthy living donors who subject themselves to risk to help another person. Although full exploration of these topics is beyond the scope of this article, we briefly discuss some of these concerns.

Special Populations

Achieving justice in allocation of organs is difficult. Consensus may be difficult to achieve on some issues, and most programs prefer to rely on empirical data in setting policies. Age of the patient to be transplanted is frequently of concern. In the past, transplant programs set age cutoffs on the basis of poor outcomes in the elderly, but with more experience it has been demonstrated that carefully selected elderly patients have outcomes comparable to those of younger patients (Filipponi et al., 2001; Laks, Marelli, Odim, & Fazio, 2001). In light of these data, along with our society's laws against age discrimination, debate concerning the relative value of added years for a younger versus an older patient has largely disappeared. The adolescent age group also faces special problems. Frequently rebellious or irresponsible, with conflicts about identity, conformity, and body image, adolescents are often seen as poor candidates for life-saving surgery that demands so much of them (Lurie et al., 2000). These young transplant patients need special attention to negotiate the transplant recipient role along with other developmental issues. Transplant in persons with mental retardation or serious mental illness also raises concerns because such patients may be incapable of adhering to a complex medical regimen over a long period of time.

Patients with drug and alcohol abuse histories, including patients who require methadone maintenance therapy, are often looked on as contributing to their illness and therefore worthy of less consideration than others (M. Koch & Banyas, 2001; Sears, Marhefka, Rodrigue, & Campbell, 2000; Ubel et al., 2001). Such attitudes are inappropriate and should be confronted. Equally concerning is the tendency for some transplant programs to minimize concern about addictive problems and the emotional pain caused by these problems for patients and family members. Comorbid medical conditions that may influence outcome, such as HIV+ status, cancer, and even more common problems like diabetes, must be reassessed as barriers to transplant as newer treatments are developed and data about long-term outcomes accumulate. Likewise, transplant programs must be open to data that demonstrate that transplant does not improve or may even detract from patient outcome in some instances (e.g., bone marrow transplant for patients with breast cancer).

Transplant of prisoners is a thorny issue given that their medical care is paid for by government, whereas law-abiding patients on public assistance may not qualify for transplant coverage. Transplant of foreign nationals raises questions about the ability of certain persons to buy access to medical care that is not available to less well-off citizens. Finally, although celebrity transplants improve public awareness of transplant issues for the community, they also raise questions about fair access and equal burden (e.g., whether celebrities experience shortened waiting times).

Duties of Transplant Professionals

Careful selection of patients likely to survive and do well with transplant surgery is an important responsibility of transplant teams. For example, transplant physicians and others on the team may have formed an enduring relationship with a patient and a desire to do everything to help, even when the odds of success are low. This desire must be balanced against a concern for all patients who need transplant surgery, as well as loyalty to the program itself, which will not survive by transplanting patients who do not

succeed. Psychologists who evaluate and treat transplant recipients may find themselves in conflicting roles, both as advocate and as objective evaluator (Olbrisch, 1996).

Living Donors

Living donors are increasingly used in both kidney and liver transplant (Marcos et al., 1999; UNOS, 2001). Issues to be addressed in the psychosocial evaluation of living organ donors include informed consent, the decision process, motivation, coercion, social support, behavioral health, psychological health and coping, the donor-recipient relationship, and management of the relationship between recipients and donors who are unknown to them (Olbrisch, Benedict, Haller, & Levenson, 2001). Data that answer questions about the characteristics and motivations of donors are needed, especially as more programs experiment with Good Samaritan or living anonymous donation (Dixon & Abbey, 2000). Because motivations are different for related (genetically and emotionally) and unrelated donors, the donor assessment protocol may also need to be different. As living donation becomes more frequent, it will be important to study outcomes for psychosocial as well as medical variables for both donors and recipients (Switzer, Simmons, & Dew, 1996). Ultimately, donations by strangers may prove to be less complex than donation between biologically and emotionally related individuals.

Directions for Future Research

The early research regarding psychological aspects of transplant consisted primarily of case reports and descriptive reviews emphasizing intrapsychic and interpersonal issues (Dew, Switzer, et al., 2000). Later, small, mostly cross-sectional groups of patients were described. Most studies focused on different phases of transplant, using structured approaches to diagnosis and a variety of symptom-rating instruments. Subsequently, larger studies, some longitudinal, examined the extent to which transplant outcomes were affected by pretransplant psychosocial factors. Each of these was limited to particular transplant centers, raising questions of generalizability. The single issue of this type most often studied has been the outcomes of patients with alcoholic liver disease who received hepatic transplant. Although it has been possible to gain greater perspective on many issues as a result of comprehensive qualitative and quantitative reviews of the literature (Bravata, Olkin, Barnato, Keeffe, & Owens, 1999; Bunzel & Laederach-Hofmann, 2000; Dew et al., 1997, 2000; Dew, Goycoolea, Switzer, & Allen, 2000; Dobbels et al., 2001), aggregation of the findings of better and more poorly designed studies may be misleading.

Understanding the obstacles to psychological research in transplant encountered in the past enhances the potential for future opportunities. Obtaining funding was once very difficult, as mental health sources (e.g., the National Institute of Mental Health) did not view organ failure and transplant as part of their research mission, and medical sources (e.g., the National Institutes of Health branches) did not view psychopathology in transplant patients as within their domain of interest or expertise. This has begun to change in recent years, and interdisciplinary studies now have a better chance of being funded. Funding is only one of the critical obstacles to meaningful research. Before and after transplant, these are medically complex patients who are in and out of the hospital and often live distant from the transplant center,

making longitudinal psychological research difficult. In addition, the validity of many psychological instruments in the severely medically ill is questionable.

What type of research is needed? Generalizability would be improved by conducting research at multiple sites (national and international). More research is needed regarding the reliability and validity of the psychosocial dimension of the candidate selection process. One fundamental limitation in studying the effect of pretransplant psychological factors on transplant outcome is that no transplant program can transplant every potential recipient. In addition, referral bias cannot be eliminated.

There has been very little study of psychosocial aspects of pediatric transplant. Adherence and quality of life in adults after transplant has received attention (see Dew et al., 1997, for a comprehensive review), but more studies that can make a difference are needed. The psychophysiology of transplanted organs has been studied only for hearts (Shapiro, Sloan, Bigger, Bagiella, & Gorman, 1994; Sloan, Shapiro, & Gorman, 1990). Further work might shed light on basic mechanisms, as could studies of psychoimmunology in immunosuppressed transplant recipients, so far studied only in animal models (Grochowicz et al., 1991).

Although we have much to learn regarding psychological aspects of current modes of transplant, the field is rapidly changing. Psychological investigators are needed on the frontiers of transplant. Technological innovations such as expansion of living-donor pools to include donations between strangers, transplant of external body parts such as hands (e.g., Klapheke, Marcell, Taliaferro, & Creamer, 2000), and transplants from animal donors (e.g., Schlitt, Brunkhorst, Haverich, & Raab, 1999) will drive the research agenda into new territories.

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