J Clin Psychol Med Settings (2015) 22:122–135
DOI 10.1007/s10880-015-9435-6

Psychosocial Challenges in Solid Organ Transplantation

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Abstract Organ transplantation is often a life-saving surgery for individuals with end-stage organ disease. However, for most types of solid organ transplant, the demand for organs outweighs the supply, resulting in the need to institute a waiting list for suitable patients who cannot immediately receive an organ. Individuals who need transplants must undergo an assessment process that includes medical, surgical, and psychosocial evaluations. The transplant psychosocial evaluation considers whether surgical candidates are able and willing to care for the transplanted organ for many years. The evaluation must also consider a number of psychosocial risk factors that can lead to complications, which may cause premature loss of the graft. Some of these risk factors include a history of poor medical adherence, psychopathology (including substance use disorders), poor social support, and cognitive dysfunction. This article briefly summarizes the assessment of each of these risk factors and how they can be mitigated to ensure the best outcomes for patients and their families.

Keywords Organ transplantation · Psychosocial assessment · Non-adherence · Psychopathology

Introduction

Last year, in the United States, 28,954 solid organ transplants were performed (Organ Procurement and Transplantation Network, 2014). Though a number of transplant patients receive their organs from living donors, the majority of transplant recipients get their organ(s) from a deceased donor. There continues to be a shortage of organ donors to meet the demand of those in need. Given that organs are in short supply, it is crucial that organs are allotted fairly and to those who will achieve the most optimal outcomes (Olbrisch, Benedict, Ashe, & Levenson, 2002). All transplant programs attempt to minimize morbidity and mortality, given the scarcity of available organs for transplant (Butt, Parikh, Skaro, Ladner, & Cella, 2012; Butt, Yount, Caicedo, Abecassis, & Cella, 2008; Jay, Butt, Ladner, Skaro, & Abecassis, 2009). Thus, the pre-transplant psychosocial evaluation has an important role in identifying individuals who are appropriate transplant candidates. Caring for a transplanted organ requires a lifelong commitment by the recipient that involves adhering to a daily medication schedule, getting routine blood draws and/or biopsies, attending doctors' appointments, and making significant lifestyle and behavioral modifications. Failure to adhere to any of these responsibilities can lead to rejection of the transplanted graft, graft failure, or death (Laederach-Hofmann & Bunzel, 2000).

When patients reach end-stage organ failure, they can be referred by their physician or self-refer to a transplant center to pursue listing for transplant. Once a transplant referral is initiated, the patient is contacted, usually by a transplant nurse coordinator, to start the evaluation process. Though exact procedures differ across centers and organ groups, the evaluation process entails a medical/surgical evaluation and a psychosocial evaluation. Often the first

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step is obtaining financial clearance for patients, ensuring they have sufficient insurance and the ability to pay for post-transplant costs. The medical process then begins typically with formal education about transplant, evaluation by a transplant physician and surgeon, and a meeting with the transplant nurse coordinator. The psychosocial evaluation typically consists of patients meeting with a social worker and also a transplant psychologist or psychiatrist if they are part of the team. Some transplant centers have all patients evaluated by a psychologist or psychiatrist while others only use these specialists on an as-needed basis. When the evaluation is complete, a committee of transplant specialists related to each organ group convenes to decide whether a patient is an appropriate candidate. If a patient is approved as a transplant candidate, he or she can go on the transplant list, a computer database containing medical information on all who are awaiting transplant (United Network for Organ Sharing, 2015). Transplant hospitals must notify potential candidates within 10 days of a decision to inform them of their date of listing. Once patients are on the waiting list, they are typically seen on a regular basis at the transplant center for "wait-list visits" to ensure they remain medically and psychosocially appropriate candidates. When an appropriate organ becomes available for the patient, he or she is called to the hospital to receive the transplant. For more information about the details of the transplant evaluation and listing process, please refer to Skillings and Lewandowski (2015) and Sullivan et al. (2012).

A transplant psychologist may receive a referral from multiple team members ranging from the surgeon to the social worker. It is most helpful if an algorithm is created and distributed to transplant team members to help them determine when a psychology or psychiatry referral is appropriate. Once a referral is initiated, there are several goals including identifying patients' psychosocial strengths and weaknesses, making a plan for remediation with the patient when applicable, and sharing the findings of the evaluation with the transplant team. During the psychosocial evaluation, a medical, psychological, and social history is obtained to identify patients' strengths and weaknesses as they relate to managing a complex post-transplant regimen. The information may be obtained through a semi-structured or structured interview. Several rating scales have been developed for the pre-transplant psychosocial assessment including the Transplant Evaluation and Rating Scale (TERS; Twillman, Manetto, Wellisch, & Wolcott, 1993) and the Psychosocial Assessment of Candidates for Transplantation (PACT; Olbrisch, Levenson, & Hamer, 1989). More recently, the Stanford Integrated Psychosocial Assessment for Transplantation (SIPAT; Maldonado et al., 2012) was developed as a comprehensive pre-transplant psychosocial screening tool. It has excellent inter-rater reliability and has demonstrated the ability to predict which patients will have poor outcomes after transplant. Any psychosocial factors identified in the pre-transplant psychosocial assessment that could interfere with the successful management of a transplant are brought to the attention of the transplant team at the multidisciplinary committee meeting. If a patient is found not to be a candidate for transplant because they have psychosocial or medical issues that are considered by the team to be too high-risk, they may be deferred as a candidate at that center. They are then free to pursue listing at another transplant center or return to the care of their referring physician for continued medical management. In cases where the identified issues are thought to be amenable to change, a plan for remediation may be implemented (Collins & Labott, 2007).

Multiple psychosocial factors have been identified as having an impact on the success of transplant outcomes. Some of these psychosocial factors are considered to be absolute contraindications, in the sense that the risk factor is judged to preclude transplant. On the other hand, relative contraindications are factors that put a patient at higher risk for complications, but may be outweighed, mitigated by other considerations, or successfully dealt with by interventions prior to transplant. Transplant centers (and even different organ programs within a transplant center) differ in their criteria for what constitutes an absolute versus relative psychosocial contraindication (Levenson & Olbrisch, 1993). For example, while active cigarette smoking is seen as an absolute contraindication to lung transplant, many liver transplant teams may still consider transplanting an active smoker, while encouraging smoking cessation. Because there is not always agreement among various transplant professionals about which psychosocial factors warrant deferral and which can be dealt with by remedial intervention, it is important to have clear, well-established psychosocial criteria to guide decisions about which risk factors constitute absolute contraindications and which constitute relative contraindications.

This paper is designed to provide a broad overview of some of the important psychosocial factors in organ transplantation. It is geared toward the psychologist who may have little to no experience with the field of transplantation. The most common risk factors for poor outcomes are reviewed, including non-adherence to the medical regimen, active psychopathology, substance use disorders, lack of social support, and cognitive dysfunction.

Non-Adherence to the Medical Regimen

Adherence to the post-transplant regimen plays a significant role in transplant outcomes. The most sensitive factor affecting patient and graft survival post-transplant is adherence to immunosuppressant medications. A literature review from 2005 revealed that non-adherence to immunosuppression (measured in multiple ways across 38 studies) contributed to 20 % of late acute rejection episodes and 16 % of graft losses in kidney transplantation (Denhaerynck et al., 2005). The authors asserted that given the lack of standardization in measuring non-adherence, this is likely an underestimate of the contribution of non-adherence to poor outcomes (Denhaerynck et al., 2005). In a prospective study of renal grafts that failed, 47 % of those lost to rejection were identified as related to non-adherence by the patient's physician (Sellarés et al., 2012). In heart transplant, 23 % of patients receiving a transplant have been observed to be non-adherent to their medication regimen within the first year after transplant, often resulting in an adverse impact on survival. In other organ systems, rates of non-adherence to immunosuppressant medication have been reported to range from 0 to 68 %, highlighting considerable variability in study methodology, assessment measures, and patient perceptions of their conditions (Dew et al., 2007).

Prior to transplant, patients often have to adjust to managing a chronic healthcare regimen. Many times, patients have been taking medications, following specific dietary recommendations, monitoring physical markers (e.g. blood sugar, weight, blood pressure), and engaging with medical providers for prolonged periods of time. Obtaining information about patients' pre-transplant behavior regarding their medical care is important so it can be used to help predict their behavior post-transplant (Lieber & Volk, 2013).

When considering patient adherence during the pre-transplant assessment, teams should consider identified factors that have been shown to be predictive of poor outcomes in solid organ transplant. Some of the demographic variables noted include younger age, being female, being unmarried, and having lower income (Dobbels, Van Damme-Lombaert, Vanhaecke, & De Geest, 2005; Frazier, Davis-Ali, & Dahl, 1994). Psychological factors, such as depression, anger and hostility have been shown to independently affect adherence and predict acute rejection (Dew et al., 1999). In addition, monitoring the way patients have interacted with healthcare team members can provide a window into patients' personalities and highlight patients with traits that may affect engagement and adherence to a medical regimen (i.e. narcissism, antisocial tendencies).

When patients who have been non-adherent with their medical regimen are referred for transplantation, the transplant team must decide how to proceed. At present, individual programs make judgments as to what level of adherence is required by patients being evaluated for transplant (Levenson & Olbrisch, 1993). Often, non-adherent patients are given an opportunity to demonstrate improved adherence prior to being listed for transplant. This is often done through "compliance contracts" or "behavioral contingency contracts" (Cupples & Steslow, 2001). These contracts clearly outline the expectations patients must follow for a period of time, often 3–6 months. After that period of time has passed, the transplant team re-assesses patients' adherence and determines whether it is likely they will be able to maintain adequate compliance with their medical regimen. Patients sometimes use the need for a transplant to make changes in their lives, such as addressing mental health concerns, altering substance use habits and re-establishing support networks, all risk factors which, unless changed, might work against being approved for transplant (Berlakovich et al., 1994).

After transplant, non-adherence is a common reason transplant psychologists are consulted. Patient non-adherence may be a key indicator of the presence of psychopathology or motivational difficulties, and the psychologist can play a role in identifying emotional or mental barriers. Multiple strategies to improve adherence have been recognized such as using a weekly pill box for medications, setting an alarm to remember to take medication doses, and keeping a calendar of all upcoming appointments and lab draws. Relatively recent technological innovations of smart phones, fitness trackers and internet- connected devices have yet to be widely incorporated into post-transplant regimens to aid adherence. However, a clear benefit is possible if patients choose to integrate these technologies into daily health reminders (Anglada-Martinez et al., 2015). The transplant team can increase the odds of adherence by developing long-term relationships with patients that involve open communication. Ensuring patients understand the rationale behind each part of their medical regimen will increase the likelihood that patients will be adherent. A behavioral contract post-transplant may also improve adherence to post-transplant medications and reduce hospitalizations (Chisholm-Burns et al., 2013). The case study below illustrates how psychosocial stressors can affect adherence and how transplant teams carefully review patients' past behavior and monitor their current behavior as predictors of adherence after transplant.

Case Study

H.J. is a 24-year old female who presented to the emergency room after developing significant symptoms of postpartum cardiomyopathy 5 weeks after the birth of her first child. She was urgently evaluated and determined to be a candidate for advanced mechanical circulatory support as a bridge to heart transplantation. The patient was implanted with a Left Ventricular Assist Device to treat her low ejection fraction of 10 %. Following a 4-week hospital recovery, the patient was discharged home to live with her mother and new baby. Over the ensuing 6 months, H.J. attended cardiology appointments sporadically and failed to complete regular laboratory tests that ensure good functioning. The team psychologist and social worker identified multiple stressors affecting this new mother that were interfering with her adherence including financial, relationship, substance use, childcare and employment stressors. Multiple attempts were made to engage the patient in psychosocial services with little reciprocal engagement by the patient who only presented to the emergency room when she had medical concerns. Eight months post-implantation of the assist device, after multiple attempts to engage H.J. and follow up on her self-care were unproductive, the transplant team decided to pursue de-listing her for transplant. At the present time the patient continues to sporadically attend medical appointments and presents to the hospital emergency room when in crisis. The team may consider a listing re-evaluation if her adherence to treatment improves. With the growing rates of left ventricular assist device implants, heart transplant teams have the opportunity to follow patients for a longer period of time prior to a decision about transplant listing. When psychosocial risk factors are present, the more time a transplant team can follow a patient before listing, the better.

Psychopathology

It is not uncommon for transplant patients to experience psychological distress throughout the transplant process. Prior to transplant, many patients have been living with a chronic illness which can be accompanied by mental and emotional difficulties (Kuntz & Bonfiglio, 2011). These patients may be aware for some time that a transplant will be necessary at some point. Others develop an acute illness where the best treatment option is an emergency transplant. This gives the patient little to no time for psychological preparedness in relation to the post-transplant lifestyle and responsibilities. Once the transplant process has been initiated, there is uncertainty related to whether a patient will be approved as a transplant candidate. The many tests and appointments can invoke anxious feelings about whether the results might exclude one's candidacy (Heinrich & Marcangelo, 2009). While on the waiting list, patients may become progressively sicker, leading to or exacerbating feelings of depression and anxiety. While on the waiting list, patients also report worry about whether they will survive long enough to receive a transplant, and they may have increased thoughts of death. Though transplant often results in improved mental health (Pegum, Connor, Young, & Feeney, 2015), some recipients endorse increased psychological distress in the early post-transplant period (Annema, Roodbol, Stewart, Porte, & Ranchor, 2014). Patients with a history of depression and anxiety prior to transplant may be especially prone to psychological distress after transplant; however it should be noted that even patients with no mental health history may be subject to significant worries and stressors in the early post-transplant period.

During the heart transplant waiting period, the presence of clinically relevant depressive symptoms, determined by scores on the Hospital Anxiety and Depression Scale, has been associated with increased risk of significant events (death, high-urgency transplantation, delisting due to clinical deterioration, and mechanical circulatory support device implantation; Spaderna et al., 2014). Depression and health-related quality of life are often closely associated during times of illness, and this holds true for transplant as well (Spaderna et al., 2014). A coping style of denial in pre-transplant patients has been related to higher depression scores on the Hamilton Depression Scale thus acceptance of illness and the need for transplant may be a focus of psychotherapy in the pre-transplant phase (Burker, Evon, Marroquin Loiselle, Finkel, & Mill, 2005). Post-transplant, factors contributing to psychological distress may include experiencing survivor's guilt, unmet surgical expectations, medical complications, and strained relationships with caregivers (Michaelsen & Arnold, 2013).

Addressing mental health issues prior to transplant is important because the presence of psychological distress after transplant has been associated with poorer adherence to the medical regimen and medical complications (Cukor, Newville, & Jindal, 2008; Shapiro et al., 1995). In addition, higher levels of depression and anxiety after transplant have been associated with poorer quality of life, more sleep problems and more interpersonal distress (Noohi et al., 2007). Thus, decisions about listing patients with psychiatric disorders for transplant must be made with care. Patients who are experiencing significant psychological distress at the time of the transplant evaluation are referred for treatment whether it is initiating psychotropic medication, psychotherapy, or both in order to be considered for placement on a transplant waitlist. This referral is often made based on the psychologist's assessment of how a patient's depressive or anxious symptoms are affecting the patient's functioning and ability to care for himself or herself. There are unique considerations for psychotropic medication in those with end-stage organ failure and in transplant recipients (Crone & Gabriel, 2004). Therefore, it is helpful to consult with psychiatry colleagues in the medical management of transplant patients. Interpersonal therapy paired with SSRI use and mindfulness-based interventions have been shown to decrease depressive symptoms in transplant patients (Gross et al., 2010; Miller, 2002). After a patient has engaged in psychiatric treatment for a period of time, their symptoms can be re-assessed by the psychologist; if there is found to be adequate improvement of symptoms, the patient can be cleared to proceed to the next steps of the transplant evaluation or to consideration by the transplant committee.

Evaluating the course and present state of a patient's psychiatric stability is often based on the transplant psychosocial evaluation as well as a review of past medical and psychiatric records (Heinrich & Marcangelo, 2009). If a patient is currently receiving psychiatric care, reviewing records or having discussions with his or her provider is warranted. It is important for the transplant team to feel confident that the patient has healthy coping skills to manage the sometimes unpredictable course of the transplant process.

Often, some assessment tools measuring anxiety and depression are administered as part of the pre-transplant evaluation. These may include the Beck Depression Inventory-II (Beck, Steer, Ball, & Ranieri, 1996), Beck Anxiety Inventory (Beck, Epstein, Brown, & Steer, 1988), Generalized Anxiety Disorder-7 item Scale (Spitzer, Kroenke, Williams, & Lowe, 2006), and the Patient Health Questionnaire (Spitzer, Kroenke, & Williams, 1999). It should be noted that a close review of endorsed items should be completed when scoring these inventories, as symptoms of chronic illness often mimic psychological distress. For a broader assessment of personality factors that may affect coping after transplant, the Minnesota Multiphasic Personality Inventory-2 Restructured Form (Tellegen et al., 2003) or Millon Behavioral Medicine Diagnostic (Millon, Antoni, Millon, Minor, & Grossman, 2006) could be administered.

In many transplant centers, the presence of psychopathology is not an absolute contraindication to transplant, as psychopathology is often a modifiable risk factor. However, in an anonymous survey of 251 liver transplant providers, psychiatric diagnoses were ranked as one of the three most controversial risk factors for transplant (Secunda et al., 2013). Many centers agree that active suicidal or homicidal ideation, psychosis, and dementia at the time of evaluation are contraindications for listing (Huffman, Popkin, & Stern, 2003). In addition, personality disorders that impede patients from working collaboratively with the transplant team are often a contraindication, as they have been associated with non-adherence (Chacko, Harper, Kunik, & Young, 1996). Conversely, the presence of mood and/or anxiety disorders most often are managed by establishing effective pre- and post-transplant treatment plans. The case study below illustrates the challenges of dealing with post-transplant depression and its potential impact on adherence to the medical regimen.

Case Study

J.N. is a 37-year old male who was diagnosed with end-stage renal disease secondary to focal glomerular sclerosis. During the pre-transplant psychosocial evaluation, the patient reported that he suffered from depression from the ages of 25–27 in response to "being sick all the time." He saw a psychiatrist one time who prescribed an antidepressant. However, J.N. said he only took it for a month because it made him nauseous, and he did not think it helped his symptoms. He saw a counselor for 6 months then stopped when he started vocational school. He denied any current symptoms of depression at the time of the transplant evaluation but felt anxious about planning for his future. He did not feel the need for any psychological intervention but reported that he would seek help if he experienced a major depressive episode in the future. J.N. was listed for renal transplantation, and after waiting approximately 1 year he received a deceased donor transplant. Approximately 2 years after his transplant the patient became non-adherent with his lab draws and medications. He was hospitalized for a rejection episode at which time psychological assessment revealed that he had been experiencing a major depressive episode. He was attending outpatient counseling but did not feel it was helpful. During his hospitalization he was started on an antidepressant by the consultation/liaison psychiatry team and was referred to the hospital's psychiatric partial hospitalization program. He attended several sessions there then stopped going due to cost. Six months later, he was re-hospitalized for another rejection episode and admitted to only taking his anti-rejection medication "half the time." He reported having an erratic sleep schedule and was not always feeling motivated to get up to take his medications. He was open to referrals for counseling which were given to him. However, the patient remained non-adherent with his labs, medications, and maintained little contact with the transplant center. His kidney rejected, and he returned to dialysis. This case speaks to the need for close psychosocial follow-up with high-risk patients. Ideally, this would be done at routine outpatient visits, not just when patients are experiencing a medical crisis.

Substance Abuse

One of the most critical risk factors to assess as part of the pre-transplant evaluation is substance abuse, given its potential impact on immediate and long-term recovery from the procedure. A transplant psychologist is in a unique position to elicit substance use information from patients, help guide patients to appropriate treatments, and monitor ongoing adherence for patients who receive a transplant (Ehlers et al., 2006; Rodrigue, Hanto, & Curry, 2013; Wagner, Haller, & Olbrisch, 1996). This section provides an overview of the assessment and remediation of substance misuse and abuse.

In addition to obtaining information on a patient's substance use, it is important for the transplant psychologist to assess motivation for quitting and past attempts to quit. The transplant psychologist will also want to determine how long the longest quit attempt lasted and what contributed to any relapse in use. Patients who are currently using should be assessed for their motivation for abstinence, reduction, and ongoing substance abuse treatment (Ehlers et al., 2006; Rodrigue et al., 2013). For the candidate who is currently abstinent, it is important to determine whether the patient experiences any urges or cravings to return to use (Weinrieb et al., 2001).

Substance abuse treatment for organ candidates is not as straightforward as it might initially appear. Some patients present with substance abuse as the cause for their organ failure, as in the case of the alcoholic patient who presents for liver transplant workup due to cirrhosis (Singal, Chaha, Rasheed, & Anand, 2013). In other cases, substance abuse may not be directly related to organ failure but is discovered during the routine pre-transplant workup (e.g. the patient in need of a kidney transplant, who has also smoked a pack of cigarettes a day for the past 25 years). In both cases, the transplant psychologist must consider the abuse in the context of other risk factors to recommend a reasonable, ethically defensible course of action that best ensures a good outcome (Corbett, Armstrong, & Neuberger, 2012). While there are a number of protocols that describe treatment for substance abuse, the need for abstinence for a certain time frame, and the relative value of post-transplant behavioral contracts for ongoing treatment and abstinence, these decisions are often made based on the risk-tolerance and volume of an individual transplant program (Parker, Armstrong, Corbett, Day, & Neuberger, 2013; Rice & Lucey, 2013). As a general rule of thumb, many programs institute formal or informal guidelines for 6 months of sobriety (Dew et al., 2008; Lim & Keefe, 2004); however, what may be more important than pre-transplant abstinence is ongoing, post-transplant relapse prevention treatment (Rodrigue et al., 2013).

Alcohol, nicotine, and other drugs all have associated lab tests that can help detect recent use (Dimartini & Dew, 2012; Merrill & Duncan, 2014). However, most critical for the pre-transplant evaluation is the assessment of lifetime use, misuse, and/or abuse of these substances, gathered during the psychosocial evaluation. The interview should include an evaluation of substance use that addresses age of first use, patterns of use over time, amount of current use (if any), and date of last use. This can help the examiner determine the need for substance abuse treatment and/or to assess the risk of relapse to these substances after transplant. In some cases, there is a clear linkage between substance use behavior and end-stage organ disease (e.g. alcohol abuse leading to cirrhosis, necessitating liver transplantation). Information should also be solicited to determine whether the patient has experienced any social/legal, psychological, or medical sequelae of substance use (Levenson & Olbrisch, 1993; Olbrisch et al., 2002; Olbrisch & Levenson, 1995). To complement a semi-structured interview, the transplant psychologist may select from a number of self-report measures that have been developed to assess substance misuse (Jay et al., 2009; Presberg, Levenson, Olbrisch, & Best, 1995; Rodrigue, Kanasky, Jackson, & Perri, 2000). Among the more commonly used screening instruments are the Alcohol Use Disorders Identification Test (AUDIT; Allen, Reinert, & Volk, 2001); Berner, Kriston, Bentele, & Harter, 2007), the CAGE Questions Adapted to Include Drug Use (CAGE-AID; Ewing, 1984; Mdege & Lang, 2011), and the Drug Abuse Screen Test (DAST; Cocco & Carey, 1998). It is perhaps best to consider these structured questionnaires as adjuncts to a thorough psychosocial assessment.

Depending on the type of end-stage organ disease, alcohol, nicotine, and illicit drug use may be considered either absolute or relative contraindications to transplant. In some cases, the psychologist may be in a position of not advocating for transplant for a given recipient due to past history of substance use relapse, lack of motivation for life-long abstinence, or other factors. As a policy issue, attitudes towards substance use vary both across organ types and within programs (Levenson & Olbrisch, 1993; Olbrisch & Levenson, 1991). For example, lung transplant programs usually consider current use of nicotine to be forbidden for potential candidates because of the risk of cancer, cardiovascular disease, and poorer healing. There is considerably more variability in transplant program attitudes towards nicotine in kidney transplant programs (Levenson & Olbrisch, 1993). Marijuana use in transplant candidates has long been a debatable topic in the field. A survey of transplant centers in 2007 about their policies on marijuana use indicated that 37.5 % of programs required 6 months of abstinence prior to listing, 18.5 % required 3 months of abstinence, 25 % did not require any abstinence period, and 12.5 % had a policy that was unclear (Coffman, 2008). As the trend to decriminalize and to legalize medical/recreational marijuana use continues, this continues to be a highly debated subject. While there may be several advantages for the field to come to consensus on guidelines for substance use, none are available at this time. The following case study illustrates how to address pre-transplant patients who may be self-medicating mood symptoms through illicit drugs.

Case Study

E.M. is a middle-aged male diagnosed with end-stage renal disease secondary to chronic hypertension. He presents to the transplant clinic not yet on dialysis and seeking a pre-emptive transplant. He reported recreational marijuana use approximately 1–2 times per week to the social worker who conducted his initial psychosocial evaluation. He also endorsed a remote past mental health history of psychotropic treatment for depression and anxiety with modest benefit. He denied any current mood disturbance. He endorsed past suicidal ideation but denied any past suicide attempts. Because of his mental health history, he was also seen by the transplant psychologist. With the psychologist, it became clear that the candidate was using marijuana on a daily basis, smoking up to an ounce every month. E.M. reported that he used marijuana "to get high" but also to help manage his mood. Patient stated that he preferred marijuana over medications or therapy because it made him feel better. The psychologist informed E.M. and the multidisciplinary kidney transplant team the patient should seek alternate methods for mood management and treatment for signs of substance dependence. Without the team's knowledge, E.M. stopped smoking marijuana "cold turkey" which resulted in increased psychological distress and an outburst directed at one of the clinic nurses in which he said he was no longer interested in transplant. After 2 weeks, he called the clinic and requested to re-engage with his evaluation. The transplant team insisted that he seek treatment for his mood and substance use which he did. After 6 months of treatment with a dual diagnosis therapist in the community and in close contact with the transplant psychologist, the patient substantially reduced his marijuana use, started antidepressant therapy, and began a course of psychotherapy. The patient was eventually listed for transplant, with close monitoring of his marijuana use and mood. During the evaluation phase, he identified a living kidney donor and was transplanted after receiving psychosocial clearance. He has been living well with his transplant for the past several months. Though patients may be resistant to giving up their substance of choice before transplant, with professional support and proper motivation, they can be successful in developing more adaptive coping responses. In certain cases, transplant recipients may benefit from ongoing, close surveillance for substance use and mood disorders following transplant to help monitor for these risk factors.

Lack of Social Support

Medical conditions leading to transplant surgery and recovery often require prolonged hospitalizations and frequently changing medical regimens. Adjusting to major lifestyle changes can be made easier with the presence of an identified social support framework to assist with all aspects of pre- and post-transplant adjustment and recovery (Annunziato, Fisher, Jerson, Bochkanova, & Shaw, 2010). Good social support has also been shown to encourage better adherence and better treatment-related behaviors (DiMatteo, 2004), thereby likely increasing the odds of successful transplant outcomes. Support of even just one partner has been shown to be predictive of significantly improved outcomes post-transplant when compared to patients with "poor" support (Dobbels, Verleden, Dupont, Vanhaecke, & De Geest, 2006).

Social support contributions vary across the transplant process. Prior to transplantation, the identified support person can help make preparations and facilitate functional aspects of daily life. The support system can arrange for care of children, pets, finances and other responsibilities, which gives the patient more time to focus on staying healthy, and also reduces stress (House & Kahn, 1985). As the pre-transplant patient becomes increasingly ill, the support person often engages in increasing levels of patient care. After transplant and immediately post-hospital discharge, the support system helps monitor a patient for acute changes in medical status. For this reason, transplant programs may require that at least one support person be identified and able to provide 24-h care to the patient for a number of weeks post-discharge. In addition to monitoring any medical changes during the surgical recovery period, the support system helps with adjusting to necessary lifestyle changes after surgery. Supporting necessary dietary changes, facilitating adjustment to medications, helping to manage frequent medical appointments, and being a liaison between the patient and treatment team, are all potential responsibilities of a patient's support system. Assessment of social support is conducted across the course of the entire clinical evaluation, as many members of a transplant team will have interactions with patients and their support system. Transplant coordinators, nurses, and both inpatient and outpatient providers should all be alert to the absence, presence and strength of social support and should communicate concerns and observations in team meetings. While psychologists can provide insight and assessment into perceived social support, social workers are often trained in assessing all of the components of a patient's social framework and so play a critical role in the evaluation process as well (Maltby et al., 2014).

Patients' verbal reports about available social support need to be assessed and compared to actual social support (Procidano & Heller, 1983). Patients may report having good social support when it may not actually be present in an effort to get approved for transplant. Alternatively, some patients may report they do not have adequate support because they fear that asking for assistance from friends and family will result in rejection. Most centers require face-to-face meetings with at least one support person prior to transplant and some may even require a support contract to be signed which outlines the expectations of patients' caregivers. The importance of having long-term social support should be stressed, as often, medical adherence after transplant decreases with time. The support system can help to enable long-term adherence to patients' medical regimen.

Being a support person for a transplant patient can be challenging for a loved one and has been well characterized as "caregiver burden" (Adelman, Tmanova, Delgado, Dion, & Lachs, 2014). Just as the needs of the transplant recipient change across the pre, peri and post- operative stages of transplant, so will the perception of caregiver burden. Prior to transplant surgery, caregiver burden is increased by practical as well as by emotional factors. Attendance at all doctor's visits by the caregiver may be required in some transplant programs. This may require missing work or other responsibilities and potentially creating financial hardship. Additionally, the process of waiting for an organ to become available while a loved one is critically ill can be understandably emotionally taxing on caregivers as well as patients. Post-transplant, caregivers will need to provide additional practical support during the recovery, as well as support with lifestyle modification and change, as the surgical wound heals.

Clinicians are urged to emphasize the importance of self-care for caregivers as well as transplant recipients. Caregivers who actively engage in positive health behaviors have been shown to care better for loved ones recovering from medical conditions (Adelman et al., 2014). When significant caregiver strain is noted by the team, transplant psychologists can make referrals for treatment. In addition, many transplant centers have support groups which can be good sources of support for both patients and caregivers.

While social support is critical in post-transplant care, the initial lack of social support should not be seen as an absolute contraindication to transplant. If patients report that they do not have anyone to care for them through the transplant process, a transplant mental health professional can often work with them to find somebody to fulfill this role. This may mean looking outside of patients' families to neighbors, co-workers, or social groups. Social workers and psychologists can work together with the transplant team to foster the identification and development of social support mechanisms both within and external to the transplant programs. The following case study illustrates how patients may underestimate their available social support and how the transplant psychologist can help them re-assess it.

Case Study

D.H. is a 56-year old female with amyloidosis who required a dual heart-liver transplant operation. At the time of her evaluation, she expressed fear that her designated support person may not be able to meet the center-required needs for support after transplantation. Additionally, the patient stated that she did not feel that any other individuals in her immediate family or local community would be able to provide the required supervision for 3 weeks post-hospital discharge that is required by the transplanting institution. The patient's apprehension about her diagnosis and need for organ transplant resulted in occasional missed appointments with cardiologists and hepatologists as well as rescheduling of multiple procedures during the initial transplant evaluation process. The psychologist and social worker evaluated the patient extensively and identified that the patient was experiencing significant anxiety around her need to tell loved ones that she was going to require transplant surgery with a post-surgical recovery period. The psychologist worked with the patient to address anxieties and fears around telling loved ones that she was ill enough to need a transplant and helped the patient put together a plan to discuss her situation with loved ones. The social worker obtained the patient's permission to speak with family members including the patient's three half-sisters who expressed overwhelming support. Prior to transplant, each of the half-sisters attended transplant educational sessions and fully engaged with the medical team to gain a better understanding of patient needs post-transplant. The half-sisters worked with the patient to arrange for medical coverage, coverage for care of her pets, and provision of food and home care services while the patient was hospitalized. In addition, the half-sisters worked together with the patient to enlist the patient's church members in supporting the patient post-transplant. One month following transplant the patient rapidly developed a fever and syncope, which prevented her from driving. One of the patient's half-sisters was present to immediately phone the patient's transplant coordinator who arranged for a clinic visit and a brief hospitalization to appropriately treat an infection. Patient was released from the hospital 3 days after that admission and has experienced no other post-transplant complications since her surgery. Proper education about support needs directly communicated by the transplant team to the support system often increases caregiver participation in the patient's transplant experience.

Cognitive Dysfunction

Many patients presenting for transplant may be experiencing cognitive dysfunction due to their primary illness, their age, pre-existing traumatic brain injuries and/or cerebrovascular accidents (CVA's). Often, medical conditions that lead patients to needing transplants (congestive heart failure, cirrhosis, etc.) have cognitive consequences that may impair memory, psychomotor speed, and attention (Butterworth, 2014; Vogels, Scheltens, Schroeder-Tanka, & Weinstein, 2007). For example, in patients with congestive heart failure, impaired cerebral blood flow can result from low cardiac output and low cerebrovascular reactivity (Dardiotis et al., 2012). Patients with scarring of the liver, or cirrhosis, may experience hepatic encephalopathy, a build-up of toxins in the bloodstream, where symptoms range from shortened attention span and lethargy to coma (Ferenci et al., 2002). Patients with end-stage renal disease may demonstrate difficulties with attention, cognitive flexibility, memory and learning due to accumulation of uremic toxins, cerebrovascular ischemic lesions, oxidative stress, or anemia (da Matta et al., 2014). Patients with end-stage lung disease exhibit cognitive deficits related to poor pulmonary function, low levels of oxygen in the blood, and/or high levels of carbon dioxide in the blood (Lopez Torres et al., 2014). In many instances, organ transplant can reverse these deficits (da Matta et al., 2014; Deshields, McDonough, Mannen, & Miller, 1996; Kramer et al., 1996; Lin et al., 2014), although there is some indication that there may be a critical period for reversal of cognitive dysfunction due to end-stage organ disease.

There are a number of reasons to assess patients' cognitive functioning. At the beginning of the transplant evaluation process, patients are provided with extensive education about transplant so they can decide if they want to pursue this intervention. They must be able to process the material provided to make an informed decision. Cognitive status may wax and wane over time while patients are awaiting transplant. Given that patients must be able to manage a complex post-transplant medical regimen, it may be necessary to make arrangements in the case that cognitive deficits are present or remain after transplant. During the pre-transplant psychosocial evaluation, there are several ways to assess patients' cognitive functioning. A simple technique is to "quiz" patients about the information they have been taught about transplant to assess their retention and understanding of the material. This is best done by using open-ended questions to obtain their baseline knowledge. At some transplant centers, cognitive testing is a routine part of the evaluation process. At other centers, formal testing may be conducted on an as-needed basis. This could be as quick as a mini mental state exam (MMSE) or as lengthy as a standard neuropsychological battery of tests. It is important to rule out illness-related cognitive decline which may be temporary versus a more insidious process like dementia (DiMartini & Chopra, 2009). The Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) has been used in much research examining transplant patients' cognitive functioning (Mooney et al., 2007). It assesses five cognitive areas, including immediate and delayed memory, visuospatial skills, attention, and language and provides a summary score of overall cognitive functioning (Randolph, 1998).

When transplant patients are found to have cognitive dysfunction, it is especially important that they have a strong support system in place to assist with the management of their medical care. Adherence strategies such as using a daily pill box with an alarm, writing all appointments on a wall calendar, and having a support person attend all medical appointments are often recommended. Patients with cognitive impairment may benefit from outside assistance such as home nursing, or they may need to reside in an assisted living or nursing home for more comprehensive care. Also, physical activity is encouraged as it has been found to be beneficial in improving cognitive function (Gunstad et al., 2005; Tseng, Gau, & Lou, 2011). Low levels of intelligence or literacy are not often viewed as absolute contraindications to transplant. In fact, with appropriate social support, individuals with developmental delays can have transplant outcomes similar to those without them (Martens, Jones, & Reiss, 2006). However, a diagnosis of progressive dementia—a persistent and chronic condition—often is an absolute contraindication. The following case study illustrates the importance of careful assessment of patients' cognitive states and of not hesitating to refer patients for more specialized assessment if felt necessary.

Case Study

M.B. was a 67-year old male with a diagnosis of primary sclerosing cholangitis that had progressed to cirrhosis. He was referred for liver transplant evaluation by his treating hepatologist. He presented with symptoms consistent with hepatic encephalopathy. During his evaluation with the psychologist, the patient demonstrated significant cognitive dysfunction on his MMSE (scoring 16/30). Though he reported being adherent with his medications prescribed to reduce the likelihood of encephalopathy, he exhibited symptoms of confusion, significant memory difficulties and emotional lability prior to and during his assessment. Lab values drawn on the day of the psychological assessment showed ammonia levels within normal limits (high levels of ammonia often correlate with encephalopathy in liver failure). On recommendation from the assessing psychologist, the patient was referred for a full neuropsychological and neuropsychiatric evaluation. These evaluations determined that the patient was suffering from dementia related to rapidly evolving Creutzfeldt Jakob Disease. Initial findings were confirmed by brain biopsy 1 week later. Further transplant evaluation and workup was halted at that time, and the patient died in hospice care 2 months after his initial transplant evaluation. Should this patient have been transplanted, it would likely have been considered poor use of a scarce resource.

Ethnic and Cultural Considerations

As with any specific field of health psychology, psychologists performing pre-transplant assessments should be competent in the cultural and ethnic issues specific to the field (Gordon et al., 2014; Kaufman, Russ, & Shim, 2006; Olbrisch, 1996; Smith, 2015). One important issue in transplantation is equal access to all potential candidates; however, it has been noted that black patients are referred for kidney transplant less often and have incomplete evaluations more often than whites (Epstein et al., 2000). In liver transplant, black patients are sicker when listed and are listed for a shorter time before transplant than whites, suggesting barriers to early referral (Axelrod & Pomfret, 2008). Also black patients have a higher rate of liver disease than the national average but make up a smaller proportion of individuals receiving transplants (Axelrod & Pomfret, 2008). Some of the potential explanations for this include blacks being less likely to be referred to specialists and less likely to be thought of as appropriate for transplant by their physicians. In terms of outcomes, blacks are more likely than whites to have a longer time on the wait list, less likely to receive optimal post-transplant care, and have shorter graft survival (Ladin, Rodrigue, & Hanto, 2009). After heart transplant, black females have the highest rate of mortality followed by black males and caucasian females with prior pregnancy (Higgins & Fishman, 2006).

Factors other than race and ethnicity have been associated with differences in kidney transplant frequency and outcomes including socioeconomic status, language, religion, immigrant status, and housing status (Ladin, Rodrigue & Hanto, 2009). A recent study surveying dialysis centers in Georgia revealed the centers referring the fewest patients to transplant were more likely to serve patients from high-poverty neighborhoods (Patzer et al., 2015). Individuals without health insurance have fewer interactions with health care providers which may promote a perception in physicians that these patients are noncompliant with medical care or disinterested in transplantation (Higgins & Fishman, 2006). This directly affects Hispanic Americans and Native Americans who are less likely than whites and blacks to carry insurance, reducing access to transplant (Higgins & Fishman, 2006). While psychologists may not play a role in who is referred to transplant, they can pay careful attention to potential barriers that minority and disadvantaged patients may face during the transplant process. Transplant psychologists' particular awareness of these issues can lead to enlightened collaboration and discussion with the multidisciplinary transplant team.

Conclusion

Transplantation is not only a life-extending intervention in most cases, but it also results in improved quality of life for many patients who undergo the procedure (Duffy et al., 2010; Kugler et al., 2013). The psychosocial evaluation is critical in assisting the transplant team with identifying risk factors in patients that could lead to poor outcomes. There are a number of health care providers who may perform transplant psychosocial evaluations (e.g. social worker, psychologist, psychiatrist) and a number of measures and assessment tools to aid in these evaluations. The goal of the psychosocial evaluation is to ensure patients are able to manage well physically, emotionally, and mentally after transplantation (Wise, 2008) and to make recommendations for remediation when risk factors are identified.

Close interaction with other members of the transplant team in treatment planning and care discussions is an effective way for psychologists to demonstrate their value to transplant programs. For psychologists consulting to transplant teams on an irregular basis, this is a valuable way to enhance competence in assessing these nuanced medical populations.

Most transplant programs agree that the psychosocial risk factors of active psychopathology, substance use disorders, lack of social support, cognitive dysfunction, and non-adherence to the medical regimen are important to identify prior to transplanting an individual. These risk factors can be challenging to manage, and evidence shows that, if left unaddressed, they can lead to poor transplant outcomes. However, there is not yet consensus across programs as to which of these factors constitute absolute versus relative contraindications in the various organ groups (Huffman et al., 2003; Levenson & Olbrisch, 1993). The field of transplantation will benefit from the surveying of programs about their psychosocial policies to better understand the current state of psychosocial factors in patient selection. There is a likely need for large professional organizations in transplantation to address this issue more directly than has been done in the past. For example, the American Society of Transplantation (http://www.myast.org) has recently established a Psychosocial Community of Practice that provides a forum for transplant psychosocial specialists, across disciplines, to discuss relevant issues in transplantation. The European Society for Organ Transplant (http://www.esot.org) contains a division called the Ethical, Legal, and Psychosocial Aspects of Transplantation (ELPAT) that holds regular meetings. In addition, there are specialty-specific societies that may provide useful input on psychosocial issues, such as the International Society for Heart & Lung Transplantation (http://www.ishlt.org) and the International Liver Transplantation Society (http://www.ilts.org). Opportunities for gathering information about and informing current practices will now be more easily possible through collaboration across such groups. In addition, continued empirical research must be conducted associating these risk factors with outcomes. Finally, studies assessing psychosocial interventions pre- and post-transplant are rare but greatly needed to guide transplant psychologists in how best to reduce inherent disparities related to race, culture, and/or geography that prevent patients from obtaining their optimal outcomes after transplant.

Compliance with Ethical Standards

Conflict of interest Kristin Kuntz, Stephen Weinland, and Zeeshan Butt declare that they have no conflict of interest.

Human and Animal Rights and Informed Consent No animal or human studies were carried out by the authors for this article.

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