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# Why It is Important to Consider Social Support When Assessing Organ Transplant Candidates?

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*"Because donated organs are a severely limited resource, the best potential recipients should be identified. The probability of a good outcome must be highly emphasized to achieve the maximum benefit for all transplants."*

(From: OPTN/UNOS Ethics Committee General Considerations in Assessment for Transplant Candidacy White Paper–2010) (OPTN 2010; OPTN/UNOS 2010).

The number of transplant surgeries has risen steadily in the last 30 years in the United States (US), while the availability of donated organs has not kept pace with the clinical demands (OPTN 2016). According to the Organ Procurement and Transplantation Network (OPTN), every ten minutes someone is added to the national transplant waiting list (OPTN 2016). This has translated into a staggering statistic: on average, 20 patients die each day (which translates into 7,300 candidates a year) while waiting for a transplant (UNOS 2018). On average, 10%–20% of all heart, liver, and lung transplant candidates die before an organ becomes available (OPTN 2018). Therefore, transplant teams have become stewards of a very precious and limited resource.

Over the years, studies have demonstrated a strong association between pre-transplant psychosocial vulnerability factors and a number of negative outcomes. These include negative medical outcomes, such as higher infection rates, treatment adherence, increased rejection episodes, acute late rejection, hospital readmissions, increased cost of care, post-transplant malignancies, graft loss, and decreased transplant survival. In addition, there are a number of adverse psychosocial outcomes, including the development of depression, anxiety, new psychiatric diagnoses and need for admissions, relapse to substance use, as well as social complications (e.g., loss of social support, financial stress). The occurrence of these medical and psychosocial outcomes has been linked to the ultimate transplant success or failure, as

well as the recipient's own quality of life after transplantation (Barbour et al. 2006; Bunzel and Laederach-Hofmann, 2000; Chacko et al. 1996, 1996; Dew et al. 2000, 2007; Dobbels et al. 2001, 2005, 2006, 2007; Goetzmann et al. 2007, 2008; Hoodin and Weber, 2003; Huffman et al. 2003; Jowsey et al. 2001; Jowsey and Schneekloth, 2008; Karman et al. 2001; Levenson and Olbrisch, 1993; Maldonado, 2009; Maldonado et al. 2012, 2015; Olbrisch et al. 2002; Rivard et al. 2005; Rudis et al. 2000; Schweizer et al. 1990; Teichman et al. 2000).

The goals of a psychosocial pre-transplant evaluation should include:

- To identify patient's level of neuropsychiatric and cognitive functioning in order to address current psychiatric issues and help minimize preventable problems
- To identify patient's social support network, thus allowing the identification of candidates with sub-optimal social support systems; allowing for strengthening of existing systems; and providing the needed resources to develop a robust support system
- To promote fairness and equal access to care
- To maximize optimal outcomes and the wise use of scarce resources
- To ensure that the potential for benefits outweighs surgical and medical risks to the patient by identifying potential risk factors (i.e., substance abuse, adherence issues, or serious psychopathological conditions) that may result in increased risk of postoperative nonadherence and morbidity
- To provide clinicians the information required to develop and implement treatment plans addressing psychosocial vulnerabilities for individuals at high risk, in order to reduce harm, mitigate risk, and optimize graft survival and patient's level of functioning and overall quality of life (Maldonado, 2009).

Psychosocial consultants can enhance the candidate selection process by fine-tuning the psychosocial criteria to be used when assessing candidates being considered for transplantation (Barbour et al. 2006; Dobbels et al. 2006; Jowsey et al. 2001; Levenson and Olbrisch, 1993; Olbrisch et al. 2002). This can most effectively be done by focusing on risk factors that are associated with poor adherence/compliance and ultimate medical and psychosocial transplant success (Denhaerynck et al. 2005; Dew et al. 2007; Dobbels et al. 2009; Drent et al. 2005; Havik et al. 2007; Karman et al. 2001; Owen et al. 2006). Indeed, available data suggest that there is not only a strong association between pre-transplant psychosocial vulnerability markers and post-transplant psychosocial outcomes (Goetzmann et al. 2008), but also between specific psychosocial factors and ultimate transplant success or failure (Bunzel and Laederach-Hofmann, 2000; Chacko et al. 1996; Dew et al. 2000; 2007; Dobbels et al. 2007; Hoodin and Weber, 2003; Huffman et al. 2003; Karman et al. 2001; Levenson and Olbrisch 1993; Maldonado 2009; Messias and Skotzko 2000; Molassiotis et al. 1997; Olbrisch et al. 2002; Rivard et al. 2005; Rodriguez et al. 1991; Rudis et al. 2000; Schweizer et al. 1990; Teichman et al. 2000).

In fact, studies have demonstrated that many pre-transplant psychosocial problems continue after transplantation; and that psychiatric problems after transplantation lead to a higher risk of infection, hospital readmissions, and higher medical costs (Paris et al. 1994). Others have demonstrated that a global psychosocial risk assessment performed during the pre-transplant period was associated with the number of rejection episodes and medication adherence after transplantation (Shapiro et al. 1995). While others found that a high pre-transplant psychosocial risk classification (i.e., high risk versus acceptable versus good candidates) was associated with a greater hazard of post-transplant mortality (Owen et al. 2006). These include negative medical outcomes, such as higher infection rates, treatment adherence, increased rejection episodes, acute late rejection, hospital readmissions, increased cost of care, post-transplant malignancies, graft loss, and decreased transplant survival. In addition, there are a number of adverse psychosocial outcomes, including the development of depression, anxiety, new psychiatric diagnoses and need for admissions, relapse to substance use, as well as social complications (e.g., loss of social support, financial stress). Indeed, the occurrence of these negative medical and psychosocial outcomes has been linked to the ultimate transplant success or failure (Barbour et al. 2006; Bunzel and Laederach-Hofmann 2000; Chacko et al. 1996, 1996; Dew et al. 2000, 2007; Dobbels et al. 2001, 2005, 2006, 2007; Goetzmann et al. 2007, 2008; Hoodin and Weber 2003; Huffman et al. 2003; Jowsey et al. 2001; Jowsey and Schneekloth 2008; Karman et al. 2001; Levenson and Olbrisch 1993; Maldonado 2009; Maldonado et al. 2012, 2015; Olbrisch et al. 2002; Rivard

et al. 2005; Rudis et al. 2000; Schweizer et al. 1990; Teichman et al. 2000).

## RATIONALE FOR THE INCLUSION OF SPECIFIC PSYCHOSOCIAL VARIABLES

For organ transplantation to be an effective treatment, many factors must work in concert: the quality of the donated organ and degree of match between the donor and recipient, the surgical skill, ischemic time, the right post-surgical immunosuppressant therapy regimen, and the active cooperation of the patient with the therapeutic plan. The presence of psychosocial factors appears to be a major contributor to poor post-transplant adherence, reduced quality of life (Crone and Wise 1999; Dew et al. 1997, 2000; Mai et al. 1990; Maldonado et al. 2012, 2015; Surman 1994; Surman et al. 2009), and increased physical morbidity in the years after transplantation.

Treatment adherence (i.e., the active cooperation of patients with their health care professionals regarding attendance to clinics and laboratory appointments, the ability to follow a specified drug schedule without deviations, the ability to adhere to a dietary and/or exercise/rehabilitation plan, and the ability to recognize and provide timely notification to the treatment team of any evolving problems) significantly affects the life span and quality of life of recipients. Conversely, non-adherence is a major risk factor for graft rejection episodes and is responsible for up to 25% of deaths after the initial recovery period in all organ transplants (Dew et al. 1999). Overall, it has been estimated that post-transplantation nonadherence rates range between 20 and 50% (De Geest et al. 1998; Dew et al. 1996; Geest et al. 1995; Grady et al. 1993; Paris et al. 1994; Shapiro et al. 1997).

Thus, it is fair to say that the main purpose of pre-transplant psychosocial evaluations is to “assess for the presence of psychosocial vulnerabilities that may contribute to treatment non-adherence and diminish post-transplant quality of life. Indeed, others have demonstrated that perioperative psychosocial characteristics are strong and significant predictors of post-transplant nonadherence (Dew et al. 1996).

## ISSUES SPECIFIC TO THE IMPORTANCE OF THE SOCIAL SUPPORT SYSTEM

There are an abundance of studies in the scientific literature that validate the essential role of social support and its link to treatment adherence, quality of life, and graft survival in transplant patients (Chacko et al. 1996; Dew et al. 1996; Dobbels et al. 2005; Jowsey et al. 2001; Lopez Sanchez et al. 1999; Skotzko et al. 2001). There is no doubt that the family and psychosocial support network play an important role with respect to survival and morbidity (Christensen et al. 1989; Debray and Plaisant 1990; Feinstein et al. 2005; Molassiotis et al. 1997; Schlebusch

et al. 1989; Teichman et al. 2000). In fact, in some studies social support was one of the most important factors in predicting transplant success (Dew et al. 1998; Jalowiec et al. 2007). For example, a study of liver transplant candidates demonstrated that the absence of a psychosocial support network was a significant risk factor predicting failure to meet listing requirement among end-stage liver disease patients ( $p = 0.006$ ) (Karman et al. 2001).

Similarly, a prospective study of transplant patients confirmed that the presence of low social support prior to transplant was an independent predictor of post-transplant non-adherence (OR = 0.9) (Jowsey and Schneekloth 2008). In addition, among transplant patients, living in an unstable relationship predicted post-transplant graft loss (OR = 4.9) (Dobbels et al. 2009). Others have demonstrated that marital status and living with another person increase adherence modestly, suggesting that the functioning of the social support network may be equally, if not more influential (DiMatteo 2004).

Not only is the presence of a social support system imperative for transplant success, but the functionality of this support network exerts significant influence. In considering the support system's functionality, we must understand that sheer numbers are not enough. Significant quality and functionality, versus a large quantity, is imperative when considering the complex medical regimen and care of the transplant patient in both the pre and post-transplant phases (Bolckhir et al. 2007; Cohen et al. 2007). The literature regarding the emotional, physical and financial toll on caregiver's who have provided care for loved ones suffering from chronic illness is well established (Brodaty and Donkin 2009). A study of patients with end-stage heart disease found that spousal behavioral disengagement (i.e., giving up or withdrawing effort from attempting to reach the goal that is blocked by the stressor) during the pre-transplant evaluation was significantly associated with HT candidates' depression (Burker et al. 2006).

A meta-analysis of studies over a 50-year period demonstrated that practical support had the highest correlation with post-transplant adherence (DiMatteo 2004). In fact, adherence was 1.74-times higher in patients from cohesive families, but 1.53-times lower in patients from families in conflict (DiMatteo 2004). Similarly, among lung transplant patients, the absence of an adequate caregiver support system was associated with the development of major depressive disorder (MDD) after transplantation (Dew et al. 2012).

Finally, living arrangements, specifically in terms of distance to transplant center and appropriateness of facilities were found to be a significant risk factor for transplant failure (Karman et al. 2001; Shapiro et al. 1997). The World Health Organization (WHO) 2003 report found that nonadherence to medication regimen was associated with socioeconomic factors (e.g., demographics, social support) among chronically-ill patients (Burkhart and Sabate 2003).

The data and meta-analysis cited by the authors, fails to distinguish between variability in the rigor of development and application of the social support criteria and the importance of the criteria. It is unclear exactly what was the psychosocial criteria considered by the various programs, or the exact data utilized by the authors and how they truly compare between one program and the next. Similarly, the authors concede that some of the data used to achieve their conclusions were influenced by the observational nature of the studies, the small sample sizes of some of the studies or the types of organ transplants, the varying degrees of study quality, as well as a paucity of studies examining pre-transplant social support, thus affecting finding interpretation. Also importantly, "few studies examine the relationship between social support and long-term transplant outcomes." Finally, the studies included were very heterogeneous, compounding the interpretation of an already complex social support construct, making it difficult to draw clear conclusions from the study findings. In fact, a closer look at the authors' reported data (e.g., forest plots) even suggest a trend towards "better" odds for adherence and clinical outcomes for most included studies, regarding both marital status and social support. An influence analysis, such as the leave-one-out methodology, may assist in determining whether some of the studies included may have unduly influenced or distorted the meta-analysis results. As the authors' reported, "our findings suggest that social support may be protective for transplant outcomes." Therefore, "understanding how different types of support affect adherence and outcomes is important." We agree with that premise and estimate that more uniformly defined and applied guidelines should both improve clinical outcomes and fairness in the organ allocation process.

The study also raises questions as to whether medication adherence is the best proxy of transplant success, or whether the criteria of success should be broader, including both medical (e.g., rejection episodes, rate of post-surgical hospitalization, medical complications, and graft longevity) and psychosocial (e.g., psychiatric decompensation, development of new behavioral problems, and support system failure) outcomes (Maldonado et al. 2015). As the authors' appropriately caution, "our findings may not be completely generalizable and should be interpreted with caution." Abandoning consideration of social support because of inconsistent definition or application is throwing the baby out with the bathwater.

## CONCLUSION

The assessment of transplant candidates is challenging and includes potential clinical, social, and ethical factors. The data available to date confirms that in addition to typical medical factors, psychosocial and behavioral issues may affect the ultimate success of the

transplantation process. There is data to suggest that pre-transplant psychiatric history can predict psychological outcomes after transplant, and that post-transplant psychosocial outcomes may predict physical morbidity and mortality. Accordingly, most guidelines suggest that the pre-transplant screening process must include both a comprehensive medical evaluation and a thorough psychological assessment. As argued by pediatric ethicists “under a transplant ethics framework, the transplant team cannot only think about [the identified patient] best interests. Rather, health care professionals have concurrent obligations to the potential organ recipient, the organ donor, and other candidates on the transplant waiting list... In the context of the scarcity inherent in organ transplantation, the transplant center must weigh the interests of many deserving patients seeking the same transplant organs and services as well as the center’s obligations to donors and their families. Although it may not be possible to do what is in the best interests of all, it is ethically most supportable for the transplant center and medical team to do the best they can to serve the interests of stakeholders to the greatest extent possible. This commits them to following an approach that maximally serves the interests of all patients and donors while potentially making tradeoffs and placing limitations in individual cases” (Mabel et al. 2019).

I agree that the inconsistent and nontransparent use of the social support criterion is both unfair and undermines the public perception of fairness in the wider transplantation system. However, a number of factors must be taken into consideration, when we suggest ways to adjust the transplant distribution process. First, we must consider that the process of transplantation is arduous and lengthy. It often takes months to years, from the beginning of the transplant evaluations process to the time of transplantation. Second, unlike many other medical disorders, where the surgery is the definitive treatment (e.g., appendicitis), in the case of transplantation, with surgery the recipient begins his new life as a professional patient, and requires close collaboration with the transplant team and needs to closely follow up a rather complex treatment regimen. The data suggest that for a transplant recipient to become a successful transplant patient, he or she would depend on a robust social support network.

According to the latest UNOS data, 74,269 patients are actively waiting on their list (OPTN 2018). Multiply that number many-folds to reach the total number of patients who have been actively evaluated for potential transplantation. The current medical system is already taxed to its limits. The pool of limited donor organs is a public resource and it must be distributed fairly. Accordingly, the Organ Procurement and Transplant Network (OPTN) has identified three general principles to guide organ allocation and listing decisions: maximizing the overall net benefit to organ recipients, promoting

justice, and showing respect for persons (OPTN 2015). With respect to listing, considerations endorsed include psychosocial factors affecting patient adherence and “ethical rules” such as honesty. There is a dearth of both descriptive research and normative analysis regarding the task of balancing benefit and justice considerations (Mabel et al. 2019). A recent systematic review (including thirty-seven studies published between January 2009 to December 2014) of factors relevant to treatment adherence following renal transplant found that youth ( $\leq 50$  years old), male, low social support, unemployment, low education,  $\geq 3$  months post graft, living donor,  $\geq 6$  comorbidities,  $\geq 5$  drugs/d,  $\geq 2$  intakes/d, negative beliefs, negative behavior, depression and anxiety were the factors significantly related to non-adherence (Belaiche et al. 2017). Even among adolescent transplant recipients, having a supportive and functioning family environment is key to the success of the adolescent heart transplant recipient (Steuer and McCauley 2017). In fact, impaired family function and compromised child psychological function have been associated with higher rates of nonadherence (Shellmer et al. 2011).

A study of 50 adult patients undergoing heart transplantation compared pre-transplant psychosocial variables with data regarding the clinical success of surgery (Bunzel and Wollenek 1994). Statistical evaluation by discriminant analysis resulted in the following predictors for successful surgery (all psychosocial): empathy, care and support by one partner (affective involvement), few demands for emotional communication (affective expression), self-control, ability to take stress, emotional stability, high frustration tolerance, low aggression level, and younger age. The results show effective psychosocial support to be the most significant psychosocial variable that can influence the clinical success of heart transplantation.

Given the available evidence, if we were to include “weakly supported” patients, and expect the transplant team to assume the responsibility of providing the necessary support, it would likely translate into a substantial over-stretching of already limited resources. Thus, by including all patients regardless of their ability to put together a social support network, we may potentially not only cause harm to the patients receiving the organ, but will adversely harm other transplant candidates, both active and on the waiting list.

The social support criteria currently required is not just a threshold to be met. The reason transplant programs require the social support criteria is because, without adequate support, many patients will not succeed, either during the pre-transplantation period, as their organ failure progressively decompensates the patient’s overall functioning; or after the transplant process, due to post-surgical weakness, compounded over the complexity of the new medical regimen, and the frequency of medical appointments. I agree that the transplant selection process should attempt to minimize infringements on equity and respect for all transplant



candidates, but not to sentence a patient to fail the transplantation process, suffer a painful death, and in the process deprive other equally deserving candidates.

The suggestion that transplant institutions could offer accommodations for those without adequate social support has many limitations. Like many other transplant centers, our institution has a multitude of mechanisms to offer additional support to transplant patients, including a Patient and Family Advisory Council (PFAC), psychosocial experts (i.e., transplant psychiatrist and social workers) dedicated to each of the transplant programs, and treatment navigators, which facilitate the patients ability to engage with their care. Yet, medical institutions cannot provide all candidates the in-home moral, emotional, psychological and logistical support these patients need. The institution could organize a ride share service to pick up the patient at home and deliver him to the hospital. However, who will assist the patient get out of bed, get dressed and ready and out the door on time for the ride? Similarly, patients need someone to assist them to make certain they are appropriately dressed, are able to follow the correct dietary advice and restrictions for their specific circumstances, and make certain they have taken all their medications prior to leaving home. Once the patient leaves the hospital after each appointment, they need assistance to pick up new prescriptions at the pharmacy, get them home and sorted, then make certain the patient takes all his or her medications throughout the day and prior going to bed.

I agree that at some point in the future, new technologies may assist some of these patients. Nevertheless, without broader societal changes, which would likely require government participation and funding, none of these are practical at this time. In fact, I propose these may just deepen the divide, as it would be the rich, the powerful, and the well connected who are likely to access these technologies and resources.

Thus, psychosocial consultants should find data regarding those risk factors for which there is evidence supporting predictive value: the patient's readiness level to serve as a partner in the management of end-organ failure and post-transplant period; the status and functionality of their social support network; the candidate's psychological stability; and the candidate's extent of substance use, sobriety and conditions under which it was achieved. These appear to be the most significant factors relating to the success of a transplant (Maldonado 2019). The use of objective psychosocial assessment tools can assist transplant teams not only in eliminating the emotional factor from the assessment, but also in presenting the facts of the case as they are, while eliminating potential biases. We strongly agree with the authors' premise that "lack of specificity regarding social support definitions and acceptable support thresholds has resulted in significant variation in transplant centers' approaches to using social support to determine eligibility." Thus, we suggest that rather than eliminating the social support as

criteria, the appropriate governing transplant administration programs should provide clear clinical guidelines establishing universal social support eligibility criteria. Some social variables may not, per se, constitute proof of support (e.g., some couples remain married so the patient may be considered as a transplant candidate, but offering little effective support; while some couples purposely divorce, so the patient qualifies for social security disability insurance, while acting as an exemplary source of social support). Therefore, the criteria should better define what constitutes optimal availability and functionality of such social support system. It would also improve the fairness of the distribution process, if transplant program could adopt a universal psychosocial assessment, including social support, such as SIPAT (Maldonado et al. 2012; 2015). The role of psychosocial consultants should not be to make a determination regarding the patient's worthiness as a candidate, but to assist the transplant selection committee in making the best clinical decision based on current available data. ■

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