

# PSYCHOLOGICAL ASPECTS OF CARDIAC TRANSPLANTATION

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**Abstract**

Since cardiac transplantation became the safest and most effective treatment for heart failure, the demand for donor hearts has increased exponentially in stark contrast to the availability of donor hearts. Candidates must be evaluated carefully to ensure that organs are allocated wisely. Psychologists play an important role in determining suitability for transplantation and supporting the patient if necessary throughout the transplant process. Unfortunately, long-term outcome data for overall quality of life is fair at best. Nonadherence, social support, and depression and anxiety continue to be the most significant challenges faced by transplant patients and contribute to these outcomes. Additional information regarding cardiac transplantation was obtained from field consultants with varying levels of expertise working with transplant patients. Findings from the literature review and consultant interviews were presented to an audience of mental health providers working on interdisciplinary teams within a medical center. Valuable insights were gained from all stages of this project and are discussed in the final chapter of this dissertation.

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## CHAPTER I.

### Introduction

From the earliest human heart transplant in 1967, there have been significant improvements in cardiology that have enhanced the transplant process (Barnard, 1967). This progress has led to an increase in transplant procedures, as well as patient survival rates (Colombo & Ammirati, 2011). However, while the number of potential transplant candidates have risen, the availability of donor hearts has plateaued, mainly due to the public's decreased willingness to provide them (Lund et al., 2015). This shortage has fueled research on artificial devices to preserve life until a donor heart becomes available or they replace human hearts altogether (Barnard & Tsiu, 2012; Harris et al., 2014). Although potentially life-saving, these devices continue to pose serious risks (National Institutes of Health, 2016). As such, cardiac transplantation continues to be the singular most efficacious intervention for individuals with cardiovascular decline and limited life expectancy (Coglianese, Samsi, Liebo, & Heroux, 2015).

Once deemed an acceptable candidate for transplantation, patients are registered with the United Network for Organ Sharing (UNOS), the national transplant waiting list. UNOS serves as the model for transplant systems worldwide (UNOS, 2016). Due to the significant disparity in the quantity of organs available relative to demand, the amount of time spent on the waiting list has increased over time (Colvin et al., 2016). As such, it is critical that patients are evaluated carefully to determine the most prudent treatment, ensuring that organs are allocated wisely. Prior to transplantation, patients encounter a pre-surgical work-up by an interdisciplinary team, that includes a psychosocial evaluation (Collins & Labott, 2007; Levine & Levine, 1991). The aim of this evaluation is to gather pertinent information that will increase the team's

understanding of the patient's current psychosocial concerns and identify high risk patients in order to facilitate appropriate support (Collins & Labott, 2007; Craven & Rodin, 1992).

Currently, there is no uniform evaluation process, which has led to a disparity in the processes for evaluating potential candidates and, subsequently, the allocation of donor organs (Levenson & Olbrisch, 2000; Olbrisch & Levenson, 1991). Most transplant institutions do follow a semi-structured interview format, which includes a patient interview, quantitative testing, gathering of collateral information, and medical records chart review (Collins & Labott, 2007). Medical problems typically present the most significant surgical and post-operative risks, and frequently delay the patient from being placed on the national transplant waiting list (Yamini & Taylor, 2010). Approximately 6% of patients are rejected for transplantation due to reasons related to psychosocial factors (Olbrisch & Levenson, 1991). Absolute and relative contraindications relating to psychosocial factors vary greatly across time and transplant program. Irrefutably, however, a history of medical nonadherence and lack of social support are common absolute contraindications (Yamini & Taylor, 2010). Despite the high prevalence rates among transplant patients, symptoms of psychopathology are seldom contraindicated, unless markedly severe (Woodman et al., 1999). Typically, social support is considered to be the best way to compensate for many of the psychosocial factors that may hinder a patient from being placed on the waitlist (Collins & Labott, 2007). Three prominent factors emerge in the literature as having significant implications for the well-being of cardiac transplant patients: nonadherence, depression and anxiety, and social support.

Nonadherence is a highly prevalent and critical issue among transplant patients, leading to medical complications, hospitalization, and even death (Fitzgerald et al., 2011; Gandhi, McCue, & Cole, 2016). There are potentially many causes of nonadherence, such as financial



hardship or medication side effects (Gandhi et al., 2016; Wong, Chaudry, Desai, & Krumholz, 2011). Nevertheless, identifying nonadherence issues is essential to implement interventions that will facilitate successful treatment outcomes. There is substantial research suggesting that pre-transplant nonadherence predicts post-transplant nonadherence (Bunzel & Laederach-Hofman, 2000; Douglas, Blixen, & Bartucci, 1996). Nonadherence has also been linked to the quality of a patient's social support system, education level, and personality style (DiMatteo, 2004; Dobbels et al., 2009; Druley & Townsend, 1998; Hagedoorn et al., 2000; Molloy, O'Carroll, & Ferguson, 2014). There is also some evidence showing an association between symptoms of psychopathology and nonadherence (DiMartini et al., 2011).

Depression and anxiety are highly prevalent among transplant candidates, 20% and 35% respectively (Dew et al., 2001; Grady et al., 2003; Magni & Borgherini, 1992; Zipfel et al., 1998). These rates reflect the level of psychological distress present during the waiting period prior to transplantation (Zipfel et al., 2010). In fact, during the waiting period, depression and anxiety have been shown to be positively correlated with post-transplant mortality (Epstein & Lucero, 2016). In the year following transplantation, symptoms of psychopathology tend to decrease (Dew et al., 1996). Patients typically report an increase in quality of life and decreased physical symptoms (Fusar-Poli et al., 2006). Long-term, however, patients tend to experience an increase in symptoms of depression and anxiety (Dew & DiMartini, 2011). Depression, specifically, has been shown to increase in the years following transplantation with anxiety remaining relatively low (Dew et al., 2001; Harris & Heil, 2013). In fact, the rates of depression, 6 years following transplantation, have been found to be parallel to pre-transplant depression rates (Zipfel et al., 2010). Dew and colleagues (2013) identified several risk factors associated

with increased prevalence of depression that include the presence of a mental disorder prior to transplant, low physical activity, and inadequate social support (Dew et al., 2013).

In the cardiovascular research, social support is regarded as a being substantially cardio-protective (Zarbo et al., 2013). In the context of cardiac transplantation, research suggests that social support has a significant impact on quality of life in multiple domains (HRQoL; Sirri, Magelli, & Grandi, 2011). Moreover, an association between adequate self-reported social support and positive post-transplant health outcomes has been established (Berry & Kymissis, 2016; Rosenberger, Fox, DiMartini, & Dew, 2012). In several studies, the source of the support (e.g. spouse, adult child, non-family) has been shown to have no influence on the positive benefits (Stimpson et al., 2015; Stimpson et al., 2016). However, other studies specifically find spousal support to be significantly key for patient health outcomes and survival (Dobbels et al, 2009; Sirri et al., 2011; Tam et al., 2011). Regardless of source, social support has been found in numerous studies to be generally rated as satisfactory and stable among transplant patients (Bohachick, Taylor, Sereika, Reeder, & Anton, 2002; White-Williams et al., 2013).

There are few interventions specifically addressing the latter key factors of social support, nonadherence, and psychopathology. The majority of interventions involve providing psychoeducation to transplant candidates and support persons (Dew et al., 2004; Hermsen, Smith, & Mokadam, 2013). Other interventions utilize technology to enhance support (Au-Yeung et al., 2011; Dew et al., 2004; Eisenberger et al., 2013).

### **Justification and Statement of the Problem**

The intent of this clinical dissertation is to discern problems, issues, and gaps in knowledge within the current body of literature, to inform best clinical practice and provide suggestions for future research. Cardiac transplantation is an extensive and life altering

experience for both patients and their support systems. It is critical that patients are evaluated thoroughly to ensure that they receive the appropriate support that will facilitate a successful outcome. Given the importance of social support, it is also necessary for the patients support system to be engaged in this process. Unfortunately, there are no uniform guidelines for pre-transplant evaluations that would ensure a sound evaluation of the potential needs of the patient.

The current research examining social support, nonadherence, and depression and anxiety among heart transplant patients present certain limitations. The research is limited and there are many studies that have not yet been replicated to solidify the previous findings. Furthermore, the literature commonly shows divergent findings between various studies. The literature is composed of wide variety of international studies, potentially confounding the overall findings. For example, the conceptualization and expression of depressive symptoms varies across cultural contexts. Therefore, in the context of cardiac transplantation, findings may have less potential for generalizability. The same is true for social support. Additionally, there is a tremendous deficit for psychological interventions within the context of transplantation. Few psychological interventions were identified, and some were in foreign languages and could not be fully reviewed. This introduces yet another issue. Given the level of international engagement with transplant research and clinical practice, there must be greater importance placed on the dissemination of research on psychological interventions to the professional community.

### **Goals and Objectives**

The principal objective for this clinical dissertation is to increase knowledge of psychosocial factors related to the transplant process. The second objective is to advocate for the development of psychological interventions to increase physical and psychological well-being for patients and their support systems. The final objective is to promote awareness of the importance of context. Psychological interventions must be tailored specifically to the transplant population, taking all of their unique experiences into account. Additionally, cultural contextual factors should be considered when contemplating the generalizability of literary findings.

Potential long-term goals involve dissemination of this project's findings to individuals from various health care disciplines to increase competency of intersectionality issues between medicine and psychology. Dissemination also has the potential to increase interdisciplinary collaboration and foster effective healthcare that reflects the patients' comprehensive physical and psychological needs.

Personal objectives involve increasing my knowledge of psychological aspects of health and illness. This was accomplished by critically reviewing the current body of literature and networking with mental health professionals that are currently working in the medical field. Additionally, I would like to expand on this dissertation at a later date to reexamine the current standards by which patients are evaluated for transplants as well as develop psychological interventions specifically for transplant patients and their support systems.

## CHAPTER II.

### Critical Review of the Literature

#### Medical History

In 1967, the first human heart was transplanted successfully by cardiac surgeon, Dr. Christiaan Barnard (Barnard, 1967). The recipient survived 18 days before succumbing to pneumonia (Brink & Hassoulas, 2009). The procedure generated a good amount of enthusiasm, peaking the interest of both the lay and medical community alike. Other surgeons promptly followed Barnard's lead. However, the survival rate was low and the number of heart transplants decreased steadily from 102 in 1968 to only 16 by 1970. The decline was primarily due to the undeveloped nature of immunosuppressive medications at the time (Brink & Hassoulas, 2009).

Subsequently, there have been considerable advances in surgical technique, organ preservation, tissue typing, immunosuppressive medications, and understanding of immune responses to transplantation (Davies et al., 2010; Guibert et al., 2011; Hunt & Haddad, 2008; Morgan & Edwards, 2005). With each passing decade, the number of transplants performed has increased exponentially, as have patient survival rates (Colombo & Ammirati, 2011). Unfortunately, the demand for donor hearts has surpassed the availability of the precious organs (Lund et al., 2015). This shortage has fueled research on the development of total artificial hearts (TAHs) and ventricular assist devices (VADs). In 1969, the first human TAH was implanted as a bridge to transplantation (Cooley et al., 1969). The device successfully stabilized the patient for several days until a donor human heart could be implanted (Cooley et al., 1969). In 1982, the first permanent TAH, Jarvik-7, was successfully implanted (Joyce et al., 1983). However, on the 112<sup>th</sup> day, the recipient passed away due to infection. The permanent implantable device, named after its inventor Dr. Robert Jarvik, has since evolved (Fox,

McKenna, Allaire, Mentzer, & Throckmorton, 2015). In 2006, the Federal Drug Administration (FDA) approved the first TAH solely for the purpose of prolonging life in patients who were not appropriate for transplantation (Nabel & Zerhouni, 2006; U.S. Food and Drug Administration (FDA), 2006).

Despite advances in medical technology, implantation of permanent TAHs continue to impose severe risks that include infection, mechanical malfunction, bleeding and blood clots (National Institutes of Health, 2016). VADs are more commonly utilized and may function as a temporary bridge to candidacy, transplantation, or recovery. In some cases, VADs provide lifetime support (Barnard & Tsiu, 2012; Harris et al., 2014). VADs have the potential to save lives and dramatically improve quality of life, however, they present with their own unique risk factors (Givertz, 2011). Despite all risks, heart transplantation is successful and remains the definitive treatment for individuals with advanced heart failure and limited life expectancy (Coglianese, Samsi, Liebo, & Heroux, 2015).

### **The Waiting List**

Once deemed to be an acceptable candidate for transplantation, the patient is registered on the national transplant waiting list, UNOS. UNOS serves as "the Organ Procurement and Transplantation Network (OPTN) under contract with the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (DHHS) (OPTN, 2016)." UNOS is responsible for organ allocation policy, organ placement, data collection and analysis, and professional and public education concerning organ policy. Notably, UNOS is the model for transplant systems worldwide (UNOS, 2016). Data from the OPTN database is used to monitor the efficacy of the organ allocation process.

Many factors weigh into the distribution of each individual organ, such as blood type and distance from donor hospital (OPTN, 2016). According to the 2014 Annual Data Report, only 2,269 of the 3,635 candidates on the waiting list were matched with a donor heart (Colvin et al., 2016). Of those recipients, half were supported by a VAD as a bridge to transplantation. At present, 4,153 candidates are on the waiting list for a donor heart (OPTN, 2016). Due to the significant disparity in the quantity of organs available relative to demand, the time to heart transplant has increased. In 2003-2004, the average wait time for a donor heart was 6.7 months compared to 10.9 months in 2013-2014 (Colvin et al., 2016).

The risk for infection and organ rejection is high following transplantation. In 2012–2013, the incidence of acute rejection within the first post-transplant year was 23.5% (Colvin et al., 2016). In 2013, 7.6% died within the first 6 months and 9.4% within the first year (Colvin et al., 2016). Deaths occurring within the first year following transplantation were primarily the result of infection, organ rejection, and cardiovascular diseases. By the second year, cardiovascular disease was most prevalent cause of death (Colvin et al., 2016). Among 2011 recipients, 15.2% died within three years. In 2009, 23.2% died within 5 years and 42.3% of recipients in 2004 died within 10 years (Colvin et al., 2016). As such, it is critical that organs are allocated wisely and patients are evaluated to determine the course of treatment best suited for them, ensuring the most successful outcome with a donor heart or artificial device.

### **Pre-Transplant Psychological Evaluation**

Once suitability for transplantation is established, patients encounter a pre-transplant workup by an interdisciplinary transplant team (e.g. cardiology, dietetics, social work; Collins & Labott, 2007; Levine & Levine, 1991). Transplant teams have an important responsibility to judiciously select candidates to ensure the success of both the patient outcomes and the

transplant program (Klapheke, 1999; Olbrisch et al., 2002). The majority of teams include a psychologist whose role varies from conducting an initial pre-surgical psychological evaluation to determine suitability for transplantation, to providing complete psychological support to the patient and their support system throughout the entirety of the transplant process (Collins & Labott, 2007). Psychologists are able to uniquely contribute to the transplant process by working with their interdisciplinary team to increase the quality and quantity of the patient's life.

The importance of the pre-transplant psychological evaluation is greatly valued and widely endorsed because of the significant risks, side effects, and potential for organ failure (Collins & Labott, 2007; Debray & Plaisant, 1990; Dobbels et al., 2001; Olbrisch & Levenson, 1991). The main purpose of the evaluation is to elicit vital information that will facilitate the team's understanding of the patient's well-being and factors that could both impede and support the transplant process (Collins & Labott, 2007). It is also intended to identify patient's that are high risk in order to facilitate treatment planning and reduce psychological risk factors, supporting outcomes and long-term success following transplantation (Collins & Labott, 2007; Craven & Rodin, 1992). There appears, however, to be considerable dissimilarity in the protocol for evaluating patients when transplantation is indicated (Levenson & Olbrisch, 2000).

Despite lack of uniformity, it is typically agreed that evaluations must assess for a range of psychosocial factors (Freeman et al., 1992). Pre-transplant psychological evaluations vary somewhat from general mental health assessments, in that they focus on areas of patient's lives that have specific implications for transplantation (i.e. history of nonadherence, severity of psychopathological symptoms, degree of social support, and ability to collaborate with their transplant team; Collins & Labott, 2007). Despite the dearth of empirically supported guidelines for pre-transplant psychological screenings, the latter psychosocial factors are considered to be



the most crucial when determining one's suitability for candidacy (Burker, Madan, Evon, Finkel, & Mill, 2009; Dobbels et al., 2009; Paris, Muchmore, Pribil, Zuhdi, & Cooper, 1994). Since there is a good amount of information to cover in the pre-transplant psychological evaluation, psychologists typically utilize a semi-structured interview format (Strouse, 1996). In addition to the patient interview, information is also gathered from support persons, medical records, and data from quantitative testing (Collins & Labott, 2007).

**Patient Interview.** The patient interview is considered to be the most useful source of information in the evaluative process (Collins & Labott, 2007). Psychiatric history and symptomology, substance use, current stressors, social support, coping styles, education, and occupation must be assessed clearly and directly in order to obtain comprehensive information about the patient (Bowie Bryant & Reams, 1998; Collins & Labott, 2007). Perhaps most important, is to gauge the patient's degree of motivation for transplantation (Collins & Labott, 2007). During the interview, the patient may be asked about difficulties keeping medical appointments, taking medications, following a nutritious diet or other lifestyle behaviors (Collins & Labott, 2007). A serious concern in transplantation is the issue of post-transplant nonadherence to the discharge plan. Incidents of organ rejection and infection are the most common consequences of post-transplant nonadherence (Dew et al., 2001). For this reason, nonadherence is the most significant psychological concern and may be viewed as an absolute contraindication (Frierson & Lippmann, 1987). Albeit less common, another important issue involves the patient's willingness to communicate and collaborate with their transplant team in the decision making process. Patients with relationship or characterological problems will likely not work well with the transplant team which may affect their treatment and consequently surgical outcome (Collins & Labott, 2007).

**Quantitative testing.** In the interview, patient's may be questioned about their cognitive functioning and administered a brief cognitive screening test (e.g. mental status exam; MSE) to identify cognitive deficits that may include delirium or dementia (Collins & Labott, 2007; Freeman et al., 1992). This type of screening is essential because it may uncover impairments that have not yet been noticed by the patient or patient's support system. If cognitive difficulties are observed during the interview or the patient performs poorly on a cognitive screening test, more comprehensive neuropsychological testing may be recommended prior to being listed and accepted as a candidate for transplantation (Tartar & Switala, 2000). Generally, neuropsychological testing is not part of the evaluative process for transplant programs in the U.S. Neuropsychological testing does, however, serve as an additional resource for diagnostic clarity when cognitive and personality factors are a potential concern (Dobbels, Put, & Vanhaecke, 2000; Greene & Sears, 1994; Levenson & Olbrisch, 1993b). In any case, many patients are vulnerable to the cognitive challenges due to the sequela of most medical conditions (Olbrisch et al., 2002). Evaluating the patient's cognitive functioning provides important information that will facilitate the treatment planning process and more accurately address the patient's needs (Strouse, 1996). To provide the best treatment possible, the treatment team should work together to maintain (e.g. medication adjustments, restoring electrolyte imbalance) cognition functioning throughout the transplant process (Collins & Labott, 2007).

Aside from information regarding the patient's cognition, other qualitative data is collected to facilitate the evaluation process. Several brief assessment instruments have been developed exclusively for the transplant population. The Psychosocial Assessment of Candidates for Transplantation (PACT) and Transplant Evaluation Rating Scale (TERS) were created to facilitate the evaluative process (Olbrisch, Levenson, & Hamer, 1989; Twillman, Manetto,

Wellisch, & Wolcott, 1993). The PACT and the TERS correlate well with one another and have demonstrated parallel levels of validity and inter-rater reliability (Presberg, Levenson, Olbrisch, & Best, 1995). A number of other psychodiagnostic assessment instruments may also commonly be used that provide information to providers about how patients cope with health issues, adjust to illness, and manage their medical problems (Derogatis, 2014; Millon, Green, & Meagher, 1982; Millon, Antoni, Millon, Meagher, & Grossman, 2004). The latter instruments are an important part of the evaluation and aid teams in the medical decision-making process.

**Collateral information.** Collateral information is of great importance in the evaluative process. For instance, vital information regarding social support can be assessed through patient report as well as the patient's support system (Olbrisch, Benedict, Ashe, & Levenson, 2002). Following transplantation, patients are not adequately able to care for themselves for a range of reasons including pain, a complex prescription regimen, and mobility issues (Collins & Labott, 2007). These challenges require the presence of a full-time caregiver throughout the recovery process (Collins & Labott, 2007). For this reason, the absence of adequate social support is perceived by many as a contraindication to cardiac transplantation (Collins & Labott, 2007; Yamini & Taylor, 2010). Obtaining collateral information from the patient's family or friends allows psychologists to assess the quality and quantity of support. It also provides an opportunity to observe ideas, attitudes, beliefs, and dynamics within the system, and provide support where necessary (Strouse, 1996).

Additionally, collateral information may reveal important details that the patient did not provide forthright, such as information regarding substance use or noncompliance (Collins & Labott, 2007; Olbrisch, Benedict, Ashe, & Levenson, 2002). With regard to substance abuse, collateral information can be useful to confirm details surrounding substance use history and

guide the team in preparing a treatment plan best suited for the patient (Beresford, 1992). In addition to corroborating information obtained in the patient interview, collateral interviews can often provide other information that the patient may have trouble articulating, such as information regarding deterioration in cognition or mood (Beresford, 1992). When patients are poor medical historians, collateral interviews become that much more valuable (Collins & Labott, 2007). In fact, there are cases in which patients may be unable to be interviewed due to a medical condition or emergency and information from collateral sources is required (Collins & Labott, 2007).

**Medical records.** Additionally, a medical records chart review can be a valuable resource, highlighting psychological issues or concerns that should be evaluated further by the psychologist. Documented medication history may provide useful information regarding psychiatric diagnosis. It is important to note that many non-psychotropic medications have mood altering side effects. These side effects must be differentiated from psychopathology when determining suitability for candidacy (Collins & Labott, 2007). Additionally, physicians often document behavioral observations and issues with compliance, which facilitate and enhance the information gathering process.

**Decision making.** Overall, the greatest barriers to transplantation are medical issues such as Human Immunodeficiency Virus (HIV), advanced diabetes, recent stroke, and morbid obesity (Yamini & Taylor, 2010). Clearing a patient to be listed as a candidate on UNOS requires the careful consideration of a variety of factors. Although psychosocial factors addressed in the evaluation may be used as a means to prioritize patients or determine suitability for transplant, this is not typical practice (Craven & Rodin, 1992; Olbrisch & Levenson, 1995). Research has shown that most psychosocial concerns have minimal influence on treatment outcomes (Sponga

et al., 2016). However, there is also research showing that pre-transplant psychosocial predictors may predict post-transplant adherence and clinical outcome (Dobbells et al., 2009). According to Olbrisch and Levenson (1991), approximately 6% of patients are ineligible for transplant due to psychosocial factors. There seems to be considerable debate over the relevance of any psychosocial factor other than nonadherence when determining transplant suitability (Freeman, Davis, Libb, & Craven, 1992). There is also considerable debate over contraindications pertaining to tobacco use, morbid obesity, noncompliance, recent substance abuse, criminality, neurodevelopmental disorders, and schizophrenia (Levenson & Olbrisch, 1993).

Guidelines at the Cleveland Clinic advise the following absolute and relative psychological contraindications: current alcohol or drug use, ongoing tobacco use, active psychosis, cognitive deficits that interfere with decision making, history of nonadherence, and absence of a social support (Yamini & Taylor, 2010). Across medical institutions contraindications vary greatly, especially when they pertain to psychosocial factors. Historically, substance use has been indicated as an absolute contraindication, however, transplant programs are typically more willing to list a patient for transplant if they have had periods of sobriety (Woodman et al., 1999). Mental health conditions are rarely contraindicated unless the patient poses a significant risk of harm to self or others (Woodman et al., 1999). Psychosocial factors are not considered absolute contraindications if the patient is able to benefit from resources to improve that particular area of functioning, as is the case with neurocognitive and neurodevelopmental disorders (Collins & Labott, 2007). Adequate social support is typically the best way to compensate for many of these factors (Collins & Labott, 2007). Psychologists performing pre-transplant evaluations typically take on a role as an advocate, focusing their efforts and shifting their attention towards identifying patient's strengths, addressing risk factors

and empowering the patient to be a strong candidate (Collins & Labott, 2007). In general, psychological factors seem to be less relevant for determining suitability for transplant, and more pertinent in attending to the patient's needs during and after the transplant process, but rather increasing overall quality of life to obtain the best outcome possible (Geller & Connolly, 1997; Sponga et al, 2016).

### **Nonadherence**

In much of the literature the term noncompliant has been used to describe the behavior of patients “who [do] not take a prescribed medication or follow a prescribed course of treatment (MedicineNet.com, 2016).” This term places the patient in a subordinate role to their provider with the expectation that they are to take a passive role in their health, regardless of their right to consent. The term nonadherence, however, is a more acceptable term. It implies the need for mutual agreement and empowers the patient to agree or disagree with provider recommendations before accepting them (Gandhi et al., 2016). This particular language is powerful, in that, it can be effective in shaping providers' perceptions of patients by increasing collaboration and decreasing blame.

Nonadherence is a critical issue among the heart transplant population. However, there is limited research exploring this issue, and even less in regard to nonadherence associated with LVAD implants and potential intervention strategies. A probable reason for this, is that it can be difficult to measure adherence due to the reliance on patient's willingness to report behaviors honestly, despite disapproval from their provider. Despite advances in medical technology, perhaps the greatest limitation to patient treatment outcomes, is the patient's willingness to adhere to medical instructions and advice. It is widely known that medication and diet nonadherence is highly prevalent among transplant patients, leading to an overall increase in

symptomology, increase in hospitalizations, and ultimately death (Fitzgerald et al., 2011). For instance, one of the most common causes of organ failure and mortality post-transplant is nonadherence to immunosuppressive medications. For example, nonadherence to warfarin administration following LVAD implantation may result in catastrophic pump thrombosis (Gandhi, McCue, & Cole, 2016). Therefore, nonadherence is of critical importance in order for the patient to achieve optimal outcomes.

There are various causes of noncompliance among transplant patients. Financial hardship is common in the context of an extensive and expensive medication. At any given time, patients with heart failure are taking a combination of six or more medications (Wong, Chaudhry, Desai, & Krumholz, 2011). Many immunosuppressive medications provide life sustaining benefits to patients that are not readily perceptible, which may lead to premature self-discontinuation of medications (Gandhi et al., 2016). Patients might also experience adverse side effects that contribute to self-discontinuation. Common side effects associated with cardiac medications are impotence, gynecomastia, vertigo, and migraines. Other issues such as poor healthcare literacy, lack of education from medical providers, and increased age with associated cognitive deficits may also be key factors. Additionally, a unique study conducted in Poland investigated adherence in “urgent” versus “planned” cardiac transplantation (Sobieszcańska-Małek, Mierzyńska, Jerzak-Wodzyńska, Zieliński, & Korewicki, 2011). In their study, patients who experienced an urgent transplant self-reported higher levels of medication and dietary adherence than those who experienced a planned transplant (Sobieszcańska-Małek et al., 2011). The researchers hypothesized that patients who encountered an urgent transplant were potentially less vulnerable to developing mental health concerns that may influence adherence (Sobieszcańska-Małek et al., 2011).

**Pretransplant predictors of posttransplant nonadherence.** Identifying nonadherence prior to transplant is necessary to initiate interventional efforts that will facilitate successful treatment outcomes. In general, there is a wealth of research showing that the best predictor of adherence is history of adherence (Dunbar-Jacob, Sereika, Rohay, & Burke, 1998). Among cardiac transplant recipients specifically, there is sufficient evidence to suggest the same (Bunzel, & Laederach-Hofmann, 2000; Douglas, Blixen, & Bartucci, 1996). According to Dobbels and colleagues (2009), patients with a pattern of nonadherence pre-transplant are eight times more likely to be nonadherent post-transplant compared to adherent peers. Prior to transplant, some patients are treated with in home inotrope infusions as a bridge to transplantation or LVAD (Gandhi et al., 2016). Patients are responsible for managing the infusions independently at home. Due to the complex nature of inotropic infusions, some transplant programs use this treatment as a means to assess patient's suitability for transplant or LVAD. It is assumed that adherence to in home treatment will generalize to adherence following a transplant or LVAD implantation (Gandhi et al., 2016).

There is a strong correlation between social support and adherence. Research suggests that adherence may facilitate the effects of social support on health (Hagedoorn et al., 2000). These effects are substantial, however, vary depending on the type of social support (Dobbels et al., 2009; George-Levi et al., 2016; Helgeson & Cohen, 1996; Seeman, Lusignolo, Albert, & Berkman, 2001; Vitaliano, 2001). For example, functional social support (e.g. emotional) seems to have a superior influence on adherence more so than structural support (e.g. marital status). This suggests that the quality of support is most essential (Martin, Davis, Baron, Suls, & Blanchard, 1994; Penninx et al., 1998). Unfortunately, the specific ways that adherence and a patient's support system are related are not well understood (DiMatteo, 2004).



There appears to be some discrepancy in the literature regarding the link between level of education and medication adherence (DiMatteo, 2004; Dobbels et al., 2009). The most recent data suggests that education level and post-transplant medication nonadherence are negatively correlated (Dobbels et al., 2009; Kung, Koschwanez, Painter, Honeyman, & Broadbent, 2012). One hypothesis, is that education level is positively correlated with higher rates of employment and a busier lifestyle, which is known to affect medication usage (DeGeest & Sabaté, 2003). It is also a possibility that patients with higher levels of education possess certain personality characteristics that make them more likely to exercise independent decision-making regarding their health (Greenstein & Siegal, 1998).

Post-transplant nonadherence also seems, in part, to be associated with personality characteristics. Specifically, conscientiousness has been linked to medication adherence (Dobbels et al., 2009; Molloy, O'Carroll, & Ferguson, 2014). Conscientiousness is defined as “a fundamental personality trait that influences whether people set and keep long-range goals, deliberate over choices or behave impulsively, and take obligations to others seriously (Psychologytoday.com, 2016).” Research has also suggested a relationship between low conscientiousness and medication nonadherence (Stilley, Sereika, Muldoon, Ryan, & Dunbar-Jacob, 2004). Medication nonadherence has been associated with “Type D personality (Molloy et al., 2012; Williams, O'Connor, Grubb, & O'Carroll, 2011; Wu & Moser, 2014).” "Type D personality" is a “distressed” personality type, made up of “negative affectivity” and “social inhibition” traits (Denollet, 2000; Wu & Moser, 2014). Individuals with this personality type tend to experience high negative emotion and likely refrain from sharing their emotions with others, including feelings about their prescribed medical regimen.

It has been noted in the literature that transplant recipients contend emotionally with guilt over having wished that a suitable donor would die (Sanner, 2003). In a recent study by Shemesh and colleagues (2017), Israeli researchers examined the link between guilt and immunosuppressive medication nonadherence among transplant patients. They learned that "patients with guilt feelings were found to have a lower probability of implementation, persistence, and overall adherence to immunosuppressive medications."

**Nonadherence in cardiac transplantation and LVAD.** Although LVAD's significantly increase patient survival, patients are at significant risk for complications following implantation, such as infection, stroke, gastrointestinal bleeding, and pump malfunction (Gandhi et al., 2016; Slaughter et al., 2009). According to recent data, approximately 70% of patients with an LVAD experience at least one LVAD-related health crisis within one year following device implantation (Kirklin et al., 2013). Therefore, the patient's strict adherence to medical treatment is critical to avoid a catastrophic event. There is a paucity of research examining patient adherence on LVAD morbidity and mortality. It is generally agreed upon, however, that patients' self-care behaviors lead to an optimal life with their device (Kato, Jaarsma, & Ben Gal, 2014).

There is one known study examining the effects of nonadherence behavior among patients with an LVAD (Hackmann et al., 2013). Hackman and colleagues (2013) retrospectively reviewed the medical charts of 111 patients. They found that nonadherence increased the risk of device malfunction but had no significant effect on survival rates. Together, 51 patients accumulated a total of 490 nonadherence "events." The most common events were failing to have labs drawn (54%) and nonadherence to their medication protocol (26%). Thirty-seven percent of the nonadherent patients experienced a device malfunction compared to 17% of those who were adherent (Hackman et al., 2013).

LVADs are complex and require significant change in a patient's life immediately following implantation. In an effort to streamline LVAD self-care behaviors, Kato and colleagues (2014) organized necessary behaviors into three components: "self-care maintenance," "monitoring," and "management." Self-care maintenance consists of medication, diet, and exercise adherence. It is the most patient involved component. Monitoring self-care involves a high degree of patient education and careful observation of physical and psychosocial signs, symptoms, and conditions. Lastly, self-care management is concerned with the patient's response to specific signs, symptoms, and conditions. For instance, knowing "when" and "who" to call when experiencing a new symptom (Kato et al., 2014).

As demonstrated above, maintaining self-care following LVAD implantation is a significant burden on the patient and their caregiver, yet imperative to successful outcomes. Heart transplant patients encounter similar challenges to those of the LVAD population. Post-transplant, adherence is critical in order to avoid organ rejection and infection, and to improve overall sense of well-being (Gandhi et al., 2016). Recipients are discharged home with multiple medications that include, on average, at least three immunosuppressive medications (Lindenfeld et al., 2004). According to a study by Dew and colleagues (1999), 36% of candidates fail to adhere to their immunosuppressant regimen within the first two months post-transplant. Approximately 40% of hospital admissions following cardiac transplant are medication related, 58% percent of those admissions are deemed to be preventable (Repp et al., 2012). Despite the fact that complications typically occur shortly following transplant, lifelong adherence is necessary, as the risk of graft failure and potential death will always be present (Laederach-Hofmann & Bunzel, 2000).

**Interventions addressing nonadherence.** Known interventions targeting medication nonadherence among LVAD and heart transplant populations involve the packaging and delivery of patient education (Gandhi et al., 2016). For example, the self-administration of medications (SAMs) model is utilized at the University of Washington (Hermsen, Smith, & Mokadam, 2013). Consistent with the model, both heart transplant patients and patients with an LVAD receive education regarding their medications prior to leaving the hospital and returning to their home. Education is typically provided by a nurse or pharmacist and covers all prescribed medications. Typically, clinicians spend a good amount of time with each patient, using a variety of teaching aids (e.g. medication lists and pill identification sheets) to ensure understanding (Christensen & Lundh, 2016; Hermsen et al, 2013). SAMs is cost-effective and provides some benefit to patients (e.g. education), however, a National Institutes of Health funded study pointed out the paucity of research showing any effect on adherence using the SAMs model (Hermsen et al, 2013; Richardson, Brooks, Bramley, & Coleman, 2014).

The “Circle of Caring” model is a “holistic” nurse driven intervention developed to increase patient adherence (Dunphy & Winland-Brown, 1998). Application of the model was first examined with a case study of a cardiac transplant patient (Palardy & March, 2011). This approach involves identification of psychosocial barriers that may contribute to nonadherence. It also requires the provider to properly assess for learning barriers and determine the patient’s readiness to learn as well as their learning style (Palardy & March, 2011). Providers also assess the patient’s values, perception of their medical condition, and their view of outcomes. In this way, patients are actively and meaningfully engaged in their own healthcare. Palardy and March (2011) found that provisions of care utilizing this broadened approach resulted in patient’s ownership of their healthcare and increased medication adherence.

Other medical intervention strategies seek to engage technology to monitor medication adherence (Eisenberger et al., 2013). The first “digital pill” was approved by the Federal Drug Administration (FDA) in 2012 (Eisenberger et al., 2013). The pill contains a microsensor that is activated once it interacts with digestive juices (Au-Yeung et al., 2011; Eisenberger et al., 2013). Although this technology has not yet been used with cardiac patients, it has proved to be highly accurate and effective in monitoring adherence (Au-Yeung et al., 2011; Eisenberger et al., 2013). However, its use still requires the patients’ engagement, willingness, and commitment to change.

Finally, with regard to psychological interventions, Cognitive Behavior Therapy (CBT) has been found useful in increasing patient adherence; however, there are no known outcome studies using cardiac transplant patients (Cupples & Steslow, 2001).

**Associations with medication beliefs and perception of medical condition in nonadherence.** Recent research has addressed the Necessity-Concerns Framework and the Common-Sense Model of Illness to better understand nonadherence (Horne, Cooper, Gellaitry, Date, & Fisher, 2007; Leventhal, Meyer, & Nerenz, 1980). In both theories, the patient is an active problem solver. The problem solver creates a psychological model of their medical condition, wherein they develop beliefs regarding their medication use, for example. The patient’s perception of their medical condition tends to involve thoughts about the identity of the condition, possible etiology, prognosis, the impact of the condition on their life, their ability to cope, and potential medical interventions. Patients experience an emotional reaction in response to their thoughts regarding their condition, which, in turn, influences their behaviors associated with their medical condition.

There is some research to show that patients' medication-related beliefs and perceptions of their medical condition are associated with adherence in several non-cardiac conditions (Broadbent, Donkin, & Stroh, 2011; Dalebout, Broadbent, McQueen, & Kaptein, 2011; Horne, & Weinman, 1999). One study conducted in New Zealand further investigated the role of medication beliefs in nonadherence and patients' perceptions regarding their transplants in 326 combined heart, lung, and liver transplants (Kung, Koschwanez, Painter, Honeyman, & Broadbent, 2012). The findings were parallel to those referenced above, in that, nonadherence was associated with decreased beliefs regarding medication benefits, increased beliefs regarding the potential harm of medications, decreased understanding of the transplant process, increased symptoms, increased distress, and increased perception of transplant related consequences (Kung et al., 2012).

Recent studies, utilizing a text message program and Adherence Therapy (AT), have demonstrated that medication adherence can be increased with modification of the beliefs and perceptions of one's medical condition (Alhalaq, Deane, Nawafleh, Clark, & Gray, 2012; Petrie, Perry, Broadbent, & Weinman, 2012). These studies were conducted with a hypertension and asthma population; however, it is possible that these results may also be generalizable to cardiac transplant patients.

### **Depression and Anxiety in Heart Transplantation**

**Waiting period.** Since the first transplant in 1967, many of the acute medical and immunological issues in transplantation have been resolved, which has led to increasing interest in many psychosocial factors associated with the transplant process (Barnard et al., 2006; Zipfel, Schneider, Jünger, & Herzog, 2010). The period prior to transplantation introduces significant psychological distress on transplant candidates (Zipfel et al., 2010). When candidates are listed

for an organ they are informed of the increased demand for organs and the stagnating supply (Zipfel et al., 2010). During the waiting period, physical and psychological symptoms tend to worsen (Zipfel et al., 1998). The wait for approximately 30% of patients results in death (Zipfel et al., 2010). Candidates tend to experience a high level of ambivalence prior to transplantation. It is common to experience a waxing and waning of symptoms. When patients are feeling physically well, they may question the necessity of transplantation. Conversely, when patients feel poorly, they may wonder whether or not a donor heart will be made available in time. At the time, patients may be faced with thoughts directed towards hoping someone would die so that a donor heart would become available sooner (Bunzel, 1993). Kuhn and colleagues (1988) described this ambivalence as a “dance with the dead.” It is this ambivalence that creates tremendous stress on patients and their families.

Depression and anxiety are common among the pre-transplant population, regardless of having a bridge to transplantation with an LVAD (Dew et al., 2001; Grady et al., 2003; Zipfel et al., 1998). In fact, the rates of depression among patients with heart failure awaiting transplant are approximately three times greater than those of the general population (Rutledge, Reis, Linke, Greenberg, & Mills, 2006). Some estimated 48–64% of patients on the waitlist meet criteria for at least one mental disorder (Engle, 2001; Kuhn et al, 1988; Lang, Klaghofer, & Buddeberg, 1997). Approximately 35% of patients experience an anxiety disorder prior to transplantation, and over 20% suffer from a depressive disorder (Magni & Borgherini, 1992). What is more, Zipfel and colleagues (2010) indicated that symptoms of depression reached clinical significance within four months of being placed on the transplant waiting list. In addition to patient distress, the wait is psychologically demanding for family members. Many report that

their lives have been significantly and negatively impacted as a result (Collins, White-Williams, & Jalowiec, 1996; Bunzel, 1993).

There are limited findings on the relationship between mental disorders and transplant outcomes (Dew et al., 2015). Across various solid organ transplant populations, there is some research indicating that pre-transplant anxiety or depression increases patients overall risk for morbidity and mortality, with the assumption that it leads to issues such as poor adherence (DiMartini et al., 2011; Smith et al., 2014). Unfortunately, this relationship has yet to be supported in other studies (Rogal, Landsittel, Surman, Chung, & Rutherford, 2011; Rowley, Hong, Chapman, & Crippin, 2010).

In a recent study conducted by Epstein and colleagues (2016), researchers investigated the effects of pre-transplant depression and anxiety on mortality post-transplant for 130 patients. The one year survival rate for all patients was 93.1% (Epstein & Lucero, 2016). The one year survival rate for patients who did not meet criteria for depression or anxiety was 100% (Epstein & Lucero, 2016). The one year survival rate for patients with clinically significant symptoms of anxiety was 92.3% (Epstein & Lucero, 2016). Twenty-two patients who met criteria for depression had a one year survival rate of 90.9% (Epstein & Lucero, 2016). Lastly, the one year survival rate for patients who met criteria for both depression and anxiety was 86.7% (Epstein & Lucero, 2016).

These findings suggested that depression and anxiety are significant predictors of mortality (Epstein & Lucero, 2016). What is more, the risk of mortality peaked within the first two years following transplant and remained significant at year three (Epstein & Lucero, 2016). However, by year five, the mortality rate was no longer significant (Epstein & Lucero, 2016).



These findings suggest that pre-transplant symptomology of depression and anxiety are positively correlated with mortality following transplantation (Epstein & Lucero, 2016).

**Postoperative Period.** During the first year following successful transplantation, the rates of psychopathology decrease significantly (Dew et al., 1996). This is primarily due to a perceived increase in physical and psychological well-being (Fusar-Poli et al., 2006). One study examined the presence of depression and anxiety postoperatively and found that approximately 20% of their patients met criteria for a mental disorder (Dew et al., 1996). An estimated 17% of patients met criteria for a depressive disorder. Surprisingly, there were no patients who met the criteria for an anxiety disorder. In a Polish study of transplant recipients, researchers found a positive correlation between the severity of depressive symptoms and the manifestation of physical maladies (Milaniak, Wilczek-Rużyczka, Wierzbicki, Kędziora, & Przybyłowski, 2017).

Following transplantation patients typically report feeling as if they were on “a second honeymoon” and describe themselves as “flying high” (Christopherson, 1987; Kuhn et al., 1988). At the same time, the patient is confronted with the alarming reality of life threatening infections and potential organ rejection (Zipfel et al., 2010). The transition from the highly-supervised hospital environment to the patient’s home is an important time. Although the patient may experience comfort and relief in returning to their home environment, there are typically concerns regarding the responsibility of new self-care behaviors (Zipfel et al, 2010). Both the patient and their family are confronted with new and challenging routines and tasks (Zipfel et al, 2010). Regardless, patients seem to do well and soon experience increased functional capacity and perceived quality of life (Dew, 1998).

**Long-term outcomes.** Unfortunately, decreases in psychopathology rates during the immediate postoperative period seem to be short lived. During the first several years after

transplantation, approximately 63% of recipients experience depression or anxiety, compared to three percent and 10%, respectively (Dew & DiMartini, 2011; Eaton et al., 2008; Fusar-Poli et al., 2007; Katon, 2003; Polsky et al., 2005; Zalai, Szeifert, & Novak, 2012). Rates of depression have been shown to increase in subsequent years following transplant (Harris & Heil, 2013).

Dew and colleagues (1996) identified several risk factors associated with the prevalence of depression. They found a positive correlation between pre-transplant history of mental disorders and depression three years post-transplant. Female patients that had been on the waitlist longer than 6 months were significantly more vulnerable to developing depression than their male peers. Depression was also more prevalent among patients who had a VAD implanted as a bridge to cardiac transplantation. In addition, the patient's level of physical activity beginning at two months post-transplant was shown to influence the trajectory of depressive symptoms long-term for the better (Dew et al., 1996). Finally, there was a negative correlation between perceived quality of social support and mental disorder symptoms (Dew et al., 1996). Zipfel and colleagues (2010), also identified the correlation between psychosocial support and severity of depressive symptoms. Specifically, patients who described the quality of their social support system as "strong" and "supportive" demonstrated the lowest levels of depression (Zipfel et al., 2010).

Between 12 and 18 months post-transplant, 13% to 14% of patients experience a new depressive episode (Dew et al., 2001). By year three, approximately 25.5% of recipients meet criteria for a mood-related disorder (Dew et al., 1996). Additionally, the long-term prevalence of anxiety disorders is relatively low among heart transplant patients, thus, is seldom discussed in the research (Dew et al., 2001). Zipfel and colleagues (2010) also noted a progressive increase in

depressive symptoms over time, from 8 weeks to one year post-transplant. By 6 years, depressive symptoms were found to parallel those observed in the preoperative period (Zipfel et al., 2010).

Similarly, in another study, 75% of patients surveyed one year post transplant, rated their physical and psychological well-being to be “excellent,” and reported few physical complaints (Bunzel & Laederach-Hofmann, 1999). After five years, patients reported experiencing an overall positive body image and high degree of physical well-being. Conversely, they rated their psychological well-being to be poor. Their psychological symptoms had significantly increased (Bunzel & Laederach-Hofmann, 1999). Hetzer and colleagues (1997) studied a group of patients nine to 13 years post-transplant and found a similar phenomenon. Almost 80% of patient reported that their overall physical health was excellent. Meanwhile, they reported a significant increase in symptoms related to disability and suffering, and a decreased sense of personal accomplishment (Hetzer et al., 1997).

Despite the latter reported symptoms, recipient’s quality of life is typically found to be parallel to that of other healthy control samples (Hetzer et al., 1997). Patients tend to score relatively high on all dimensions (Zipfel et al., 2010). The general idea among clinicians is that the latter idealized impression of their general health may actually represent a marked display of gratitude (O’Brien, Donaghue, Walker, & Wood, 2014). Receipt of a donor organ may be viewed as a “gift of life,” and evoke certain feelings of being given another opportunity at life (Evangelista, Doering, & Dracup, 2003; Fox & Swazey, 1974). In the context of cardiac transplantation, the nature of gratitude is complex. It involves a wide range of accompanying emotions (O’Brien et al., 2014).

**Psychopathology in patients with an LVAD.** Patient’s on a bridge to transplantation with an LVAD also experience a high occurrence of clinically relevant symptoms associated

with depression and anxiety (Brouwers et al., 2013; Modica et al., 2015). In a study investigating the psychological demands of patients implanted with an LVAD, patients were found to have higher rates of clinical depression and anxiety pre-operatively compared to patients awaiting cardiac transplantation. In contrast, Modica and colleagues (2016) reported more conservative rates of clinically relevant depression (18%) and anxiety (18%). Both depression and anxiety were positively correlated with avoidant coping in response to LAVD implantation. Avoidant coping involves effortful avoidance of stressful but inevitable situations. It is strongly associated with depression (Penley, Tomaka, & Wiebe, 2002). Factors affecting LVAD acceptance involve type of device, experience of disease while waiting for transplant, perceptions of the individual's heart as a diseased organ, doctor-patient communication, opportunity to share LVAD experience with others, and psychological characteristics (Modica et al., 2016). Psychological characteristics broadly involve personality, presence of psychological disorder, social support, and cultural factors (Modica et al., 2016). In regard to quality of life, there is an increase immediately following implantation, but emotional distress remains high (Modica et al., 2016). These findings are parallel to those reported for quality of life in the context of cardiac transplantation (Hetzer et al., 1997).

**Posttraumatic stress disorder (PTSD).** According to the literature, approximately 17% of transplant recipients experience transplant-related symptoms of PTSD during the first year post-transplant (Dew et al., 2001; Gotzmann & Schnyder, 2002). There seems to be some discrepancy in the research, however, as to whether or not transplant-related symptoms fully meet criteria for PTSD (Bunzel, Laederach-Hofmann, Wieselthaler, Roethy, & Wolner, 2007). More recently, Supelana and colleagues (2016) indicated that although full-scale PTSD is uncommon, Posttraumatic Stress Syndrome (PTSS), subthreshold symptoms of PTSD, is quite

prevalent. They explained that this is particularly important to recognize, due to the avoidance category of PTSD. For example, patients have been known to avoid life-preserving immunosuppressive medications in an effort to avoid reminders of their transplant. This phenomenon is also prevalent in other areas of cardiology, such as with the occurrence of a myocardial infarction (Staikos, Chalkias, Tsekoura, Iakovidou, & Xanthos, 2017). Nonetheless, research on transplant-related PTSD has expanded to include exploration of the emotional consequences of transplantation on caregivers (Bunzel, Laederach-Hofmann, Wieselthaler, Roethy, & Wolner, 2007; Supelana et al., 2016).

**Psychological interventions.** Only one intervention study was identified that attempted to manage symptoms of psychopathology in the transplant population. Riedel-Keil and colleagues (1994) targeted psychological disorders with the use of relaxation techniques. Unfortunately, the study is in the German language and was not able to be fully reviewed.

### **The Importance of Social Support**

The connection between social support and cardiovascular health has been a critical area of study for some time (Lett et al., 2007). Social support has been connected with the prevalence of illness and death across a range of cardiovascular diseases (Compare et al., 2013; Zarbo, Compare, Baldassari, Bonardi, & Romagnoni, 2013). Social support has also been noted to be one of the most protective factors for cardiovascular health and is associated with both decreased symptoms of anxiety and cardiovascular disease (Zarbo et al., 2013). Although having good quality social support is generally known to provide cardiovascular benefits, the research evaluating social support among heart transplant patients is limited. There are a number of studies that include social support as a research variable, however social support is not identified in the study as the main focus (Grady et al., 2007; Wang, Chang, Shih, Sun, & Jeng, 2006).

Additionally, there is limited research examining social support beyond the post-transplant phase (Dobbels et al., 2004). This phase is particularly critical due to the major psychosocial adjustments in the recipient's life.

In several studies, social support has been associated with successful post-transplant outcomes (Berry & Kymissis, 2016; Rosenberger, Fox, DiMartini, & Dew, 2012). These outcomes may be result from a variety of factors such as management of comorbid conditions, medications, increased access to transportation, medical adherence, economic benefits, or emotional support that may improve self-esteem and overall life satisfaction (Tam et al., 2011; Zarbo et al., 2013). It is known that patients who have adequate and satisfactory social support cope more effectively and are better equipped to manage stress (Lazarus & Folkman, 1984; Rankin & Fukuoka, 2003). As such, researchers recommend that patients identify reliable social support persons due to the high level of stress involved in the transplant process (Mehra et al., 2016; Rudis, Rudis, Lupo, Safady, & Bonne, 2000). Furthermore, inadequate support is associated with increased rates of post-transplant nonadherence and mortality (Chacko, Harper, Gotto, & Young, 1996; Dew, Roth, Thompson, Kormos, & Griffith, 1996; Dobbels et al., 2004).

**Quality of life.** There is an abundance of research providing evidence for a significant association between social support and "Health-Related Quality of Life (HRQoL), a multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning (Ferrans, 2005; Grady et al., 2007; Sirri, Magelli, & Grandi, 2011; White-Williams et al., 2013)." On the other hand, there is also research that has not showed any significant association between social support and HRQoL (Heo, Moser, Lennie, Zambroski, & Chung, 2007). There is also conflicting support in the literature for a relationship between emotional support and HRQoL. Emotional support typically involves empathy, compassion, and genuine

concern for another's well-being (House, Kahn, McLeod, & Williams, 1985). In some studies, it is suggested that emotional support is positively correlated with HRQoL (Bennett et al., 2001; Friedman & King, 1994). However, more recently, emotional support has been associated with decreases in HRQoL (Cohen, Gottlieb, & Underwood, 2001; Heo et al., 2007). What is more evident, is that emotional support is positively correlated with life satisfaction, whereas, tangible support was not being shown to have the same effect (King, Reis, Porter, & Norsen, 1993). Of note, tangible support consists of support with issues such as "Instrumental Activities of Daily Living (IADLs; House et al., 1985)."

**Type of supportive relationship.** Researchers at Cedars-Sinai Hospital in Los Angeles, California investigated whether a specific type of supportive relationship would affect post-transplant outcomes (Stimpson et al., 2015). Two hundred ninety-four patients were examined. All patients were appropriate for transplant and considered their current support network to be adequate. Social support was categorized as spouse, sibling, parent, adult child, other family, and non-family. After one year post-transplant, there was no significant difference in hospital readmissions, adverse cardiac events, organ rejection, or survival among any of the relationship types (Stimpson et al., 2015). The study was later replicated with a larger sample size of 495 patients, and yielded the same results (Stimpson et al., 2016).

Several transplant studies were identified that looked specifically at the quality of the patients' supportive relationships (Dobbels et al., 2009; Sirri et al., 2011; Tam et al., 2011). In an Italian study, married patients more frequently endorsed items on the Interpersonal Support Evaluation List (ISEL) that related to both increased self-esteem and sense of belonging. The researchers hypothesized that marital support is an important contributor to positive health outcomes (Sirri et al., 2011). What is more, Dobbels and colleagues (2009) examined pre-

transplant psychosocial predictors of post-transplant medical adherence. Their most significant finding, was a predictive value of partnership on organ rejection between 6-12 months post-transplant (Dobbels et al., 2009). Another study identified a survival benefit among married recipients one year after transplantation. At five years, married patients had a greater rate (15%) of survival compared to their non-married peers (Tam et al., 2011).

Of note, a qualitative study conducted in Canada, investigated illness representations among cardiac transplant recipients (Janelle, O'Connor, & Dupuis, 2016). Many patients identified social support as a relevant and essential factor in their transplant process. However, some patients reported that support from their medical team was more helpful than familial support. One patient explained, "The medical staff is even more important than your family members, because when family members visit, they bring love but they also create stress (Janelle, O'Connor, & Dupuis, 2016)."

**Long-term fulfillment of adequate social support.** There is some literature suggesting that cardiac patients experience increased satisfaction with their social support system over time (Burg et al., 2005). There is one study that suggests the opposite trend (Kristofferzon, Löfmark, & Carlsson, 2005). White-Williams and colleagues (2013) measured cardiac-transplant recipients long-term satisfaction with their support system following transplantation. Recipients reported a high level of satisfaction with their support system five years following transplantation. At 10 years, they consistently reported high levels of social support satisfaction. Long-term, there appeared to be no association between level of satisfaction with social support and long-term survival. The level of satisfaction between different types of support was found to be relatively constant over time. In general, recipients reported less satisfaction with their level emotional support compared to tangible support. It was hypothesized that emotional support is



more ambiguous and therefore potentially more challenging to fulfill (White-Williams et al., 2013).

Similarly, Bohachick and colleagues (2002) confirmed the stability of social support over time. They also identified a decrease in “social network helpfulness” and “sense of attachment” at 6 months post-transplant. An integral component of these two factors involved postoperative interactions and level of helpfulness from healthcare providers. Therefore, the decline was attributed to the typical expected decrease in provider contact following successful transplantation (Bohachick, Taylor, Sereika, Reeder, & Anton, 2002).

**Associations between social support and depression.** Transplant patients with reportedly inadequate levels of social support are at a greater risk for psychological disorders, especially depression and anxiety (Dew et al., 2005). It seems that recipients are particularly vulnerable to these disorders between 6 months to four years post-transplant (Dew et al., 2005; Milaniak, Wilczek-Rużyczka, Wierzbicki, & Przybyłowski, 2015). German researchers further expanded on this research and discovered that recipients with limited social support and a diagnosis of clinical depression are significantly more vulnerable to physical deterioration and death post-transplant (Spaderna et al., 2010). This vulnerability is most salient within the first year following transplantation. The association between the latter factors were found to be significant regardless of the severity of physical and psychological pathology (Spaderna et al., 2010). Adaptive coping strategies are thought to facilitate the relationship between emotional and tangible support, and clinical depression (Milaniak et al., 2015). More specifically, patients with reportedly inadequate social support have been found to utilize wishful-thinking style of thinking (i.e. hoping and wishing things could be better, rather than taking action to improve a situation), subsequently exacerbating depressive symptomology (Milaniak et al., 2015).

Additionally, depression and perceived level of social support appear to share a bidirectional relationship. Italian researchers concluded that, as a result of present clinical depression, patients may experience a decreased level of satisfaction with their social support, which may have otherwise been perceived as adequate (Sirri et al., 2011).

**Depression in caregivers.** There is a small body of literature examining psychological disorders among caregivers of cardiac-transplant patients (Annapoorna & Ward, 2015; Burker, Evon, Loiselle, Finkel, & Mill, 2005; Dew et al., 2004). Clinical depression and anxiety among caregivers is thought to be more prevalent than what is found in the general population (Annapoorna & Ward, 2015; Dew et al., 2004). Dew and colleagues (2004) evaluated caregiver symptomology throughout the first year following transplantation, and again at three years. Rates of depression and anxiety increased progressively and were highest at 36 months, 31.6% and 7.3% respectively (Dew et al., 2004). Additionally, depression among caregivers has been associated with increased difficulties in daily functioning and physical maladies (Burker, Evon, Loiselle, Finkel, & Mill, 2005).

### **Other Interventions**

In recognizing the significant impact of transplantation on the entire family system, Dew and colleagues (2004) developed an internet-based intervention for both recipient and their family caregiver(s). The goal was to increase psychosocial outcomes for all participants. The websites content included post-transplant skills workshops designed to increase quality of life and increase medical adherence. Workshops focused on stress management and management of the medical regimen. They included a sequence of chapters, as well as homework that could be completed at the individuals own pace. Patients and their caregivers had access to separate discussion groups, organized with bulletin boards and threaded comments. Another feature of the

intervention, was the “ask an expert” section, where individuals could submit questions and comments to the transplant team. These questions and their answers were stored in the “question and answer library” for all other participants to see. Additionally, the intervention offered “healthy living tips” to achieve and maintain a healthy lifestyle, as well as a comprehensive “resources and references library.” Patients and caregivers utilized the website for four months. At four months, symptoms of depression and anxiety significantly decreased compared to the control group. At this same time, caregiver’s symptoms of anxiety were found to have been significantly decreased. There was no meaningful change in medication adherence; however, patients who participated in the management of medical regimen workshop showed significantly higher adherence rates relative to the other patients in the study for blood work, nutrition, and medical appointments (Dew et al., 2004). The time of the follow up interview was not noted in the research.

### CHAPTER III.

#### Methodology

##### Design

The main objective of this clinical dissertation is to disseminate clinical information to mental health providers working on interdisciplinary teams in the medical field. I developed a professional presentation to help providers acquire relevant knowledge pertaining to the cardiac transplantation process. I then disseminated the information through a PowerPoint presentation. The presentation provided key information regarding psychological aspects of cardiac transplantation. It also provided a platform for professional dialogue, the promotion of research, and evidenced-based psychological interventions.

##### Procedures

I conducted a critical review of the current body of literature regarding psychological aspects of cardiac transplantation. The reviewed literature focused on three significant factors associated with transplantation: nonadherence, depression and anxiety, and social support. The information was accessed from various sources that included peer-reviewed journals, books, and professional websites. Furthermore, I interviewed 5 clinical experts (i.e., field consultants) in the field of clinical health psychology and cardiology to supplement the information found among the other sources. The information gathered from the literature review and field consultant interviews was integrated into a formal presentation. The presentation was presented to a group of mental health professionals working in a medical center. At the end of the presentation, audience members completed an evaluation form.

**Target Audience**

The audience was composed of four psychology interns and one clinical health psychologist on November 17, 2017, at the Battle Creek VA Medical Center, in Battle Creek, Michigan.

**Field Consultant Interviews**

Five clinical experts were interviewed to supplement information found in the current body of literature. Field consultants were recruited through professional associations, medical institution directories, and an independent search of researchers who have expertise working with cardiac and transplant patients. One consultant was identified from a podcast interview. Each field consultant provided their consent to be interviewed. Consultants were given the option of being interviewed via telephone, video teleconference, or email. Given reported time constraints, all consultants requested to be interviewed via email. A structured list of interview questions was emailed to each consultant. Consultant responses are discussed in Chapter IV of this dissertation. Relevant content from the interviews was included in the final product of this clinical dissertation.

**Final Product**

The contents of this clinical dissertation were disseminated in the form of a PowerPoint presentation. The presented topics included a brief history of cardiac transplantation, the psychosocial evaluation process, nonadherence, depression and anxiety, social support, and clinical interventions (Appendix C).

**Product Evaluation**

At the end of the presentation, audience members completed an evaluation form

consisting of 8 questions on a 5-point Likert scale (Appendix D). Precoded responses were as follows: 1 = *Strongly Disagree*, 2 = *Disagree*, 3 = *Neutral*, 4 = *Agree*, and 5 = *Strongly Agree*. There was space provided at the bottom of the form for the audience members to provide additional comments or feedback. In response to the information provided in the presentation, the audience was asked whether (a) they were able to increase their knowledge of psychosocial factors related to the transplant process, (b) they were able to increase their awareness of the need for interventions tailored specifically to the transplant population, (c) the presentation promoted reflection regarding interdisciplinary collaboration and team functioning dynamics, (d) they were able to consider the cultural context behind the current body of literature and contemplate its generalizability, (e) the presentation was concise and educational, (f) the presenter appeared knowledgeable about the topic, (f) the presenter was organized and well prepared, and (g) the presenter maintained their interest throughout the presentation.

### **Data Analyses**

Descriptive statistical data were collected on the numerical data from the evaluation form submitted by audience members. Vocal and written feedback were analyzed qualitatively. The data was used to assess: (a) the strengths and limitations of the presentation; (b) how audience members responded to the information being communicated in the presentation; and (c) the specific areas of interest that may be expanded upon in future presentation on the topic.

## CHAPTER IV.

### Results

#### Field Consultant Interviews

Based on their knowledge and expertise in cardiology and the transplant process, 5 clinicians were invited to participate as field consultants on this doctoral dissertation. Field consultants provided their clinical insights and perspectives to supplement the available published literature outlined in Chapter II of this text. All field consultants responded to a list of interview questions via email. Two of the field consultants collaborated to answer the interview questions based on their experiences as colleagues working within the same medical institution (Please see Appendix B for the list of interview questions). Brief biographies of each field consultant can be found below.

#### Field Consultant Biographies

Cinamon C. Romers, Ph.D., is a licensed clinical and health psychologist at Baylor Scott & White Health in Temple, Texas. She is also a professor of psychiatry and behavioral science at Texas A&M Health Science Center College of Medicine. Part of her clinical emphasis includes pre and post organ transplant treatment and behavioral medicine. Dr. Romers is also a researcher and currently investigating psychological comorbidity and LVAD survival in military veterans.

Jae L. Ross, Psy.D., is a licensed clinical and health psychologist at Baylor Scott & White Health in Temple, Texas. Part of his clinical emphasis consists of pre-surgical psychological evaluations, adjustment disorder, and anxiety and mood disorders.

James Levenson, M.D., “is a professor of psychiatry, medicine, and surgery at the Virginia Commonwealth University School of Medicine, where he is also Chair, Division of Consultation-Liaison Psychiatry, and Vice-chair for Clinical Affairs, Department of Psychiatry.

He has published over 175 papers and book chapters, and four books, including *Psychiatry Essentials for Primary Care*, and *The American Psychiatric Publishing Textbook of Psychosomatic Medicine*." His research expertise includes psychiatric aspects of medical illness and psychosocial issues in organ transplantation.

Lubna Somjee, Ph.D., is a licensed clinical and health psychologist in private practice in Poughkeepsie, New York. Part of her clinical emphasis includes management of chronic medical illnesses, including cardiovascular disease. Much of her work is focused on increasing adherence and motivation to exercise and long-term healthy eating, increasing medication adherence, assessing for psychological disorders that can increase risk for chronic diseases, coping with medical illness, and managing anxiety due to health fears or medical procedures. Additionally, she is engaged with the Hudson Valley Region, American Heart Association's Better U Program, a 12-week program designed to improve cardiovascular health through lifestyle changes.

Ellen Dornelas, Ph.D., "is the former director of behavioral health programs for the Henry Low Heart Center at Hartford Hospital in Connecticut and former Associate professor of clinical medicine at the University of Connecticut School of Medicine in Farmington, Connecticut. The majority of her career has been spent adapting psychotherapeutic approaches to meet the needs of cardiac patients by providing direct clinical care, training psychologists in the practice of behavioral cardiology, and conducting clinical research focused on behavioral approaches to cardiac risk-factor reduction. She is the author of the book, *Psychotherapy with Cardiac Patients: Behavioral Cardiology in Practice*." Currently, she serves as the director of the Cancer Clinical Research Office at the Hartford HealthCare Cancer Institute, in addition to her private practice where she continues to treat cardiac transplant patients.



### Field Consultation Results

**Question 1.** Field consultants were asked to identify the most important psychological concern for transplant team members to consider when treating cardiac transplant candidates and recipients. Dr. Cinamon Romers and Dr. Jae Ross explained that there is likely not one specific psychological concern that takes precedence (personal communication, June 23, 2017). Rather, there are absolute contraindications, or exclusionary criteria, to transplantation which include "active illicit substance abuse, active psychosis, active suicidal ideation, and dementia." They noted that absolute contraindications do vary depending on the institution. Additionally, they identified nonadherence as being one of the most significant concerns of treatment teams. They elaborated by stating, "past behavior is predictive of future behavior, so we want to consider how the patient has demonstrated adherence in the past." They explained that many variables often contribute to nonadherence, such as "depression, substance use, cognitive impairment, lack of support, and cost of medication." They mentioned that their goal in working with transplant patients is to "identify barriers that that may be able to remedied or solved" in order to best support the patient and improve treatment outcomes. Dr. Levenson agreed that nonadherence was one of the most important concerns to be considered throughout the transplant process (personal communication, August 27, 2017). He explained that he pays particular attention to "any factor that may interfere with adherence" and additionally, "self-care." Dr. Dornelas echoed Dr. Levenson's statements by explaining that "patient's need to have the intention and psychological resilience to adhere to the demanding medical regimens for pre and post-transplant care (personal communication, October 5, 2017)." She added, "It's also important that patients are able to cope with stress without resorting to use of alcohol, illicit drugs, or misuse

prescription drugs." Additionally, she mentioned that it is important that "patients have the capacity for effective communication and trust in their healthcare providers."

**Question 2.** Field consultants were asked to discuss specific challenges that they have encountered while working within interdisciplinary teams. Dr. Levenson commented that "some teams function poorly," which can be due to a number of reasons (personal communication, August 27, 2017). Overall, the consensus among field consultant psychologists, was that, the climate does seem to be improving. Dr. Somjee stated, "it is still a challenge for psychology to have a place at the table (personal communication, June 23, 2017)." Dr. Somjee spoke specifically to difficulties she has encountered "getting buy in" from physicians on her team regarding general psychology or health psychology interventions (personal communication, October 3, 2017). She explained that, in general, the majority of health professionals have a limited understanding of the need for, or efficacy of psychological treatments, especially when it comes to health psychology services. She added, "they do not realize that treating depression or anxiety is not the bulk of what health psychologists do." Additionally, she mentioned that this misunderstanding is more prevalent outside of major cities. Drs. Romers and Ross echoed Dr. Somjee's statements and explained that they have experienced variable degrees of understanding from different team members in regard to "how psychology can assist in assessing potential psychosocial barriers that could negatively or positively affect transplant outcomes (personal communication, June 23, 2017)." Conversely, they mentioned that they have encountered many team members that have a great appreciation for psychology and do rely on them "to provide psychoeducation regarding barriers and strengths that they may not have otherwise considered."

Dr. Somjee elaborated on the latter statements by identifying interdisciplinary communication as an additional challenge (personal communication, October 3, 2017). She

explained that since many other health professionals do not have a good understanding of psychological services, it is difficult to train them on "how to successfully bring up the issue of health psychology services to their patients and provide a smooth transition in real time to the behavioral health clinician." She also mentioned that, "due to time constraints, it is often difficult to communicate with other professionals regarding shared patients." Additionally, she shared that it is important to be transparent with other team members in regard to your scope and limits as a clinician. She explained that "it's tempting to take [all referred patients] on in order to seem competent, and be seen as a team player," however, "it's important to be clear about what your skills are and are not, especially if you are practicing as a health psychologist, and there are general behavioral health services available within your organization."

Dr. Dornelas reported that the most difficult challenges she has encountered, "have occurred when there is a lack of consensus about whether a patient should receive a transplant (personal communication, October 5, 2017)." She stated, "when a patient seems to be a good candidate from a medical perspective, but a poor candidate from a psychological perspective, the decision can be fraught." Additionally, she shared that "it is difficult, if not impossible, to maintain strict patient confidentiality." For example, she explained that "a patient working with a psychologist, who discloses that they are abusing alcohol while on the transplant list, puts the provider in a difficult position as a member of the interdisciplinary team."

**Question 3.** Field consultants were asked to identify key clinical skills that psychologists must have in order to work effectually within an interdisciplinary team. Effective verbal and written communication were acknowledged by most of the consultants as being particularly key (personal communication, June 23, 2017; personal communication, August 27, 2017; personal communication, October 5, 2017). Dr. Romers and Dr. Ross pointed out that many medical

providers are prone to thinking about variables quantitatively, therefore, it is especially important for psychologists to be able to communicate clearly and succinctly, giving specific reasons, for example, about how psychosocial factors may impact outcomes (personal communication, June 23, 2017). Ultimately, they explained that surgical teams want the best possible outcome for their patients, so they are typically open to hearing clearly presented communication regarding potential barriers to desired outcomes, as well as possible psychosocial solutions that may include delaying surgery. From Dr. Levenson's perspective, he explained that it is necessary for psychologists to communicate effectively and build rapport "with patients who are not psychologically minded and did not ask to see a mental health professional (personal communication, August 27, 2017)."

Additionally, all the field consultants discussed matters related to competence. Dr. Levenson mentioned that "psychologists in transplant work need to learn enough of the relevant medical information to function effectively and establish credibility on the team (personal communication, August 27, 2017)." Dr. Somjee noted that, in addition to understanding medical information, it is important for health psychologists accumulate a breadth of clinical skills that will adequately equip them to work with any number of problems that they may be presented with. Specifically, she mentioned having thorough training in clinical health psychology skills that include a deep understanding of theory, research, and treatment of anxiety disorders to medication adherence, as well as additional psychosocial interventions for the specific population that is being served. Dr. Dornelas elaborated on Dr. Somjee's statements by stating that not only do health psychologists need to be competent in treating a variety of problems, such as "depression, substance abuse, and tobacco cessation," they must also have "good diagnostic assessment skills (personal communication, October 5, 2017)." Additionally, she commented,

"psychologists who are secure in themselves and the contribution they make, will become valued members of the team." Dr. Romers and Dr. Ross spoke to this as well, explaining that psychologists who are able to assert themselves and incorporate solid research into their clinical practice will be well received their team (personal communication, June 23, 2017).

**Question 4.** Field consultants were asked to describe their clinical approach to medical nonadherence. Dr. Levenson stated that his particular approach to medical nonadherence involves remaining nonjudgmental and investigating and identifying its etiology without jumping to premature conclusions about the cause or magnitude (personal communication, August 27, 2017). Dr. Somjee mentioned that she too assesses for underlying issues in order to identify the targeted problem (personal communication, October 3, 2017). Similarly, Dr. Romers and Dr. Ross explained that there are many factors that influence adherence and once those underlying factors are identified it is important for psychologists to "consider what can be monitored and potentially changed," while remaining "mindful of the relative lack of precious resources, meaning available organs (personal communication, June 23, 2017)." Dr. Dornelas explained that her approach involves identifying, depending on the nature of the nonadherence, whether or not it is within her scope to treat the patient (personal communication, October 5, 2017). She stated, "I feel confident in treating relapse to cigarette smoking with individual therapy, however, I often find that alcohol and drug abuse needs a higher level of treatment." She explained that if patients do not appear for their medical appointments or do not follow through with their medical regimen, her role is to primarily work with the healthcare team in a consultative role to improve adherence. In regard to interventions, Dr. Romers and Dr. Ross reported that they typically utilize "patient centered approaches," in order to gain a deeper "understanding around potential barriers to past and current adherence concerns (personal communication, June 23, 2017)."

Whereas, Dr. Levenson and Dr. Somjee more often consider motivational approaches (personal communication, August 27, 2017; October 3, 2017). Additionally, Dr. Somjee mentioned that she often incorporates cognitive behavior therapy when using motivational interviewing with her patients.

**Question 5.** Field consultants were asked to discuss unique challenges that they experience in their work, specifically, in regard to the treatment of psychiatric disorders in medical populations. Dr. Dornelas discussed how seeing cardiac patients in private practice has its own unique set of challenges (personal communication, October 5, 2017). She stated that she often finds it difficult to locate a prescribing provider who is able to promptly see her patients who are in need of pharmacotherapy. She also explained that sometimes patients are too ill to make their appointments or cancel without notice. Additionally, she mentioned that she is often required to complete time consuming paperwork for patients who need to scale back their working hours or take a leave of absence due to illness.

Dr. Somjee discussed a number of challenges that she experiences when working with patients, including their lack of social support (personal communication, October 3, 2017). She explained that some patients do not have the adequate social support available, such as emotional or instrumental support. Secondly, she stated that many patients do not understand the mind-body connection, and therefore, are not as motivated to address their psychological concerns, which leads to a vicious cycle of poor psychological and physical health. Lastly, she mentioned that working with patients who are in poor health and possibly terminally ill can be demanding and it can be challenging to maintain personal self-care as a clinician.

Dr. Romers and Dr. Ross stated that they work primarily with a rural population (personal communication, June 23, 2017). They explained that many patients travel long

distances for psychological and medical care, which is burdensome for patients and puts a strain on already limited resources. Secondly, they stated that it can be clinically challenging to differentiate between symptoms of mental illness versus symptoms that are secondary to, or the result of medical complications such as poor perfusion, or decreased oxygen to the brain, that could be improved with an LVAD or heart transplant.

Dr. Levenson added that he finds it "difficult to assess the response to a psychiatric drug and any side effects in medically unstable patients (personal communication, August 27, 2017)."

**Question 6.** Field consultants were asked to identify symptoms that they look for in order to detect and diagnose psychiatric disorders in patients seeking medical treatment. Dr. Dornelas stated that she often assesses for depression, anxiety, poor sleep quality, and substance abuse (personal communication, October 5, 2017). She noted that medical patients often do not perceive themselves as depressed and attribute psychological symptoms to their medical problems. In addition to depression and anxiety, Dr. Somjee shared that when she has limited time with a patient, she assesses for somatic problems and any behaviors that may be considered "risky," including suicide (personal communication, October 3, 2017). Dr. Romers and Dr. Ross mentioned that they assess their patients through a biopsychosocial lens, using as many resources as are available to them, such as chart reviews and collaboration with other providers (personal communication, June 23, 2017). They explained that this approach tends to expose a number of symptoms suggestive of a psychiatric diagnosis. Dr. Levenson added that it is often difficult to assess for psychiatric symptoms in medical patients, due to the fact that "physical symptoms of depression (e.g. fatigue, poor appetite, poor sleep, weakness), for example, might be caused by their underlying illness (personal communication, August 27, 2017)."

**Question 7.** Field consultants were asked how they evaluate the quality of a patient's social support network. Drs. Somjee and Dornelas both explained that they try to get a sense of how the patient spends their day, who is in their life, the quality of the patient's relationships, and what type of support is provided within those relationships (personal communication, October 3, 2017; personal communication, October 5, 2017). Additionally, Dr. Dornelas shared that she "looks for evidence that the patient has at least one trusted person and with whom they feel close (personal communication, October 5, 2017)." Dr. Levenson, Dr. Romers, and Dr. Ross spoke to more practical aspects of support in regard to transplantation. They stated that they assess the physical availability of the social support person, paying particular attention to their geographic distance from the patient, willingness to provide support, as well as their own health status (personal communication, June 23, 2017; personal communication, August 27, 2017). Dr. Romers and Dr. Ross added that they sometimes are able to evaluate the quality of a patient's social support, when their support person presents to provide collateral information or accompanies the patient to their appointment (personal communication, June 23, 2017).

**Question 8.** Field consultants were asked to describe their clinical approach to helping patients enhance their supportive network. Dr. Levenson explained that his clinical approach varies depending on the reason for social support inadequacy, however, he sometimes teaches health literacy in order to inadvertently produce more favorable social factors (personal communication, August 27, 2017). Dr. Somjee, Dr. Romers, and Dr. Ross shared that they assist their patients in identifying a social support person or network, and if the patient is willing, encourage them to reach out to potential support person(s) for help (personal communication, June 23, 2017; personal communication, October 3, 2017). Additionally, Dr. Somjee mentioned that she sometimes has the patient bring their support person(s) to clinical appointments as to



involve them in treatment planning (personal communication, October 23, 2017). Dr. Dornelas spoke to specific interventional approaches. She stated, "I like the behavioral activation approach of looking for an activity that has both a physical activity component and a social component (e.g. walking with a neighbor, loved one or friend); I also often focus on reducing distress in current relationships (e.g. marital distress), which in turn, improves social support (personal communication, October 5, 2017)."

**Question 9.** Field consultants were asked how I could increase my visibility as a psychologist to influence the current standards by which patients are evaluated and supported through the transplant process. Dr. Romers and Dr. Ross suggested that I "stay informed [and] know the current evidence base from both psychological and medical perspectives (personal communication, June 23, 2017). They also mentioned, as well as Dr. Somjee, that I should maintain involvement, to some degree, with research (personal communication, October 23, 2017). Dr. Romers and Dr. Ross explained that research involvement is particularly important, as "trends within medical treatment change and affect constructs [that] psychologists need to operationalize and measure (i.e. LVAD bridge to transplant patients have different quality of life concerns than do straight-to-transplant or destination therapy LVAD patients; personal communication, June 23, 2017)."

Dr. Somjee encouraged me to "market" myself "within [my institution] in various ways and consistently," by "providing regular informational seminars to medical professionals and students, circulating regular newsletters regarding this issue to increase visibility, circulating brief summaries of research articles, [and] illustrating how what you want to do impacts the bottom line (personal communication, October 23, 2017)." Dr. Romers and Dr. Ross added that it would serve me well to "shadow a variety of providers involved with transplantation, [and]

show up to interdisciplinary meetings to observe and learn - then become comfortable with offering psychologically informed thoughts and opinions when appropriate (personal communication, June 23, 2017)." Dr. Dornelas also suggested that I gain other perspectives by exploring "other areas of medicine where psychologists are better integrated into the team (e.g. cancer) and where the accreditation guidelines have strong psychosocial components (e.g. distress screening for accredited cancer centers; personal communication; October 27, 2017)." Dr. Dornelas and Dr. Somjee both recommended that I develop relationships with medical professionals and understand their role and contribution to patient care (personal communication, October 3, 2017). Dr. Dornelas pointed out that "it is important to have a champion from medicine, ideally a physician and/or nurse as a partner to advocate for the patient's psychosocial needs." She added that psychologists can gain "visibility and respect" when they nurture good relationships with every member of the interdisciplinary team." Lastly, Dr. Levenson advised me to engage with existing networks of mental health professionals working with transplants (personal communication, August 27, 2017).

### **Final Product Presentation**

The final product for this dissertation was a 60-minute PowerPoint presentation completed on November 17, 2017, at the Battle Creek VA Medical Center, in Battle Creek, Michigan. The presentation contained 21 PowerPoint slides, which included information regarding (a) presentation objectives, (b) medical factors, (c) transplant waiting list, (d) transplant surgery, (e) pre-transplant psychological evaluation, (f) nonadherence issues, (g) interventions to improve nonadherence, (h) psychopathology among transplant patients, (i) issues related to social support, (j) interventions to enhance social support, (k) field consultant results, and (l) conclusions (APPENDIX C). The presentation was delivered with use of a computer and

projector. Printouts of the slides were distributed at the outset of the presentation. The presentation lasted approximately 50 minutes. It was followed by 5 minutes of questions and answers. An additional 5 minutes were allotted for distribution and completion of the evaluation form (APPENDIX D).

### **Product Evaluation Results**

Results of the feedback evaluation form showed that the presentation objectives had been met. All audience members responded *Strongly Agree* to the statement, "As a result of this presentation, you were able to increase your knowledge of psychosocial factors related to the transplant process ( $M=5$ )." Audience members also responded *Strongly Agree* to the statement, "As a result of this presentation, you were able to increase your awareness of the need for interventions tailored specifically to the transplant population ( $M=5$ )." The audience responded *Agree* and *Strongly Agree* to the statement, "This presentation promoted reflection regarding interdisciplinary collaboration and team functioning dynamics ( $M=4.4$ )." The audience responded *Neutral*, *Agree*, and *Strongly Agree* to the statement, "As a result of this presentation, you were able to consider the cultural context behind the current body of literature and contemplate its generalizability ( $M=3.6$ )." The audience responded *Agree* and *Strongly Agree* to the statement, "The presentation was concise and educational ( $M=4.8$ )." The audience responded *Agree* and *Strongly Agree* to the statement, "The presenter appeared knowledgeable about the topic ( $M=4.8$ )." The audience responded *Agree* and *Strongly Agree* to the statement, "The presenter was organized and well prepared ( $M=4.6$ )." Finally, all audience members responded *Strongly Agree* to the statement, "The presenter maintained my interest throughout the presentation ( $M=5$ )." Three of the audience members left additional comments and feedback. One audience member stated, "Very interesting. Didn't know much about this topic and your

presentation was very informative." This sentiment was reiterated in another member's comment, "Excellent information. Understanding the common factors of organ transplants was informative." The third audience member, stated, "More discussion on cultural differences," which was highlighted in the presentation as a major limitation in the current body of transplant literature.

## CHAPTER V.

### Discussion

Since the first human heart transplant in 1967, the prognosis for heart transplant recipients has greatly improved (Barnard, 1967; Guibert et al., 2011). This has primarily been due to improvements in medicine and increased awareness of contributing psychological and behavioral factors. Nevertheless, cardiac transplantation is indisputably both a physically and psychologically demanding process. The topic of this dissertation was chosen based on my early work experience, as a Certified Nursing Assistant (CNA), with hospitalized heart transplant patients. As a CNA, I had the opportunity to observe a range of clinical presentations from pre-transplant anxiety to post-transplant delirium, as well as varying challenging situations with social support systems. At the time, I was not aware of any psychological support being offered to patients on the unit. Those experiences left me with a lingering desire to better understand psychosocial factors associated with the transplant process, and to advocate for empirically sound transplant-specific interventions.

Within this dissertation, I conducted a critical review of the literature, examining medical history, pre-surgical evaluation, nonadherence, depression and anxiety, and social support. The latter psychosocial factors were chosen, specifically, due to their established relevance to heart transplant patients. After completing the literature review, field consultants were interviewed. Their insights and perspectives were valuable in supplementing the available published literature and providing anecdotal information about what is being observed and practiced in the field. Regarding the pre-surgical evaluation, absolute and relative contraindications of transplantation are generally widely agreed upon; however, certain psychosocial factors, such as tobacco use, obesity, and history of nonadherence, continue to remain a point of contention within

interdisciplinary teams (Freeman et al., 1992; Levenson & Olbrisch, 1993). Field consultants confirmed this conflict, and collaboratively identified nonadherence as the most singular important psychological concern for transplant team members to consider.

Unexpectedly, their feedback prompted discussion regarding interdisciplinary team functioning. Consultants discussed the necessity for psychologists to develop rapport with other disciplines by acquiring adequate medical knowledge and learning how to communicate clearly and succinctly, giving specific reasons, for example, about how psychosocial factors may impact patient outcomes. Good communication is essential, they explained, to appropriately educate other disciplines about what psychology can contribute to the team. It is also necessary skill to have, in order to be viewed as a valued member of the team, increasing interdisciplinary team functioning. In other specialty areas of medicine, research has shown that interdisciplinary team functioning to has a significant and positive direct effect on patient outcomes (Baggs, Ryan, Phelps, Richeson, & Johnson, 1992; Epstein, 2014). Thus, acknowledging challenges in team functioning has important implications for cardiac care. A team that is able to function as a "well-oiled machine" can better anticipate and respond to patient needs, as well as enhance their own individual well-being and life satisfaction. The field consultants did note that as health-care systems move closer towards integrated, team-based models, interdisciplinary functioning in their individual practices does seem to be improving, and along with it, an awareness of pertinent psychological factors and how psychology can contribute.

Despite the fact that there are high rates of nonadherence, and depression and anxiety, in the transplant population, there was limited research regarding psychological interventions specifically for heart transplant patients. After interviewing field consultants and gathering additional anecdotal information, it seems clear that transplant patients likely work with the

health psychologist on their team, or another mental health provider, where they may be exposed to empirically supported treatments, such as Motivational Interviewing (MI) or Cognitive Behavior Therapy (CBT). The fact that nonadherence and psychopathology both have predictive post-transplant qualities, make it seemingly more likely that patients with psychological needs could be more easily identified, providing an opportunity for support from their transplant team early on that can be maintained throughout their recovery and long-term if needed.

Unfortunately, if patients access mental health services outside of their team, their providers may not fully recognize the impact of transplantation on psychological functioning, which is unfortunate.

Lack of transplant-specific interventions was identified as one of the two major gaps in the literature. "In an effort to promote the availability of effective psychological treatments, the U.S. Department of Veterans Affairs (VA) has implemented national initiatives to disseminate evidence-based CBT protocols for various mental and behavioral health conditions, such as depression, insomnia, and chronic pain (Karlin & Cross, 2014)." Given the growing number of transplant patients, it would behoove the psychological community to conduct research with transplant patients using empirically supported treatments, such as MI and CBT. Of note, patients supported by TAHs and VADs experience almost parallel psychological risks to transplant patients. At the very least, general psychological guidelines or recommendations for cardiac care could be immensely beneficial to the field of cardiology.

Research findings were presented to an audience of clinical health psychologists and psychology interns working in the VA. There was ample discussion regarding the generalizability of the research findings due to cultural differences in the countries of origins where the research was conducted. Adherence, psychopathology, and social support are all

largely influenced by socio-cultural factors and beliefs regarding etiology. The *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5)* recognizes that there are various symptom profiles across cultures (American Psychological Association, 2013). This insight must be applied to future research in order to appropriately operationalize symptoms and generalize findings. Additional suggestions for future research include expanded exploration of stress disorders and cardiac transplantation, as well as investigation of social support beyond the transplant phase.

Overall, this dissertation provided an invaluable opportunity to increase my knowledge in a relevant and timely area in health psychology. I learned how to become a better consumer of research, further developed my Socratic mindset, and developed greater competence in selecting appropriate evidence-based and culturally appropriate assessment measures and interventions. Many of these skills, I am able to generalize across all aspects of my work as a clinician. It is my hope that I will be able to continue this work in my clinical practice, maintaining the integrity of psychology as a discipline at the interdisciplinary team table.



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**APPENDIX A**

**Informed Consent Form for Field Consultants**

### Informed Consent Form for Field Consultants

I have been invited by Sarah Wilson to participate in a dissertation project titled Psychological Aspects of Cardiac Transplantation, which is designed to study various psychological factors associated with cardiac transplantation. I understand that Sarah Wilson is a clinical psychology graduate student at the California School of Professional Psychology (C.S.P.P.) at Alliant International University, Los Angeles, and this interview is a required component of this student's doctoral dissertation.

I understand that I was invited to participate as a Field Consultant for this clinical dissertation and not as a research participant. I have been contacted by the above student to offer professional input because I have some expertise and/or clinical knowledge about the stated dissertation topic. The input gained from Field Consultants will help supplement the available published literature with current clinical insights and perspectives on the subject area that may not yet be in print. Hence, the purpose of the interview is to fill the informational "gaps" that exist in the professional literature about this topic, and to also examine what is actually being practiced and clinically observed in the community by field professionals.

I am aware that my participation as one of the Field Consultants will involve answering some interview questions (face-to-face, if possible) designed to increase understanding of psychological aspects of cardiac transplantation based on my professional experience. I am aware that the interview will be audiotaped with my permission -- or conducted via phone or email correspondence, if preferred. The amount of response to these interview questions can be as lengthy or brief as I see appropriate for myself, and I can choose to respond only to those questions that I feel qualified to answer. The interview process may take approximately 45 ~ 60 minutes of my time to complete, and the interview will be audiotaped (if face-to-face or via phone contact) to ensure its quality and accuracy of content.

I have been informed that my participation in this interview is voluntary and I can withdraw at any time. I understand that this is a professional interview/dialogue where I will be asked to share my clinical/professional expertise on the stated dissertation topic. The interview contents will be appropriately cited within the thesis as personal communication citations, and my contributions and input will be discussed within the dissertation.

I am aware that although I may not directly benefit from this study, my participation in this dissertation project will further increase knowledge and awareness in the field of clinical psychology -- specifically, pertaining to cardiac transplantation. I understand that I may contact Sarah Wilson at [sarah.wilson@alliant.edu](mailto:sarah.wilson@alliant.edu) OR the student's dissertation Chair, James R. Noblitt Ph.D., 1000 S Fremont Ave Unit 5, Alhambra, CA, 91803 or (626) 270-3361 if I have any questions regarding this dissertation project or my participation in this interview as a Field Consultant. I understand that at the end of this study, I may request a summary of the results or additional information about the study from the above student.

I have read this consent form, understand its contents, and I voluntarily agree to participate in this professional interview as a part of the student's doctoral dissertation. I understand that I will be signing two copies of this form. I will keep one copy and the student, Sarah Wilson, will keep the second copy for his/her records. If I have received this Interview Consent Form and the Interview Questions via email, by electronically returning this consent form and the answers via reply mode, I am giving my consent and agreeing to the above-stated conditions.

\_\_\_\_\_  
Participant's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Student's Signature

\_\_\_\_\_  
Date



**APPENDIX B**

**Field Consultation Questions**

### Field Consultation Questions

1. What is the most important psychological concern for transplant team members to consider when treating cardiac transplant candidates and recipients?
2. What specific challenges have you encountered while working within interdisciplinary teams?
3. What are the key clinical skills psychologists must have in order to work effectually within an interdisciplinary team?
4. What is your clinical approach to patient nonadherence to medical treatment?
5. What unique challenges do you experience in your work, specifically regarding the treatment of psychiatric disorders in medical populations?
6. What are some symptoms that you look for in order to detect and diagnose psychiatric disorders in patients seeking medical treatment?
7. How do you evaluate the quality of a patient's social support network?
8. What is your clinical approach to help patients enhance their supportive social network?
9. One long-term goal of my dissertation is to positively influence the current standards by which patients are evaluated and supported throughout the transplant process. This will require communication at a macro-level in order to drive alignment. What advice can you provide me in regards to becoming influential and increasing my visibility as a psychologist?

**APPENDIX C**

**Final Product**

## Psychological Aspects of Cardiac Transplantation

SARAH WILSON M.A.

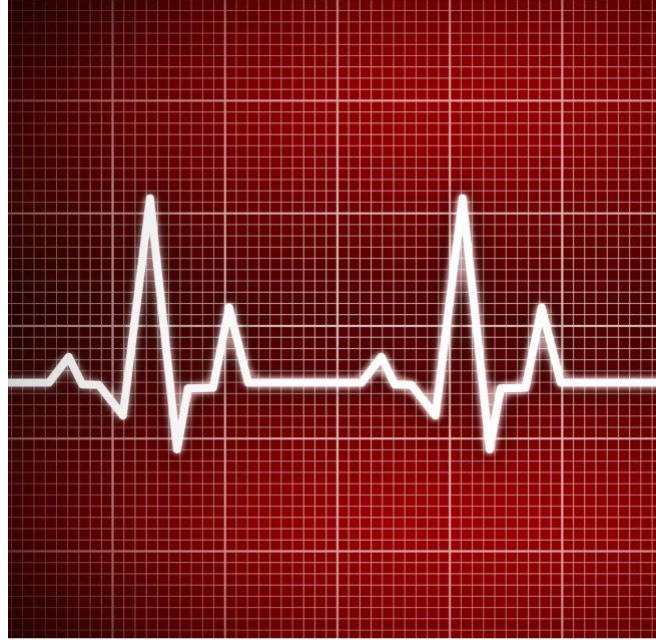
ALLIANT INTERNATIONAL UNIVERSITY - LOS ANGELES

PRESENTED AT BATTLE CREEK VA MEDICAL CENTER

NOVEMBER 17, 2017

JAMES R. NOBLITT, PH.D., CHAIR

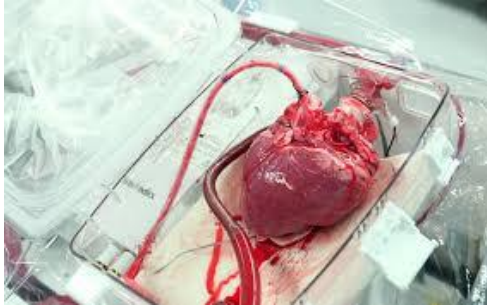
CRISTINA MAGALHAES, PH.D., COMMITTEE MEMBER



- Increase knowledge of psychosocial factors related to the transplant process
- Promote awareness of the importance of context. For example, psychological interventions must be tailored specifically for the transplant population, taking all of their unique experiences into account
- Encourage reflection of interdisciplinary collaboration and team functioning dynamics
- Encourage consideration of the cultural context behind the current body of literature and contemplate the implications of it's generalization

- The first human to human heart transplant was performed on December 3, 1967 (Barnard, 1967)
  - There is an increased demand for donor heart, but less available (Lund et al., 2015)
  - The shortage has fueled research on the development of total artificial hearts (TAHs) and ventricular assist devices (VADs)
  - Cardiac transplantation remains the definitive treatment for individuals with advanced heart failure and limited life expectancy (Coglianese, Samsi, Liebo, & Heroux, 2015)
- 
- Once deemed to be an acceptable candidate for transplantation, the patient is registered on the national transplant waiting list
    - United Network for Organ Sharing (UNOS)
  - Many factors weigh into the distribution of each individual organ
    - blood type and distance from donor hospital (OPTN, 2016)
  - Currently, 4,153 candidates are on the waiting list for a donor heart (OPTN, 2016)
  - In 2003-2004, the median time to transplant was 6.7 months
    - In 2013-2014, 10.9 months (Colvin et al., 2016)
  - In 2012-2013, the incidence of acute rejection within the first post-transplant year was 23.5% (Colvin et al., 2016)

- HEART TRANSPLANT
- UNOS



- Once medically appropriate patients are referred for transplant, they complete a pre-transplant workup by an interdisciplinary transplant team (e.g. cardiology, nutrition, social work; Collins & Labott, 2007; Levine & Levine, 1991)
  - Interview
  - Quantitative Testing
  - Collateral Information
  - Medical Records
  - Decision Making
- According to Olbrisch and Levenson (1991), only about 5.6% of patients are rejected for transplant on psychosocial grounds
- Guidelines at the Cleveland Clinic indicate Absolute and relative psychological contraindications as follows: current alcohol or drug use, ongoing tobacco use, history of nonadherence, severe deficits in psychological or cognitive functioning, and absence of social support (Yamini & Taylor, 2010)

- **Noncompliant versus nonadherent**
  - Nonadherent implies the need for mutual agreement, empowering the patient to agree or disagree with provider recommendations before accepting them (Gandhi et al., 2016)
- **Medication and diet nonadherence is highly prevalent among transplant patients, leading to an overall increase in symptomology, increase in hospitalizations, and ultimately death (Fitzgerald et al., 2011)**
  - Financial strain
  - Delay in medication efficacy (Gandhi et al., 2016)
  - Medication side effects (Gandhi et al., 2016)
- **Urgent versus planned transplantation (Sobieszcańska-Matek et al., 2011)**

## PRE-TRANSPLANT PREDICTORS OF POST-TRANSPLANT NONADHERENCE

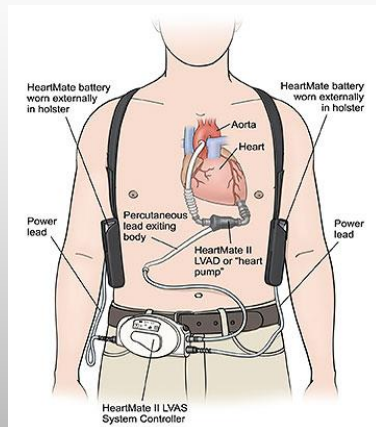
- **There is substantive evidence of pretransplant nonadherence as a predictor of post-transplant nonadherence (Bunzel, & Laederach-Hofmann, 2000; Douglas, Blixen, & Bartucci, 1996)**
  - According to Dobbels and colleagues (2009), pretransplant nonadherent patients are eight times more likely to be nonadherent post-transplant compared to their adherent peers
    - Home Inotrope Infusions (Gandhi et al., 2016)
- **Research suggests that the effects of social support on health are mediated through adherence (Druley & Townsend, 1998; Hagedoorn et al., 2000)**
  - Specifically, functional social support (e.g. emotional) has a greater effect on adherence than structural support (e.g. marital status), indicating that the quality of support is most essential (Martin, Davis, Baron, Suls, & Blanchard, 1994; Penninx et al., 1998)

## PRE-TRANSPLANT PREDICTORS OF POST-TRANSPLANT NONADHERENCE.

- Higher level of education is associated with a greater degree of post-transplant medication nonadherence (Dobbels et al., 2009; Kung, Koschwanez, Painter, Honeyman, & Broadbent, 2012)
- Immunosuppressive medication nonadherence
  - Conscientiousness (Dobbels et al., 2009; Molloy, O'Carroll, & Ferguson, 2014)
  - Guilt (Shemesh et al., 2017)
- Type D personality has also shown to be a predictor of poor medication adherence (Molloy et al., 2012; Williams, O'Connor, Grubb, & O'Carroll, 2011; Wu & Moser, 2014)



## NONADHERENCE IN CARDIAC TRANSPLANTATION AND LVAD



- 70% of LVAD patients experience a major adverse event within the first year following device implantation (Kirklin et al., 2013)
- (Kato et al., 2014)
  - Self-care maintenance consists of medication, diet, and exercise adherence. It is the most patient involved component.
  - Monitoring self-care involves a high degree of patient education and careful observation, by the patient, of physical and psychosocial signs, symptoms, and conditions.
  - Self-care management is concerned with the patient's response to specific signs, symptoms, and conditions
- Approximately 40% of hospital admissions following cardiac transplant are medication related, 58% percent of those admissions are deemed to be preventable (Repp et al., 2012)



## ASSOCIATIONS WITH MEDICATION BELIEFS AND PERCEPTION OF MEDICAL CONDITION IN NONADHERENCE

- Necessity-Concerns Framework and the Common-Sense Model of Illness to better understand nonadherence (Horne, Cooper, Gellaitry, Date, & Fisher, 2007; Leventhal, Meyer, & Nerenz, 1980)
  - Patient is an active problem solver
- Medication beliefs and nonadherence
  - Decreased beliefs regarding medication benefits, increased beliefs regarding the potential harm of medications, decreased understanding of the transplant process, increased symptoms, increased distress, and increased perception of transplant related consequences (Kung et al., 2012)

## Interventions Addressing Nonadherence

- Self-administration of Medications (SAMs) model is utilized at the University of Washington (Hermesen, Smith, & Mokadam, 2013)
- The “Circle of Caring” model is a “holistic” nurse driven intervention developed to increase patient adherence (Dunphy & Winland-Brown, 1998)
- The first “digital pill” was approved by the Federal Drug Administration (FDA) in 2012 (Eisenberger et al., 2013)
- CBT (Cupples & Steslow, 2001)



## SYMPTOMS OF ANXIETY AND DEPRESSION IN HEART TRANSPLANTATION

- **Waiting Period**
  - An estimated 48-64% of patients on the waitlist meet the criteria for at least one psychiatric disorder (Engle, 2001)
  - Approximately 35% of patients experience an anxiety disorder prior to transplantation, and over 20% suffer from a depressive disorder (Magni & Borgherini, 1992)
  - Depression and anxiety are significant predictors of mortality (Epstein & Lucero, 2016)
- **Postoperative Period**
  - “a second honeymoon” and “flying high” (Christopherson, 1987; Kuhn et al., 1988)
- **Longterm Outcomes**
  - An estimated 63% of transplant recipients experience depression or anxiety during the first few years' post-transplant, whereas, rates in the general population are estimated to be between 3 and 10% (Dew & DiMartini, 2011)
- **Symptoms of Depression and Anxiety in Patients with an LVAD**
- **Posttraumatic Stress Disorder**

- ↑ ▪ **History of psychological disorders prior to transplantation**
- ↑ ▪ **Female patients who had been on the waitlist longer than 6 months**
- ↑ ▪ **Patients who used a VAD as a bridge to transplantation**
  - **Level of physical activity beginning at two months post-transplant was shown to influence the trajectory of depressive symptoms long-term (Dew et al., 1996)**
  - **Quality of social support was also correlated with the presence of a psychological disorder (Dew et al., 1996).**
    - “strong” and “supportive” (Zipfel et al., 2010).

## SOCIAL SUPPORT

- Adequate social support has been linked to positive post-transplant health outcomes (Berry & Kymissis, 2016; Rosenberger, Fox, DiMartini, & Dew, 2012)
- Association between social support and health-related quality of life (HRQoL), “a multi-dimensional concept that includes domains related to physical, mental, emotional, and social functioning (Ferrans, 2005; Grady et al., 2007; Sirri, Magelli, & Grandi, 2011; White-Williams et al., 2013)
  - Emotional Support



- Type of supported relationship (Stimpson et al., 2015)
  - Significant other
- Lack of partnership was shown to be a singular predictor of organ rejection during the first year post-transplant (Dobbels et al., 2009)
- Support from medical team (Janelle, O'Connor, & Dupuis, 2016)
- Associations between social support and depression
- Depression in caregivers
  - Dew and colleagues (2004) evaluated caregiver symptomology during the first year and at the third year post-transplant. Rates of depression and anxiety increased progressively and were highest at 36 months, 31.6% and 7.3% respectively



- Dew and colleagues (2004) developed an internet-based intervention for both recipient and their family caregiver(s)
  - Increase psychosocial outcomes
  - Post-transplant skills workshops
    - Stress management
    - Medical regimen
  - Chapters and homework
  - Patient discussion group
  - Caregiver discussion group
  - "Ask an expert"
  - "Healthy living tips"
  - "Resources and references library"
- Resulted in higher adherence rates

- Dr. Somjee stated that although the climate seems to be improving, "it is still a challenge for psychology to have a place at the table (personal communication, June 23, 2017)."
- Dr. Dornelas reported that the most difficult challenges she has encountered, "have occurred when there is a lack of consensus about whether a patient should receive a transplant (personal communication, October 5, 2017)." She stated, "when a patient seems to be a good candidate from a medical perspective, but a poor candidate from a psychological perspective, the decision can be fraught."

- Dr. Romers and Dr. Ross pointed out that many medical providers are prone to thinking about variables quantitatively, therefore, it is especially important for psychologists to be able to communicate clearly and succinctly, giving specific reasons, for example, about how psychosocial factors may impact outcomes (personal communication, June 23, 2017)
  - Dr. Levenson mentioned that "psychologists in transplant work need to learn enough of the relevant medical information to function effectively and establish credibility on the team (personal communication, August 27, 2017)"
- 
- Cardiac transplantation is an extensive and life altering experience for both patients and their support systems. It is critical that patients are evaluated thoroughly to ensure that they receive the appropriate support that will promote a positive outcome
    - Given the importance of social support, it is also necessary for the patients support system to be engaged in this process
  - There is no uniform guidelines for pre-transplant evaluations that would insure a thorough evaluation of the potential needs of the patient
    - Therefore, it is pertinent that interdisciplinary teams function well by exercising concerted physical and mental effort when determining suitability for candidacy



**APPENDIX D.**

**Product Evaluation Form**

**Evaluation Form****Psychological Aspects of Cardiac Transplantation**

Presented by Sarah E. Wilson M.A., at the Battle Creek VA Medical Center,  
in Battle Creek, Michigan, on Friday, November 17, 2017.

**Please rate today's presentation by circling one answer for each question below.**

Question	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
As a result of this presentation, you were able to increase your knowledge of psychosocial factors related to the transplant process	1	2	3	4	5
As a result of this presentation, you were able to increase your awareness of the need for interventions tailored specifically to the transplant population	1	2	3	4	5
This presentation promoted reflection regarding interdisciplinary collaboration and team functioning dynamics	1	2	3	4	5
As a result of this presentation, you were able to consider the cultural context behind the current body of literature and contemplate its generalizability	1	2	3	4	5
The presentation was concise and educational	1	2	3	4	5
The presenter appeared knowledgeable about the topic	1	2	3	4	5
The presenter was organized and well prepared	1	2	3	4	5
The presenter maintained my interest throughout the presentation	1	2	3	4	5

**Additional Feedback:** \_\_\_\_\_

\_\_\_\_\_

**Thank You.**

\_\_\_\_\_



**APPENDIX E**

**Definition of Terms**

**Biventricular Assist Device (BVAD).** a device that performs the functions of both a right and left ventricular assist device (Harris, Croce, & Xie, 2014).

**Bridge to Candidacy.** “describes supporting a potential candidate to allow him/her sufficient time to meet the criteria for listing for transplantation, e.g. for elevated pulmonary vascular resistance to drop so that the patient can meet transplant criteria (Barnard & Tsui, 2012).”

**Bridge to Recovery.** “deploys circulatory support to allow native cardiac function to return to a sufficient level to have the circulatory support device explanted (Barnard & Tsui, 2012).”

**Bridge to Transplantation.** “describes supporting transplant-eligible [candidates] who are unlikely to survive the wait for a suitable donor heart with mechanical circulatory support devices until heart transplantation (Barnard & Tsui, 2012).”

**Catastrophic Pump Thrombosis.** “an uncommon but potentially catastrophic complication of durable continuous-flow left ventricular assist devices (LVAD; Kirklin et al., 2014).”

**Immunosuppressive Drug.** “any agent in a class of drugs that is capable of inhibiting the immune system. Immunosuppressants are used primarily to prevent the rejection of an organ following transplantation (Encyclopaedia Britannica Online, 2016).”

**Inotropes.** “medicines that change the force of your heart's contractions. There are 2 kinds of inotropes: positive inotropes and negative inotropes. Positive inotropes strengthen the force of the heartbeat. Negative inotropes weaken the force of the heartbeat (Texas Heart Institute, 2016).”

**Left Ventricular Assist Device (LVAD).** a device “implanted to receive blood from the lower

left chamber of the heart and pump it to the aorta, which supplies blood to the whole body (Harris et al., 2014).”

**Primary Graft Failure.** “a syndrome in which the transplanted heart fails to meet the circulatory requirements of the recipient in the immediate post-transplant period (Iyer et al., 2011).”

**Right Ventricular Assist Device (RVAD).** “a device that receives blood from the lower right chamber and pumps it to the lungs, where blood receives oxygen (Harris et al., 2014).”

**Tissue Typing.** “a series of diagnostic tests before an organ transplant to determine whether the tissues of a donor and recipient are compatible (Wordnet, 2016).”

**Total Artificial Heart (TAH).** “a prosthetic, experimental device implanted into the body to replace the original biological heart (American Heart Association (AHA), 2016).”

**Ventricular Assist Device (VAD).** a device “implanted to assist the natural heart, leaving the patient's own heart in place and still functioning (Jarvik Heart, 2016).”

**Warfarin.** is a prescription medication (brand names Coumadin and Jantoven) used to prevent harmful blood clots from forming or growing larger (AHA, 2016).”