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Psychosocial Considerations of Heart Transplant: Keeping Apace with the Revolution in Cardiac Care

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Abstract

The cardiac transplant social worker assumes a complex role on a transplant team: assessor, fixer, ethical conscience of the team, resource expert, ambassador to other consultative teams, and is one of the central figures to the patient and family as they move through all phases of care. The function of the cardiac transplant social worker has evolved in similar parallel fashion as has cardiac transplantation itself. Once tasked with responsibilities that included supporting patients and their families while patients waited in hospital for organs to become available, social workers now work with patients and families who, for the most part, wait at home, often for years, on left ventricular assist devices (LVAD) as a prelude to transplant. The steps between listing and transplant have elongated as has the need for critical assessment tools and skills in an ever changing and revolutionary cardiac landscape.

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Social workers in cardiac transplant have been called upon to acquire different skill sets to incorporate the cataclysmic changes in cardiac care. Developing a psychosocial assessment tool is the foundation of performing a comprehensive, thorough, and detailed evaluation of the transplant candidate and LVAD candidate and should incorporate guidelines from UNOS, CMS, and JCAHO. Assessing health literacy is crucial to ascertaining a patient and family's ability to understand, comply, and execute required care. Including the palliative care team at consistent intervals is imperative. Collective team agreement on absolute contraindications to listing and/or implanting is crucial to a shared vision of candidacy.

Keywords

Cardiac transplant social worker · LVAD (left ventricular assist device) · Psychosocial assessment · Health literacy · Substance abuse disorder · SIPAT · Contraindications · Scoring tool · Caregivers · Palliative care · Psychosocial presentation · Retransplantation

Introduction

The role of the cardiac transplant social worker has evolved in similar parallel fashion as has cardiac transplantation itself. Once tasked with responsibilities that included supporting patients and their families while patients waited in hospital for organs to become available, social workers now work with patients and families who, for the most part, wait at home, often for years, on left ventricular assist devices (LVAD) as a prelude to transplant. Once teams struggled to apply the concepts of distributional justice to initial transplants and retransplants; now VAD "change outs" are considered equally seriously. The steps between listing and transplant have elongated as has the need for critical assessment tools and skills in an ever changing and revolutionary cardiac landscape. Social workers in cardiac transplant have been called upon to acquire flexible and emerging skill sets to incorporate the cataclysmic changes in cardiac care.

The Center for Medicare and Medicaid has mandated that transplant programs have social work membership to the multidisciplinary committee (CMS 2007). Often the social worker is the only nonmedical individual on a team made up entirely of medical professionals. This can make psychosocial input seem like an afterthought in comparison to the often-compelling medical needs of the patient under consideration. Yet the medical success of the patient often depends on the ability to adhere to medical instruction and support from the "family"/network in which the patient sits among many other factors. For anyone who has been on the receiving end of the long stare and deafening silence which follows the delivery of psychosocial concerns, it can be an uncomfortable and unpopular position to take on a transplant team. Often viewed as a "soft science," transplant social work has fought hard to gain and maintain a seat at the table.

This chapter seeks to examine the psychosocial assessment tool for both LVADs and cardiac transplant; how they are similar, how they differ, and the nexus of the two. Steps to engage the team in collectively identifying absolute contraindications versus relative contraindications as programmatic policy (to avoid the pitfalls of subjectivity) will be explored. Study will be given to the assessment tool as a potential roadmap for the partnership between the patient and team. The critical role that health literacy plays in assessing any patient will be incorporated into all aspects of social work intervention. In addition, the concepts of distributional justice in combination with balancing beneficence and nonmaleficence will be approached through the lens of the social worker's role on the heart transplant team. Finally, we will discuss the role of the social worker after LVAD implantation and cardiac transplantation.

Why Evaluate Patients from a Psychosocial Standpoint?

The rate of organ donation has increased by 20% over the past 5 years according to the United Network for Organ Sharing (UNOS). After many years of stagnant numbers, the recent increase can be attributed to:

> . . .medical characteristics or a medical history that, prior years, may have been considered less often by clinicians. These include people who donated after circulatory death, as well as donors who died of drug intoxication or those identified as having some increased risk for blood borne disease. (UNOS January 2017)

In cardiac transplant, there is no living donor option, nor is donation after circulatory death (DCD) utilized as frequently in procuring hearts as it is in other organ donation scenarios. A brief explanation is offered as to why:

> The use of an ex-situ transportable cardiac perfusion platform together with modified cardioplegia, supplemented with post conditioning agents, had allowed three centers to report successful transplantation of distantly procured human DCD hearts. . .In the face of continued and significant donor organ shortage and inevitable wait list attrition, the rejection of suitable donor DCD hearts, in jurisdictions permitting this donation pathway, is increasingly hard to justify. (Dhital et al. 2017)

In his book *When Breath Becomes Air*, Paul Kalanithi writes:

> Science is based on reproducibility and manufactured objectivity. As strong as that makes its ability to generate claims about matter and energy it also makes scientific knowledge inapplicable to the existential, visceral nature of human life, which is unique and subjective and unpredictable. (Kalanithi 2016)

Transplant social workers often find themselves in a position where they are concurrently being asked to assess, alter, and predict the candidate's behavior. The psychosocial evaluation is both an opportunity to survey the candidate's network of support, history of adherence/understanding of past medical conditions or situations, and to identify the gaps in the existing structure. Once the gaps have been identified, the social worker must mobilize support, or advocate on the patients' behalf towards corrective action. Before presenting the patient to the transplant committee, the social worker must make sure that all potential moveable obstacles have been eliminated or adjusted to ensure that candidates are not eliminated inappropriately. Fitting referrals, often to psychiatry and insurance coordinators, can be part and parcel of many psychosocial evaluations. Despite the best psychosocial tools, care coordination, and supportive interventions, the transplant psychosocial evaluation is not a predictive tool, nor should a medical team expect that the assessment will bear out the best candidates.

Distributional Justice

> Being a gatekeeper necessitates difficult decisions. Using one's moral imagination or the principles of distributive justice and the maximum strategy does not in any way dictate what clinical decision one should make. Better ethics is about having better justifications for decisions; it is not about always agreeing or there being only one correct answer, especially when the benefits and harms are finely balanced. What a consideration of moral distance and distributive justice offers clinicians is an ethical framework that moves any debate regarding resource allocation away from emotion and toward rationality. (Shaw and Gardiner 2014)

Decision-making around organ transplant candidacy is not for the faltering. The decisions are weighty and lifesaving or life costing. The "team" decision process can offer individual members of a team, who differ in opinion, the safety of the balance of the views of the others. Many times, someone on the team will state how "nice" the patient may be or what a wonderful family they may have. At times, perhaps the patient was known to the practice for many years. It can be extremely difficult to say either "yes" or "no" to listing when the psychosocial evaluation leans against candidacy. Maintaining objectivity is of paramount importance and a monumental task. In regions where there is a saturation of transplant centers, the pressure to list can be ever greater as the program fears "losing" the patient to another, less discerning center. Transplant teams look to medical ethics to guide their ability to list the candidates they believe will best care for the organ as well as who may benefit most from a longevity standpoint.

Historically, there have been some shared standards between and among centers designed in large part to provide some basic structure to transplant eligibility:

- Many transplant centers will not accept people without insurance.
- Transplant teams rarely consider anyone over 75 years of age.
- Some centers exclude patients with moderate mental retardation, mental health challenges, HIV, a history of addiction, or a long criminal record.
- Though American transplant centers can list foreigners, they can make up no more than 5% of any center's list. Most non–U.S. citizens listed have substantial financial resources and pay in cash.
- Some transplant programs will admit undocumented immigrants, but most of those are children. Some transplant centers have caused controversy by refusing to retransplant organs in undocumented immigrants whose initial organs, received at the same hospital during childhood, have failed.
- Some hospitals do not accept persons who use marijuana, including medical marijuana (Caplan 2008).

Balancing nonmaleficence and beneficence is the charge of all transplant teams while remaining cognizant of the need to transplant patients to stay in existence. UNOS (the United Network for Organ Sharing) has requirements for the number of transplants a center must perform in a rolling statistical period as well as survival outcomes. The combination of the team's attempt to list patients and the UNOS requirements can bridle errant listing practices.

The advancements in heart failure medications, interventional procedures, and most certainly LVADs has kicked the can down the road with regards to difficult patient selection. Likewise, LVADs have also allowed patients who demonstrated behaviors that prevent listing to course correct with the time the LVAD can buy them. With all interventions, this too is not without risk; another surgery and wait time can only add to the risk for the patient. Teams must be careful to not use LVADSs as a bail out for difficult decision-making or difficult patients. Equally, transplants cannot be sought to salvage poor LVAD outcomes.

This discussion demonstrates in part why the psychosocial portion of transplant candidacy is crucial; it adds to the depth and breadth of the discussion and the preparation for successful outcomes. While medical knowledge of cardiac transplantation and circulatory devices are a distinctive advantage, it is not the focus of the social worker's role. The aptitude to engage with families and the medical team, awareness of the patient and family's understanding of what is expected in cardiac transplant or LVAD therapy, knowledge of resources and entitlement programs, and a keen ability to articulate issues are basic components of the transplant social workers skill set. Most teams rely on their social workers to present the psychosocial facts and interpret them, despite what can often seem like dismissiveness or outright objection to the contribution of potentially tarnishing information.

The Heart Transplant Psychosocial Evaluation

Developing a psychosocial assessment tool is the foundation of performing a comprehensive, thorough, and detailed evaluation of the transplant candidate. A solid psychosocial assessment should incorporate guidelines from UNOS (united network of organ sharing), CMS (Center for Medicare and Medicaid Services), and JCAHO (Joint Commission on Accreditation of Hospital Organization). Many cardiac transplant centers' psychosocial evaluations cover in large part the following areas: cognitive evaluation; screening for psychiatric illness; evaluate for history of alcohol, tobacco, and or substance abuse; evaluate history of compliance with medical therapies; evaluate history of compliance with medical therapies and recommendations; evaluate psychosocial obstacles that would limit chance of successful outcome; assess level of family/caregiver support and presence of caregiver burden; and verify adequate level of health insurance/ability to obtain it and maintain it (Petty and Bauman 2015).

More recently, many transplant social workers have added a thorough evaluation using the DSM V guidelines for substance abuse disorder including alcohol as well as thoughtfully posed questions about literacy and health literacy. The goal of this enhancement is an increase in the accuracy of the assessment and to accommodate for differences which could impact the interpretation of candidacy. Most centers now realize the value of the AUDIT (alcohol use disorders identification test) tool (NIH 2001) to standardize what is agreed upon as *use* versus *abuse*. In addition, there is great value to pay special attention to all aspects of diversity and to ensure that the candidate's identified gender is asked as well as couching relationship status as "partnered" first instead of "married." Establishing rapport with the patient and family is as important as information gathering; the relationship developed with the patient will likely last the life of the patient thus the approach and sensitivity to information gathering is a crucial part of the process.

A comprehensive assessment tool is one way to gather information for candidacy as well as to be able to have a source of information about the patient and family structure as patients move through listing, delayed listing, LVAD implantation, total artificial heart implantation, and possibly transplantation. There is no clear instruction on the time intervals of psychosocial reevaluation, and therefore many centers will combine it with the medical reevaluation for completion of the process (generally on an annual basis). What has been lacking for many years was a way to capture the patient's candidacy consistently for transplant from a psychosocial standpoint. In 1993, the first widely known attempt at providing a scale for transplantability was developed, the TERS.

> The Transplant Evaluation Rating Scale (TERS) classifies patients' level of adjustment in 10 aspects of psychosocial functioning that are thought to be important in adjusting to transplantation. On the basis of pretransplant psychiatric consultations, 35 liver transplant recipients received retrospective TERS ratings. Results showed significant correlations between TERS scores and visual analogue scale ratings of five outcome variables at 1-3 years posttransplant. Significant interrater reliability was also found. The TERS represents a promising instrument for transplant candidate selection as well as a valuable tool for further research. (Twillman 1993)

Often the same or a similar tool can be used for an LVAD or total artificial heart (TAH) patient. There are several tools available, most notable the Stanford Integrated Psychosocial Assessment (SIPAT). "The SIPAT is a comprehensive screening tool to assist in the psychosocial assessment of organ transplant candidates. Its strengths include the standardization of the evaluation, and its ability to identify subjects who are at risk for negative outcomes after the transplant, for the development of interventions directed at improving the patient's candidacy. Our goal is that the SIPAT, in addition to a set of agreed upon minimal psychosocial listing criteria, would be used in combination with organ-specific medical listing criteria to establish standardized criteria for the selection of transplant recipients." (Maldonado 2012). A copy of the SIPAT can be obtained by contacting the author of the SIPAT.

The LVAD evaluation has to this point predominantly emulated the heart transplant evaluation with a few subtle differences. "Psychosocial predictors of LVAD outcomes have not been standardized. There is limited data on objective psychosocial predictors of LVAD outcomes. The SIPAT (Stanford Integrated Psychosocial Assessment for Transplant) scale has been validated in organ transplant evaluation and patient selection." (Maldonado 2012). However, there are many differences, especially in the role of ultimate physical independence which transplant affords and which the LVAD may not. As LVAD technology changes, the LVAD evaluation may need to change in tandem to acknowledge the advances in the technology. A 2016 study in the Journal of Cardiac Failure concluded that "The SIPAT score may not be sensitive enough for psychosocial risk assessment of LVAD patients" (Tsarova 2016).

While the SIPAT is a promising pretransplant/pre-LVAD evaluation tool and lends itself well to an electronic medical record (EMR), its predictive strength in determining successful transplant outcomes is debatable. As Khaled Housseini writes "Human behavior is messy and unpredictable and unconcerned with convenient symmetries" (Hosseini, 2013). After all, there is not an even playing field when it comes to patients who require care, and such high levels of care. In addition, the tool is quite lengthy and gets into areas which may be better served by the social worker referring to psychiatry or psychology.

A limitation of the SIPAT can be that it tends to read as a checklist with the goal of data collection for the ultimate tabulation of the score. The psychosocial evaluation is an art, like the way physicians amass information by engaging with the patient. A very different answer can be accrued simply in the way it is posed, and the space allowed for response. Perhaps an answer to a SIPAT question may lead to another question that is not on the SIPAT but is born from the experience of the social worker's experience working with patients and families. The responses given are generally given with a context, which is the value of having an experienced transplant social worker assess a patient and family system. The risk of standardizing an assessment tool is to think that the numeric score produced is the gestalt of the patient and situation. Social workers are the translators, advocates, and detectives when it comes to making sense of the psychosocial information. As transplant programs expand and the use of electronic medical records is the norm, transplant social workers must find a way to still have the opportunity for narrative and prose not otherwise captured by the standardized tool.

A possibility to consider is for a transplant program to develop their own tool based on their specific program's philosophies and contraindications (absolute and relative), keeping the TERS or the SIPAT as the framework. Does the program even believe a scoring tool is necessary? If so, for what reasons? Some programs have piloted a scoring tool and followed their listings for 6 months to determine efficacy or increased versus decreased listings. The goal would be to create an adaptable psychosocial tool that can be developed with team input, transplant social worker experience, and a consistent objective method by which to categorize, guide, plan, and advocate for candidates. When a patient is evidently a candidate with all the required components and features for an anticipated successful outcome, that is simple. It is far more complicated when a patient is not able to be listed but has the potential to work toward psychosocial candidacy while the medical issues do not wait.

Health Literacy as It Impacts Psychosocial Evaluation

What has become increasingly clear over the past several years is the significant role that health literacy plays in a patient and family's ability to understand, comply, and execute required care. This would be especially true for chronic conditions such as LVADs or cardiac transplant, and in many cases, both.

> Low health literacy was shown to be associated with poor health outcomes, higher mortality rates, and greater health disparity. Lee and colleague studied the link between health literacy, self-care activities, and quality of lifelong type 2 diabetes patients from out-patients clinics. It suggested that health literacy was recommended in clinical practice for enhancing self-care activities and could improve health-related quality of life in patients. Therefore, it was important to identify patients at different levels of health literacy and provide adequate and effective interventions such as tailored counseling, improved provider–patient interactions, organizing information by patient preference using plain language and visual items. (Duong 2017)

Table 1 (Abel 2015) lists several questions that can assist in ascertaining the patient's overall health literacy in an objective manner.

Many times, members of the team will think and say, "the patient just doesn't *get* it" and make a referral to psychiatry or request a neurocognitive exam. It is highly likely that the patient has arrived at the point of needing transplant secondary to lack of comprehension of their heart disease, and the medical information they have received. The above 8 questions are key to determining the patients' health literacy in advance of the psychosocial evaluation for heart transplant or LVAD. The 5 minutes required by the social worker to ask these questions of the patients can put the findings of the psychosocial assessment into a context, as well as illuminate areas where patients

Table 1 Health literacy among young adults: a short survey tool for public health and health promotion research

HL1	How well do you understand instruction leaflets for medication	Very bad = 1; bad = 2; moderate = 3; good = 4; very good = 5; I do not make use of this kind of information = 0[a]
HL2	How well do you understand information brochures on health issues	Very bad = 1; bad = 2; moderate = 3; good = 4; very good = 5; I do not make use of this kind of information = 0[a]
HL3	When I have questions on diseases or complaints, I know where I can find information on these issues	Disagree strongly = 1; disagree = 2; agree = 3; agree strongly = 4; I do not have experience with these issues = 0[a]
HL4	When I want to do something for my health without being sick, I know where I can find information on these issues	Disagree strongly = 1; disagree = 2; agree = 3; agree strongly = 4; I have not been interested in these issues = 0[a]
HL5	How often were you able to help your family members or a friend if they had questions concerning health issues	Never = 1; seldom = 2; sometimes = 3; often = 4; always = 5; there have never been any questions = 0[a]
HL6	When you came up with questions concerning health issues, how often were you able to get information and advice from others (family and friends)	Never = 1; seldom = 2; sometimes = 3; often = 4; always = 5; there have never been any questions = 0[a]
HL7	How well are you doing in choosing the advices and offers that fit with you the most	Very bad = 1; bad = 2; moderate = 3; good = 4; very good = 5; I have not been interested in these issues = 0[a]
HL8	Regarding information on health on the internet, I'm able to determine which sources are of high and which of poor quality	Disagree strongly = 1; disagree = 2; agree = 3; agree strongly = 4; I do not have experience with these issues = 0[a]

[a] Answers external to the ordinal scales were seen as difficult to interpret due to ambiguity. Such responses were scored 0 points

may require additional education and support versus a referral to psychiatry.

Far and above the marketing department of the institution ensuring that their patient education material is presented in an attractive layout, a program should absolutely consider having their materials assessed for readability. Likewise, any psychosocial assessment tools should also be examined for accessibility to a general population and/or an aging population.

> The average US resident reads at an 8th grade level, and the average Medicare beneficiary reads at a 5th grade level. These statistics have implications for patients, including their ability to understand common medical terms. In a study of 249 adults at a metropolitan Emergency Department, investigators found that nearly 80% could not correctly state that "hemorrhage" meant "bleeding", "myocardial infarction" meant "heart attack", or that "fractured" meant "broken". This is despite the fact that greater than 50% of surveyed patients had a college education. (Stosell 2012)

For a rapid estimation of the materials with which your center is providing information to patients, Google has now added a search filter for "reading level" in the advanced search page. The standard method used by Google is called the "Flesch/FleschKincaid readability test."

LVADS and the LVAD Psychosocial Evaluation

A left ventricular assist device (LVAD) is a type of mechanical circulatory support that is implanted to restore the physiologic function of the damaged left ventricle in patients with stage D HF. Currently, there are two approved long-term indications: LVAD as a bridge to transplant (BTT) and LVAD as destination therapy (DT). LVAD-DT is a permanent alternative for stage D HF patients who are not transplant candidates. Once implanted, the majority of these patients will live with and die with this device in place. The main goals of destination therapy are to improve the daily function and health-related quality of life, and to improve survival compared to patients who receive optimal medical management. Studies have shown a 68% survival rate with an LVAD at 1 year and a 58% increase in survival at 2 years compared to those who are

> managed medically. Based on the current evidence, quality of life also improves post-implant. Once FDA approval, there has been an exponential increase in the use of LVAD-DT with a tenfold increase from 2006–2010.The implantation of LVADs will continue to increase with improvements in technology, scarcity of donor hearts, and the aging population. (Kitko 2013)

The introduction of the LVAD from an in-hospital device as a bridge to transplant to an FDA-approved device for use as an outpatient while waiting for transplant, or as a destination therapy, engages the social worker in a different way than in transplant. Specifically, the support system will be required for a longer period and will require more training. Assessing the caregiver's health literacy could also contribute valuably to the longevity of both patient and caregiver's endurance.

That same study concluded that "Caregivers were able to adapt and develop effective strategies to incorporate the demands of caring for a spouse with an LVAD-DT, but the role remained challenging. The findings underscore the need for continued research that may be translated into effective interventions to support patient and caregivers as they live through this end-of-life trajectory." (Kitko 2013). By extension, the support system will need ongoing support thus extending the role and reach of the social worker beyond sustaining the patient.

It is important to point out the differences between the LVAD psychosocial assessment and the transplant assessment, though there is significant overlap. As previously mentioned, the caregiver involvement will be more long term in the LVAD cohort. The wound care, battery requirements, potential for infection, and frequent blood tests to prevent blood clots cannot be underestimated. Many patients have been in heart failure for years and may have some permanent cognitive delay requiring unending supervision, albeit at varying levels. In addition, many LVAD patients cannot return to work as easily if at all, as can a heart transplant recipient; thus evaluating employment, income, and insurance is just as crucial if not more so than in transplant. Similarly, a thorough exploration for a backup layer of support should be undertaken in the event the planned support person becomes unexpectedly ill or the relationship deteriorates.

It is extremely important to take note that LVAD patients have an ability to terminate their life most immediately and directly. In the days and weeks which follow an LVAD implant, patients can confront medical setbacks and pain which could lead to "buyer's remorse." As medical professionals and those familiar with the often-undulating course that post-LVAD implantation can take, a thorough discussion should take place ahead of time to establish the parameters the team and family desire to establish. In a 2013 article, Morris and Shore (Morris 2013) strive to balance the patient's right to self-determination with what they know as the potential medical and emotional challenges after an LVAD implant. They posit that in general, a minimum of 90 days should be the baseline before which end-of-life discussions should be entertained while input and consultation from psychosocial support teams should be maximized during this time. As always, establishing a baseline trust with patients and families is critical to the process; at decision points along the way that trust will be invoked and relied upon heavily.

The role of caregivers for LVAD patients has recently gained quite a bit of attention as a sizeable cohort of long-term and destination therapy patients have allowed for study of this group. Destination therapy (DT) patients are those patients who are considered not eligible to proceed to transplant. The psychosocial support required for the caregiver in any chronic condition should not be overlooked and is nowhere more evident than with a DT patient's family. The learning curve, as with anything new and technologic, can be steep and thus the social worker can lean on questions which flesh out trends to evaluate caregiver adaptability. This distinct difference in LVAD versus transplant is one of the areas where the psychosocial assessment needs to specifically be adjusted. In one study, it was noted that throughout the process of caregiving, preimplant through postimplant, all caregivers discussed their ability to adapt within the role as a caregiver. Adaptation as a caregiver occurred through three distinct time frames following the progression of the patient's HF and subsequent LVAD implantation: caring for a spouse with HF, decision for LVAD implantation made, and caring for a spouse with the LVAD-DT (Kitko 2013). The adaptability of long-term caregiving can be difficult to assess in a tool such as the SIPAT which examines a moment in time. Specifically asking about other times in the family's history where they can describe how they adjusted to something new, different, or even traumatic can help ascertain the possibility of both strengths and areas of vulnerability and can serve as a reference point going forward.

LVAD programs will need to decide collectively how and for how long, caregiver support will be required. Often checking in with other programs of similar size and experience can be helpful. A minimum of 12 weeks of 24-hour care coverage from time of discharge was one experience in Philadelphia in the early 2000s (as compared to only 6 weeks for transplants). This time frame was based on the collective input of the multidisciplinary group considering healing, cognitive status, general age of the patient, and learning the device care. It was often challenging for patients and families to come up with the duration of coverage; thus the role of the social worker was to assist in mobilizing family and community support to assist in the family's coordination of that care.

An excellent addition to a roadmap for psychosocial support for LVAD patients is a social work led and facilitated support group. On line support groups and forums are an excellent resource for patients and families who live a distance from the hospital or who are unable to drive. So often the caregiver's needs are placed after the patient's which can affect the caregiver's mood. In addition, the need to take time off from work can negatively impact the family system and put the caregiver's job in jeopardy. Many caregivers report feelings of isolation, thus the support group, in whatever forum, was an opportunity to exchange concerns, tips, triumphs, and even clothing adjustment ideas. The importance of the caregiver's role cannot be undervalued.

> A striking finding from our study is that the risk of death was 3.1× more likely among patients who live alone compared with those who did not live alone. This suggests that having a caregiver present and available is strongly associated with mortality. Further supporting the interpretation, we also found that the risk of death for an LVAD patient was significantly lower among those who had at least 1 adult child living close by (defined as ≤50 miles). Theorizing why we found these associations, it could be that these better mortality risks are related to adherence to medical regimens and self-efficacy (the latter being a person's ability to complete a skill successfully and confidently). In the absence of caregivers who can routinely assist and monitor patients (and other caregivers to provide backup support if the primary caregiver is unavailable), mortality risks may increase because patient self-efficacy lowers in the absence of support. Specific examples include patients not taking Coumadin without reminders from caregivers, resulting in thrombosis or stroke and patients not properly adhering to hygienic practices for dressing changes or cleaning drivelines without caregiver assistance, either because of patients' cognitive detriments or because of physical limitations. There is some support for hygienic practices influencing mortality because our previous work demonstrated that persistent bloodstream infections (related to driveline infections) strongly correlated with mortality and risks of stroke. It may also be the case that without support, patients may become burned out or are otherwise so burdened that they cannot fully contribute. (Bruce 2017)

The role of the palliative care team is newer to LVAD programs, but the late to arrive addition to the LVAD evaluation process makes it no less important. In fact, in October 2014 CMS mandated that all VAD implanting centers have palliative care as part of their interdisciplinary team. The timing of the placement of the consult can be tricky: it should already be decided if the patient is an LVAD candidate by the medical team so that the consult is in sync with what is being offered. The palliative care team typically needs to respond to consults within 24 hours of receiving them, thus mastering the flow of the consult should be discussed ahead of time. Without a doubt, the emergent LVAD implants will have to have a collateral palliative care consult protocol which should be established well ahead of time by the program.

The process for a palliative care consult ideally flows as illustrated at University Hospitals Case Medical Centers:

- Heart failure (HF) places palliative care (PC) consult.
- Psychosocial assessment completed by HF team prior to PC consult.
- PC consult ideally completed prior to candidacy discussion.
- PC meets patient to introduce role and preparedness planning process.
- Follow-up meetings planned if needed.
- The following quality of life issues related to VAD are discussed:
  - Hemodialysis.
  - ICH/embolic stroke.
  - LVAD failure.
  - LVAD infection/need for long-term antibiotics.
  - Artificial nutrition and hydration.
  - Mechanical ventilation (short vs. long term).
  - Caregiver burden (Cohen 2015).

As in hospitals, inquiring as to a Living Will/Advance Directive and Health Care Proxy is of paramount importance and should be imbedded into the psychosocial evaluation. This information can be exceedingly helpful to the palliative care team as they interview and connect with families embarking on LVAD implantation. The palliative care consult in conjunction with the patient's AD can serve as a record for their initial wishes at the start of treatment. For many patients and families, it can be difficult to see how far a patient has strayed from their initial ideals on quality of life and end-of-life care issues. Likewise, complications at the time of implant or at any point along the LVAD trajectory can be immediately contextualized if the patient and family's philosophical roadmap has been concretized.

So much of the palliative care discussion at the time of LVAD implant has to do with the approach, both with the team as well as the patient. Despite the 2014 CMS recognition and mandate to include the consult, many team members find the timing discordant to the message they are trying to impart to the patient. That message is one of hope and rebirth while the PC consult may be viewed as serving to undermine or contradict the goal of the program. That is why it is highly recommended to have ideologic covenant between your VAD and transplant team and the palliative care program that in fact the message is unified and comprehensive. The presence and input of a palliative care representative at your selection criteria meeting is crucial to round out the total patient experience. Moreover, many programs have found it useful to have a revisit every 6 month to see if the patient's wishes have changed over time. This can prove extremely useful should a patient's health status decline, an established relationship with the PC team has been forged already.

Perhaps the most useful and user-friendly AD tool for this particular patient population is The Five Wishes. This tool is available through the Aging with Dignity Program (www.agigwithdignity.org). The Five Wishes provokes the following questions:

- Who you want to make health care decisions for you when you can't make them.
- The kind of medical treatment you want or don't want.
- How comfortable you want to be.
- How you want people to treat you.
- What you want your loved ones to know.

The Five wishes can also be completed on line through Aging with Dignity. In this way, should families be physically apart the document can be readily accessed in times if immediate need or medical crisis. The tool is also available in Spanish.

In an ideal world, a palliative care consult would be beneficial both for patients listed for transplant in the absence of LVAD implantation as well as those who undergo LVAD implant as either destination therapy, potential heart transplant candidacy at some point, or a listed patient. Most programs do not have the capacity to accommodate the volume of such an ambitious agenda but the value of the role of the palliative care team is inestimable. If possible, the palliative care team should be present at the selection team meeting.

Selection Committee Procedure and Presentation

The goal of every LVAD and transplant program is to implant and list/transplant patients to improve as many lives as possible. Social workers share this attitude despite having different and less binary measures. Collective team agreement on absolute contraindications to listing and/or implanting is crucial at the start of tenure with your team. Without those established standards, the ability to discuss a patient's candidacy and the proposed intervention will be unfocused. Preparing ahead of time what should be conveyed will help a busy team with limited time understand the psychosocial clearance, concerns, or contraindications to moving forward. Should the social worker anticipate not being able to "clear" a patient, it is advisable to reach out to the physician or physician extender ahead of time to share what is expected to be presented. If steps towards candidacy are needed, then a clear, measurable time frame should be outlined with team feedback as goals are met or unmet. Finally, a succinct, cogent, and well verbalized psychosocial presentation is imperative to best advocate for the patient, program, and all others who wait on a heart transplant list or LVAD implant date.

It may be helpful to standardize the psychosocial presentation, so the team can follow the cadence and rhythm of that assessment. As an example, social workers may want to begin with the patient's family constellation, history of self-care, current insurance, and any contributory psychiatric or substance abuse-related issues. This could be followed by the patient and family's desire to proceed with transplant/implant and finally the social worker's input. If the patient has steps which need to be completed, those should be outlined with a clear follow-up time frame and documentation. If the patient is not a candidate based on programmatic absolute contraindications, that should be stated as well. Below are some examples of a concise presentation.

1. Mr. Z is a married man with two adult children who reside nearby and are supportive and involved. He has been followed closely by his local physicians for many years and demonstrates adherence to the prescribed medical plan. He is currently covered by his wife's insurance plan and will have Medicare in 3 months. He and his family deny a history of mental health issues or substance abuse-related issues. Patient and family look to transplant to improve his quality of life and he hopes to return to work when medically cleared. Psychosocially cleared for transplant/VAD; reevaluate in one year.
2. Mr. Z is recently separated from his wife but has a daughter who has been involved in his care intermittently. He is, for the most part, compliant with medications and appointments but often does not have a ride to the pharmacy. He is covered under COBRA which will end 2 months before he becomes Medicare eligible. After 30 years of smoking two packs per day, he stopped smoking 3 months ago. Finally, he reports a history of sporadic depressive episodes for which he did not receive treatment, but these episodes did not interfere with his overall health or adherence. He is psychosocially cleared but with a plan for random urine nicotine checks and the need for his daughter to accompany him for the first six visits while listed for transplant/post-VAD implant. Transportation needs to be secured and a financial coordinator obtained to develop a plan for the transition from COBRA to Medicare with prescription plan in place. Reevaluate in one year or sooner if there is a deterioration of the psychosocial situation.
3. Mr. Z lives alone but came for his transplant/LVAD evaluation with a neighbor who is willing to help. He has been newly diagnosed with heart failure though he had symptoms for years but no insurance to seek medical care. He continues to smoke but has cut back to a half pack per day. He reports that smoking cannabis has helped his anxiety a great deal since he completed a dual diagnosis treatment program for bipolar disease and heroin abuse 20 years prior. He has not had any psychiatric follow-up

> since his discharge from the program. Patient is not cleared for transplant until he has been evaluated by psychiatry and has stopped smoking both cigarettes and cannabis. He should be reevaluated for listing for transplant in 3 months but a vigorous discussion about LVAD candidacy should be entertained.

The medical contraindications for smoking are clear. A study first published in 2016 looked at smoking and mortality while listed for transplant.

> During the study period (April 2005 to March 2010), 14% of those who never smoked died, 18% among former smokers died, and almost half (42%) died among those who reported smoking at time of wait listing. Multivariate Cox regression models controlling for age, sex, and disease severity revealed smoking at time of listing was associated with significantly higher risk of mortality compared to never smoking (hazard ratio [HR] = 3.43; P = .03). The relationship between smoking and mortality risk appeared to follow a dose-dependent pattern: adjusted HRs were 1.80 for those who quit ≤1 year ago, 1.25 for those who quit >1 to 10 years ago, and 0.90 for those quit >10 years ago, compared to never smokers. Smoking at time of listing may increase risk of mortality during the waiting period, indicating the need for improved strategies to achieve smoking cessation as early as possible in the course of heart transplant. (Gali 2016)

The rate of cancer increase after immunosuppression is also indisputable. "Hard core" drug use and abuse such as cocaine, heroin, opioids, and similarly classified drugs is consistently an absolute contraindication for listing for transplant. Less clear is what role, if any cannabis, plays both medically and psychologically often rendering marijuana a relative contraindication to listing for transplant.

Although cannabis use remains illegal under federal law, at the time of the writing of this chapter, 24 states have passed laws which legalize marijuana use for medical or recreational use. This places transplant programs in a difficult position in terms of deciding if marijuana use is a relative or absolute contraindication to listing for transplant. Arguments can be made on either side and without a doubt the personal opinions of team members can play a role in this determination, much the way alcohol use can also be perceived relationally. In fact, "several states have passed legislation prohibiting marijuana-using patients from being denied transplant listing based on their use of the substance" (Neyer 2016). That study, conducted in 2016, surveyed transplant providers and concluded that "The majority of heart and lung transplant providers in our study sample support the listing of patients who use medical marijuana for transplant after a period of abstinence. Communication and collaboration between the medical community and legislative groups about marijuana use in transplant candidates is needed to ensure the best patient outcomes with the use of scarce donor organs" (Neyer 2016). From a social work perspective, a detailed substance use/abuse history might be helpful in determining if the cannabis use is a maladaptive behavior which could be replaced by a better strategy (psychiatric treatment, medication, or an alternative methodology). In addition, there remains the concern that the relaxing effects of cannabis could contribute to lack of initiative in medication adherence, ultimately contributing to potential noncompliance.

Ultimately, each team will decide what are their criteria medically and psychosocially, and where the two meet. It cannot be stated enough how important it is to visit and revisit these criteria, as team members change, as laws change, and as the transplant climate in your community changes. As much as it goes against the social work grain, the reality is that competitive markets where there are many transplant centers from which to choose can liberalize listing criteria from center to center. More data will be needed, especially in an area so under studied as cannabis use, for teams to make a best practices decision.

Alcohol use and abuse is another area that is often quite controversial. To avoid controversy and subjective input, a constant definition should be sought and utilized consistently. According to the National Institute on Alcohol Abuse and Alcoholism, drinking levels are defined as:

Moderate alcohol consumption:

According to the *"Dietary Guidelines for Americans 2015-2020," U.S. Department of Health and Human Services and U.S. Department of Agriculture*, moderate drinking is up to one drink per day for women and up to two drinks per day for men.

Binge drinking:

NIAAA defines binge drinking as a pattern of drinking that brings blood alcohol concentration (BAC) levels to 0.08 g/dL. This typically occurs after four drinks for women and five drinks for men—In about 2 hours.

The Substance Abuse and Mental Health Services Administration (SAMHSA), which conducts the annual National Survey on drug use and health (NSDUH), defines binge drinking as five or more alcoholic drinks for males or four or more alcoholic drinks for females on the same occasion (i.e., at the same time or within a couple of hours of each other) on at least 1 www.niaaa.nih.gov/alcohol-health/overview-alcohol-consumption/moderate-binge-drinkingday in the past month.

Heavy alcohol use:

SAMHSA defines heavy alcohol use as binge drinking on 5 or more days in the past month.

NIAAA's Definition of Drinking at Low Risk for Developing Alcohol Use Disorder (AUD):

For women, low-risk drinking is defined as no more than 3 drinks on any single day and no more than 7 drinks per week. For men, it is defined as no more than 4 drinks on any single day and no more than 14 drinks per week. NIAAA research shows that only about 2 in 100 people who drink within these limits have AUD (NIH 2015).

Organizing the Family Meeting

Whether performing an inpatient of outpatient transplant or LVAD evaluation, gathering the support team that will assist the patient throughout the many steps in their journey is a critical first step in even establishing candidacy to move forward with the evaluation phase. The inability to accrue a base group of individuals is a telling sign. Without being considered insensitive to work and family obligations, the patient must be able to mobilize support. In addition to be a litmus test for the patient, those who plan to commit to an individual must be made aware of what they can expect and what will be expected of them. It can be helpful to have a document summarizing the responsibilities of the support structure at each phase of the process so families can refer back as they move through the process. Similarly, creating a document which specifically outlines the support people within the patients' family can help the team recall and refer to what has been agreed upon and adjust accordingly.

Retransplantation and LVAD Exchange

Approaching the concept of retransplantation is extremely complicated. Clearly, the dearth of available organs for so many who need them is the foundation of the struggle in considering retransplantation. Teams all over the world confront this issue especially when a patient was transplanted as a child and has reached adulthood and needs retransplantation. From a psychosocial evaluation standpoint, most of the guess work is eliminated with retransplantation consideration; compliance has either been demonstrated or not, family support over time has declared itself, and the patients desire to reinvest in the transplant process is evident by virtue of their consideration of moving forward with reevaluation. What can get complicated is the ensuing discussion if a patient's obstacle to relisting is founded upon psychosocial indications-how the team interprets those issues can get sticky. For example, supposing a patient was noncompliant with medications because they lost their insurance? On the surface, this can seem like a punishing reason not to relist. From a psychosocial standpoint, the questions that need to be asked fall into the realm of what created the inability for the patient to reach out to the transplant center for guidance and resources? What happened to the support system that had been in place? Was isolation a contributing factor? There is tremendous reluctance to proceed with retransplant if the afore mentioned issues contributed to the loss of the organ.

Consideration for LVAD exchange is less complicated but should none the less be approached with similar serious consideration as retransplantation, especially if medication noncompliance was a contributing factor. Likewise, device-related noncompliance (such as driveline infection due to lack of support or carelessness with equipment) should be factored in. Though not short in supply such as an organ, an LVAD remains a costly intervention and relies heavily on a support network. Obtaining input from those who are involved with either an LVAD or transplant patient can help explain or fill in vital information when considering either LVAD exchange or retransplantation.

Helping families feel comfortable in sharing their knowledge of the patient's situation without creating an environment where they feel contributory to the denial of care is very important. The finesse required to engage the family to reveal the truth about the reasons for device failure or allograft dysfunction may require widening their perspective on the shortage of organs and the continued risk to the patient, among many other possible approaches. Helping families and the team decipher what types of interventions may help with candidacy is a role that the social worker can assume. Conversely, social work is equally obligated to the awareness of organ shortage, human behavior, and distributional justice. Requesting a palliative care consult as well can be extremely helpful in retransplantation or LVAD exchange conversations for the family, patient, and team.

Maintaining Social Work Relevancy in Cardiac Transplantation

It is imperative that social workers be at the forefront of policy changes in all areas to be the best advocates for patients, families, the transplant team, and donor families. There are many opportunities for heart transplant social workers to continue to be relevant to the process including attending the UNOS region meetings in whichever region they work. The agenda can often seem very medical but there are policies which are discussed as well as those which can be read on line in advance of approval to be considered. The regional meetings are also wonderful opportunities to network with others in the region and bring awareness and recollection that singularity in transplantation in nonexistent.

In regions across the country there are transplant centers who exists with blocks of one another. In Philadelphia alone (UNOS Region 2), there were at least five fully functioning cardiac transplant centers at one time. This seeming deluge of centers, each vying for the same limited number of organs had the potential to lead to psychosocial secrecy. Instead, The Delaware Valley of Transplant Social Workers was formed and remains operational to this day. The goal of the group was to meet every other month and share information through organized guest speakers as well as to formally present difficult cases for collegial input and to bring awareness to the commonality of some of the challenges patients and centers face. In addition to the acquisition of knowledge germane to our unique group was the sequela of the opportunity to obtain information when a patient transferred care to the other's center. The group often invited transplant financial coordinators to join so that changes in Medicare and Medicaid coverage could be shared with all centers. More recently, the group was besieged with the contests that undocumented patients often face when requiring transplants which then called upon the invitation for community legal services to speak to the group.

There has been much discussion of late in all work sectors about work/life balance, self-care, and similar such concepts. In all professions, we grapple to attain that coveted nirvana. Social work in cardiac transplant is not for the faint of heart; the vicissitudes of the journey of transplantation calls upon the ability to stay the course through the heights of the incredible victories and be stalwart during the darker and less successful outcomes. Undoubtedly, there is vicarious trauma associated with our profession and while there is no magic bullet to avoid such exposure, hopefully some of the suggestions within the chapter can assuage the full impact of the by-product of such courageous work.

Conclusion

The cardiac transplant social worker assumes a complex role on a transplant team: assessor, fixer, ethical conscience of the team, resource expert, ambassador to other consultative teams, and is one of the central figures to the patient and family as they move through all phases of care. The ability to have longevity with the family and in the field is dependent upon the relationships formed with colleagues, patients, and caregivers. As social workers, we are privileged to work with expert transplant teams and patients alike, who each demonstrate bravery in the field and personal courage to pursue life altering medical care, respectively. No chapter would be complete if not to mention the pioneers of transplant surgery, donor families, and those patients and families who joined in that initial and continued leaps of faith with each new disruptive medical innovation. As social workers, we honor their valor by committing to judge candidacy without being judgmental, to guide without being directive, to be knowledgeable without arrogance, and to walk alongside with strength and humility for the miracle of transplant.

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