

Psychosocial issues in ventricular assist device implantation and management

Michael Petty, Lillian Bauman

University of Minnesota Medical Center, Minneapolis, MN, USA

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Correspondence to: Michael Petty, PhD, RN. University of Minnesota Medical Center, 420 Delaware St. SE, Minneapolis, MN 55455, USA. Email: mpetty1@fairview.org.

Abstract: The primary goal of mechanical circulatory support (MCS) is to increase quantity and quality of life (QOL) in patients with systolic heart failure refractory to medical therapies. A key contributor to the success in MCS therapy is a comprehensive assessment of the candidate for device implantation. A crucial element of that assessment is an evaluation of the individual's psychosocial status, recommended by most current MCS guidelines. By focusing on criteria including drug, alcohol and tobacco abuse, ability to learn and problem solve, history of adherence to medical regimens, and adequate psychosocial support following implant, the team has an opportunity to create an individualized post-discharge plan that addresses identified gaps and optimizes the patient's likelihood for success. Information gathered also provides the team with a setting in which to discuss the patient's personal goals for the therapy and advanced care planning. We explore all of these issues and offer recommendations for approaching psychosocial assessment for MCS patients.

Keywords: Psychosocial assessment; social worker; neuropsychology; mechanical circulatory support (MCS); ventricular assist device

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Introduction

Mechanical circulatory support (MCS) devices, primarily LVADs, have been used for more than 20 years to treat patients with end-stage systolic heart failure. The goal of this therapy has been to increase the quantity and quality of the patient's life, whether as bridge to transplantation, destination therapy, or bridge to recovery (1-3). To that end the INTERMACs investigators most recently reported an 80% 1-year survival and 64% 2-year survival (4). In addition, patients have consistently reported significant improvements in various aspects of quality of life (QOL) on measures including the Minnesota Living with Heart Failure Questionnaire, Kansas City Cardiomyopathy Questionnaire, the EQ-5D and the Visual Analog Scale (2,4,5).

Various authors and groups have proffered recommendations regarding patient selection for MCS (3,6,7). Each of those guidelines includes assessment of the patient's psychosocial as well as medical condition. Appropriate psychosocial functioning and support is linked to success in the post-implant and post-discharge periods. Cigarette smoking, chemical and/or alcohol dependence, psychiatric conditions, or evidence of non-adherence to medical regimens cause significant concerns for the medical team. If the patient is found to have any of these challenges, most programs invoke strategies to assist them with overcoming such barriers to implant and device success prior to surgery whenever possible (8,9). Psychosocial support includes personal support, housing, vocational status, financial support, and environmental concerns (10). Inadequate housing, finances, or lack of an adequate support

Table 1 Key elements of a comprehensive psychosocial evaluation prior to MCS

Cognitive evaluation
Screen for psychiatric illness
Evaluate for history of alcohol, tobacco and/or substance abuse
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
Verify adequate level of health insurance/ability to obtain it

MCS, mechanical circulatory support.

system in any of these domains are also challenges which must be overcome in order for the patient to experience the improvements offered by MCS therapy (11).

This article will review the elements of the psychosocial assessment of the individual being evaluated for MCS implantation. Included will be the accepted model for evaluation, discharge planning strategies, post-discharge support to patients and their caregivers, and strategies for when the post-discharge period doesn't go as planned.

Psychosocial evaluation

Psychosocial evaluation for MCS patients has become part of the standard of care for MCS programs. Included in that assessment are screening for cognitive dysfunction; determination of the level of family emotional support (including caregiver burden); screening for evidence of significant psychiatric illness; identifying a history of compliance with medical recommendations; confirming a history of alcohol and/or substance abuse; verifying the presence of health insurance and/or resources to obtain it; and evaluation of the patient's financial circumstances (*Table 1*). The 2013 ISHLT guidelines provide generic recommendations for assessing the psychosocial function of the patient and his/her support structure (6). The lack of specificity allowed each center to develop its own unique protocols within the boundaries of the guidelines.

Why is psychosocial evaluation so important for the MCS program? It is a key element to assuring that we are providing appropriate care for patients and that there is the highest likelihood that the patient will experience the expected benefits of circulatory support. MCS remains expensive and requires a lot of chronic care. It would be counterproductive to provide this type of intervention to a patient who was unable to care for himself/herself or who might inadvertently harm themselves after MCS

was implanted. The evaluation isn't simply a matter of evaluating compliance history (although that will be important too). Rather it is looking at the ability of patient and family (or caregiver) to learn to change the batteries, to understand what the alarms are telling them and to respond appropriately. Will they be able to understand the medications and the impact that each medication has on the patient's well-being? Can they communicate difficulties to the medical team and call with either emergent needs or to seek clarification? These abilities can be evaluated by a neuropsychologist, psychologist, or social worker.

As a result of frequent overlap in candidates and personnel, many centers use a modified heart transplant psychosocial evaluation protocol for their MCS program. However, while the elements for heart transplant and MCS evaluations can look very similar, there are some significant differences. For instance, the scarcity of donor organs for heart transplant provides an ethical imperative to require more rigid adherence to guidelines prohibiting the use of tobacco, alcohol, and/or substance abuse to reduce the risk of wasting a precious resource—the donor heart. While some would argue that more leniency in adhering to the guidelines for MCS also wastes resources—the financial resources of the patient, family and insurer as well as the human costs of supporting the device, the patient and the caregivers—often MCS prohibitions are less imperative. In fact, some programs use MCS intervention to allow the patient to demonstrate abstinence from cigarettes, alcohol and drugs as well as to further evaluate whether the patient would be capable of caring for a transplanted heart. Such adherence in the MCS support period is deemed acceptable evidence of the patient's ability to adhere to the protocols and expectations involved in transplant. However for many, caring for a MCS device is more difficult than caring for a transplant (frequent dressing changes, attendance to having electrical power available, etc.).

The objective of the psychosocial evaluation is to consider the patient from a different perspective than the rest of the medical team. It looks more closely at family dynamics or other relationships, and asks more pointed questions about mental health and chemical dependency. The goal of psychosocial evaluation is not to put up road blocks to provision of therapy, but rather to ensure that the appropriate resources are available to care for the whole patient. Unlike for transplant recipients, the community resources for MCS patients are more limited. This requires more intense support from the patient's family and support system.

Each program determines who will perform the psychosocial evaluation. Some use social workers where as others routinely involve both social workers and a psychologist or neuropsychologist. It is uncommon for a VAD coordinator to perform the evaluation, but their assessment and input in the course of providing pre-implant education provides critical information to inform team decisions. Baseline information is obtained from the patient, from the family (or caregiver), and from chart review. The evaluation itself may take the form of a semi-structured interview with a resulting narrative report; a series of "check boxes" with room for narrative notes in the document; a structured interview such as the Stanford Integrated Psychosocial Assessment for Transplantation (SIPAT); or a combination of these along with the use of validated questionnaires [e.g., Alcohol Use Disorders Identification Test (AUDIT); CAGE Assessment for Alcohol Abuse; or Patient Health Questionnaire (PHQ-9)] (12-14). If the patient has an emergent need for MCS or if only limited records are available, then it is more difficult to be sure that all information gathered is accurate. This may impact post-discharge needs and outcomes.

Clarifying who will provide care of the patient after MCS is implanted is one of the key discussion points that is covered during the evaluation process. Unfortunately MCS isn't totally implantable so there are elements of the patient's care that are best done by another person (e.g., dressing changes). Each MCS program has their own requirements. Some expect very little after care by a caregiver while others demand more intense care, especially in the first few weeks and months after implant. Thus the evaluator must also attempt to uncover whether supporting the patient with an MCS device will cause excessive stress on the family system or caregiver. If the relationship is already unstable or strained, how will the burden of being a caregiver effect their relationship? One of the hardest parts of evaluating who will care for the patient is the inability to predict

how a patient's recovery will progress and what, if any, complications may arise. If there are major complications after a patient is implanted resulting in an inability to live independently with their MCS device, how would the family/support system cope with the more intensive need for care? For those implanted for destination therapy, a backup plan may be explored in case the caregiver becomes ill or unable to provide care or if the patient outlives the caregiver.

Psychiatric diagnoses and treatment plans can be difficult to ascertain in the short time that is allotted for MCS psychosocial evaluation. The impact of this information going forward depends the actual diagnosis (e.g., depression with or without suicidal ideation, anxiety, or psychosis) and the availability of effective treatments for the diagnosis. The availability of mental health interventions for patients and their willingness to participate when treatment is needed is also an important consideration. The key factor is the patient's psychiatric stability and ability to cope. Part of the assessment calls for gathering more information from the patient's outside mental health provider if he/she has one. If the patient has none but is deemed to require therapy it is common to ask the patient to establish care with a mental health provider so if they notice an increase of symptoms they already have an established relationship for care. If the patient experiences an exacerbation of the psychiatric disorder following device placement, finding a psychiatric hospital that is also able to manage an MCS patient is almost impossible. On the other hand, most medical units that care for the MCS device patients don't have the staff or training to manage a psychiatric emergency. One of the biggest barriers is the ability to provide treatment to these patients if their mental health becomes their primary diagnosis. Depression and anxiety are not uncommon for patients who are facing the need for MCS (15). While that literature is extrapolated from statistics related to depression and anxiety in heart transplant patients, there is no newer literature about the prevalence in of these disorders in the MCS population.

Compliance or adherence is defined as the patient's ability to understand and willingness to follow the recommendations of the medical team. There are many tasks involved in caring for an MCS device and performing each one of them correctly and consistently is important to the longevity of device and patient's life. Compliance is a factor that is hard to evaluate when a patient needs emergent MCS. Often in those situations the patient is sent to an MCS facility where they have no relationship and little history is available to

understand their previous level of compliance. When patients have been followed at an MCS facility it is easier for the team to evaluate the patient's willingness to participate in their medical care.

ISHLT guidelines state that, "alcohol and drug treatment programs should be required for patients with a history of substance abuse" (6). It is better for the patient to attend treatment prior to MCS implantation as getting into a treatment facility post MCS is much more difficult. Alcohol and substance abuse within the previous 6 months prior to implant has been demonstrated to pose significantly increased risks of adverse outcomes following MCS implant (8), and is a strong contraindication in many programs. While the frequency and intensity of prior use helps the medical team to understand the patient's current involvement and need for chemical dependency assessment and therapy, during this portion of the evaluation it is important to talk with all patients about the contraindications to continued alcohol or drug use when supported on MCS. The setting of emergent MCS implant can impede both the patient's (and family's) willingness to be fully honest with the medical team about alcohol and substance abuse. There are some assessment tools which can help providers to gather a more comprehensive and detailed history (CAGE & AUDIT) (12,16). However, neither of these tools have guidelines in which they address abuse or dependence in patients with significant medical issues nor potential negative consequences due to their medical condition. The patient's age and lack of information or understanding of the negative impact of their use on their cardiac condition can further complicate the decision about implant timing.

Insurance and financial status continues to be a barrier in the MCS field. With the goal of MCS being improved QOL it would seem counter-intuitive to give a patient a device that they can't afford. Unfortunately undergoing MCS implant can impact a person's financial stability. If the patient has been working and suddenly is unable to work due to heart failure this may leave him/her without income. If the individual is married (or partnered) and his/her spouse or significant other is anticipated to be the primary caregiver, caring also may disrupt the caregiver's employment/employability. If the family was already struggling financially and hasn't been able to pay the electric bill, the lack electricity prevents the patient from being able to plug in the device and charge batteries. While insurance will pay for the hospitalization and implantation, patients may have a large deductible or out of pocket co-pays depending on their specific policy. Also, if

they are out of work they may have to pay for Consolidated Omnibus Budget Reconciliation Act (COBRA) charges to keep their insurance active. Another potential financial barrier is related to when the patient lives far away from the implanting center. Most insurance policies (except many Medicaid policies) will not assist in travel or lodging costs. Many centers require that patients and a caregiver remain locally for a minimum of 2 weeks to several months after hospital discharge to demonstrate their ability to manage the pump and post-discharge cares. The costs of follow up care and the need to travel back and forth between home and the implanting center pose additional financial burden on patients and their families.

Discharge planning and patient/caregiver preparation

Discharge planning commonly begins even before surgery to implant the MCS device takes place. Often the results of the psychosocial assessment will direct the team to focus on specific areas of concern uncovered in the evaluation. In addition evidence in heart failure and heart transplant literature emphasizes that involving not only patients but also their caregivers in the early stages of care planning and discharge planning will lead to increased success and decreased stress in the caregiver (17,18).

There is evidence of concordance in concerns of patients and their caregivers in MCS therapy (19). Both groups identify apprehension regarding complications such as device malfunction, infection, and stroke. As a result discharge preparation for MCS must address issues not only related to safe device operation, but also to sternal precautions, energy conservation and exercise, signs and symptoms of infection and other potential complications, along with strategies to manage activities of daily living such as bathing, eating, etc. In addition, attention must be given to managing medications including anticoagulants, heart failure medication, and others indicated for the individual patient's condition (20). Having a plan for emergencies (closest emergency department and EMS providers, closest reliable source of emergency power, 24-hour contact for the MCS team) gives both the patient and caregiver increased confidence that they will be able to manage outside the hospital.

For those patients in whom support has been discovered to be limited, strategies built on the foundation of the psychosocial evaluation are important opportunities to enhance the likelihood that the patient will be successful

following discharge. MCS team members should develop an individualized plan for reaching out to the patient and caregiver with specific inquiries about their post-discharge experience. These contacts, commonly by telephone between clinic appointments, can provide an early warning system for when coping is inadequate. This information can be shared with the social worker, MCS coordinator, and other members of the team to develop a focused intervention to help them through the challenging situation. Seeking support services in the local community, referral to MCS support groups either in person or on line, or telephone counseling have been found to be helpful in heart failure patients (21).

Psychosocial needs after implant

Psychosocial needs post implant vary both by program and by patient population. The social worker is a key team member to help to address psychosocial needs or changes that arise before, during, and after implantation. During the implant hospitalization social workers have the skill set to help patients and families adapt to their new normal, adapt to new family roles, provide adjustment to illness counseling, assist in finding resources for lodging or transportation, and coordinate placement in a transitional rehabilitation facility if needed.

Many patients identify more challenges after they are discharged from the hospital. Some of the support that they require involves continuation of work begun pre-implant and during the implant hospitalization. Helping patients and families to strengthen coping strategies, find solutions and alternatives to meet resource needs, and deal with the unique stressors that appear after the patient and caregiver return to the home environment are common elements of post-discharge requirements. One way to support patients and families is to offer support groups where patients and caregivers who have had similar experiences offer the solutions they found to problems after discharge. The skills possessed by the social worker, psychologist, and/or VAD coordinator to facilitate groups make him/her an excellent choice to lead such important sessions.

At times the patient's and family's needs change after implantation. For example, the patient suddenly may become eligible for Medicare and needs help choosing a supplement; the caregiver has his/her own health issues or passes away; the patient's level of care needs changes so that it is no longer safe to remain in their own home; or the stress of providing ongoing care has changed the dynamics

in the family. It is beneficial for the social worker to have an ongoing relationship with patients and families so when there is a need they will identify the social worker as a source of support. The social worker may also be asked by other members of the team (providers, coordinators, etc.) to follow up on concerns.

When things don't go as planned

Things don't always go as planned in healthcare. We anticipate one outcome and then need to develop a new plan when something changes. Even the most complete medical and psychosocial evaluation cannot fully predict the patient's post-implant course and caregiver team responses with precision. Discussing the unknown with patients and their caregiver team is difficult. However, the addition of a palliative care member to the core MCS team in the most recent CMS Disease Specific Certification requirements for Destination Therapy as well as palliative care inclusion in the ISHLT guidelines has created an important venue for discussion of the "what ifs" (6).

It is evident that, despite most patients having faced their own mortality prior to receiving an MCS implant, most still do not have an Advanced Healthcare Directive or Living Will developed at the time they go home (22,23). Using advanced directives to establish a baseline understanding of the patient's individual goals of therapy can aid the team in identifying interventions consistent with the patient's desires in the event of a change in medical condition, either gradual or sudden. For instance, kidney failure has often been cited as a medical contraindication for MCS. While some patients have expressed that they would not want to undergo hemodialysis in the event that their kidneys stopped functioning, patients who want this therapy have been successfully referred to both outpatient and home hemodialysis settings. For those whose complications prevent them from living at home (or whose caregivers are no longer able to provide them with care), there is a growing experience with successfully referring patients to skilled nursing homes for longer term rehab and long term care; to long term acute care hospitals for those with complex medical needs; and even inpatient chemical dependency units have been willing to care for MCS patients who have relapsed in alcohol or substance use in some areas. Each of those types of facilities requires significant resourcing and relationship management to successfully manage the MCS patient. As MCS population grows in number, demand for placement in assisted living facilities and psychiatric care

facilities will grow as well.

Hospice is a resource that is difficult to put in the category of “when things don’t go as planned” since MCS as destination therapy is part of the palliative care continuum. If things go as planned, patients may not be dying of heart failure, but eventually will have other medical complications. There are cases, though, when patients and providers expect things to go well and a major complication (stroke or life threatening bleed or clot) occurs and the need to talk about hospice develops earlier than planned. Another example would be when a patient has been listed for transplant, but a new diagnosis changes eligibility and forces revision to the goal of implant. Giving patients the opportunity to participate in the decisions at end of life should be expected.

Summary

Psychosocial evaluation of patients considered for MCS therapy is a key element to the comprehensive evaluation of the patient and his/her support system. Utilizing an accepted model for evaluation, developing discharge planning strategies and post-discharge support to patients and their caregivers based on that evaluation, and identifying strategies for when the post-discharge period doesn’t go as planned are central to optimizing the experience of heart failure patients supported with MCS devices.

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Footnote

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