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Comprehensive Care for Mechanical Circulatory Support: A New Frontier for Synergy with Palliative Care

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Heart Failure (HF) is a chronic and progressive illness and is a leading cause of death in the United States. Patients with end-stage HF have limited therapeutic options and thus Mechanical Circulatory Support (MCS) is increasingly being used to treat patients with end-stage disease. Between June 2006 and June 2010, 2,680 adults in the United States received an FDA-approved durable MCS device as treatment for end-stage HF.¹ Roughly 82% of patients receiving MCS were either listed for transplant at time of implant (bridge to transplant, BTT) or had at least a moderate probability of being listed for transplant at some point during MCS (bridge to candidacy), while 11% were implanted as destination therapy (DT). Currently, more than 98% of patients implanted with a durable MCS device receive a continuous-flow left ventricular assist device (LVAD).¹ Duration of MCS and survival is influenced by a number of factors, including timing of implant, strategy of support at time of implant, age of patient, and medical co-morbidities. Within the INTERMACS registry, 87% of BTT patients have been transplanted or are still alive on MCS at 12 months compared to 67% of DT patients. Stratifying by type of device to account for the shift to continuous flow pumps that began in 2008, 12 and 24 month actuarial survival for all patients receiving a primary continuous-flow LVAD as BTT is 83% and 75%, respectively, while 12 month actuarial survival for DT patients is 74%. Outcome data on patients supported by continuous-flow MCS past 2 years are limited.

The combination of the increasing number of patients reaching the end stages of HF, the stable but inadequate number of available donor organs, and the continued improvements in MCS technology predicts that an increasing number of patients will be living longer on these devices. The challenges faced by patients and their caregivers in managing chronic illness on MCS are poorly characterized. While quality of life scores, NYHA functional class, and distance walked in six minutes are improved following LVAD implant,²⁻³ little is known about the long-term psychosocial impact of MCS on patients and their families. Although several comprehensive reviews have been written on the optimal relationship between palliative care and patients with heart failure,⁴⁻⁷ there is a paucity of literature on the value of palliative care services working in collaboration with the MCS team. The goals of this manuscript are to: 1) clarify how palliative care may assist the MCS team caring for patients and their families; 2) review the impact of palliative care on outcomes among patients with other chronic diseases similar to heart failure; 3) review key points in the

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chronology of illness of MCS patients when palliative care might be beneficial; and 4) discuss communication techniques to help MCS patients and their families make decisions at key points over the course of their illness.

What is Palliative Care?

Palliative care is interdisciplinary care focused on the relief of suffering and improving the quality of life for patients with advanced disease and their families.⁸ It is offered *simultaneously* with other medical treatments. Palliative care teams consist of physicians, nurses, social workers, chaplains, and other clinicians (e.g. psychologists, massage therapists) who work together to integrate treatment of medical illness with psychological, emotional, and spiritual support in order to provide “whole person” care.⁹⁻¹⁰ Palliative care is not synonymous with hospice and should be offered to all patients being considered for MCS as early as possible. Eligibility for non-hospice palliative care is based on patients’ needs, and is independent of prognosis. In contrast, hospice is an insurance benefit providing palliative care specifically limited to the care of dying patients who must have a prognosis of under 6 months and agree to forego insurance coverage for treatments aimed at curing their primary illness.¹⁰

The core elements of care delivered by palliative medicine clinicians include: expert symptom assessment and management, particularly pain, anxiety, depression, and dyspnea; helping patients and caregivers understand their illness, treatment options, and prognosis; and assisting with medical decision-making about achievable goals of care with patients and families.^{8, 10} By partnering with the MCS team, palliative care can help meet the complex needs of patients and their families. Palliative care augments and supports the work of the MCS team, with the two teams working together to provide comprehensive, synergistic care. Current consensus panels and guidelines recommend the integration of palliative care in the treatment of patients with end-stage heart failure.⁴⁻⁵ All MCS programs accredited by the Center for Medicare and Medicaid Services and The Joint Commission are located at hospitals that already have palliative care programs (authors’ analysis), although the degree of integration of MCS and palliative care is variable. Table 1 outlines opportunities for integrating palliative care into the MCS team and identifies how such integration addresses Joint Commission requirements for MCS destination therapy program certification.¹¹

Palliative Care Improves Outcomes for Patients with Serious Illness

To date, there are no intervention studies of palliative care outcomes in HF or MCS populations¹²⁻¹³ but studies of integration of palliative care into the care of patients with serious and complex illnesses (such as cancer) suggest that co-provision of palliative care improves outcomes. Palliative care has been associated with improved symptom control, reduced re-hospitalization, increased patient/caregiver satisfaction, and decreased costs in patients with cancer, heart failure, and critical illness.¹⁴⁻¹⁷ A recent study of simultaneous palliative care consultation at the time of diagnosis of patients with advanced lung cancer found that while patients in both groups received life-sustaining cancer-specific treatments, those who received simultaneous co-management from palliative care consultants had markedly better quality of life, better psychological health, and significantly *longer* survival as compared to those patients who did not. Similarly, Medicare beneficiaries with heart failure who received hospice demonstrated an *increased* mean survival of 81 days as compared to those heart failure patients who did not receive hospice.¹⁸

Palliative care interventions have also been shown to improve patient and caregiver psychological outcomes, communication, and satisfaction with care.^{17, 19-20} An observational study of cancer patients demonstrated that palliative care recipients were more likely to have their treatment wishes followed and that bereaved family members had

markedly lower rates of post-traumatic stress disorder and prolonged grief disorder as compared to family members whose loved ones did not receive palliative care.²⁰ Christakis et al demonstrated that wives of husbands who had received hospice services prior to death had significantly lower 18 month mortality rates than bereaved wives of men not receiving hospice (4.9% vs. 5.4%).²¹

One of the chief concerns of both patients living with serious illness and their families is not having enough time to talk with their physician.¹⁹ When patients with serious illness are asked their needs and desires from the healthcare system, they state that their priorities are: adequate control of pain and other symptom; avoiding prolongation of the dying process; achieving a sense of control; relieving burdens on their family; and strengthening their relationships with loved ones.^{22,23} Despite physician fears that honest discussions about prognosis will cause patients to lose hope, studies demonstrate that patients with HF and their caregivers want realistic information about prognosis and what to expect, and there is evidence that providing such data is not harmful.²⁴⁻²⁶ In view of this accumulating evidence of benefit in quality and quantity of life from palliative care, it is reasonable and appropriate to consider integrating palliative care into the management of patients on MCS to both treat symptoms, improve communication, and assure needed support in the community.⁴

Role of Palliative Care at Key Points in the Clinical Care of MCS Patients

The palliative care principle of establishing clear and informed goals for care applies across the trajectory of illness for MCS patients and their families. There are four key time points when integration of palliative care services might be considered: 1) during the time of evaluation and preparation for MCS implant; 2) after decisions are made about device implantation, either to assist with delivery of comprehensive care for patients/caregivers who proceed with MCS or assisting with transitions in care for those patients who forego MCS; 3) when the patient with MCS experiences a major complication or is hospitalized for serious illness; 4) and as MCS patients near the end of their lives. At each of these junctures, palliative care experts may assist the MCS team by facilitating patient and caregiver understanding of the purpose and limitations of the device, determining whether the device is consistent with goals of care, and improving the patient's physical, emotional, and psychological health.

When the device is first considered, palliative care experts may be called in to assist the MCS team with assuring understanding of the purpose and limitations of the device, to determine that device placement is consistent with goals for care, and to assess emotional and psychological preparation for life changes associated with MCS. For patients who do not wish to consider MCS, palliative care services can work with the primary team on the transition to appropriate supportive care services and referral to hospice when appropriate. Regardless of the patient and family's decision about whether to proceed with MCS, the expertise of the palliative care team augments the MCS team with management of patients' physical (e.g. pain, fatigue, insomnia, dyspnea), social (family distress and burden) and psychological (anxiety and depression) symptoms. (For a complete discussion of the role of palliative care in treating physical and psychological symptoms in patients with advanced heart failure, see ^{4,7}.)

Advance care planning should be provided for all patients undergoing evaluation for MCS. Recent studies demonstrate that advance care plans and health care proxies are associated with substantially higher likelihood of receiving care concordant with patient wishes and goals.²⁷⁻²⁹ For patients receiving devices as either BTT or DT, having a surrogate decision maker (i.e. healthcare proxy) is essential because of the loss of decisional capacity during the peri-operative period or in the setting of a complication such as a disabling stroke. A recent single center, retrospective study demonstrated that 47% of patients receiving MCS

had advanced directives, but none of these documents specifically addressed the device or the circumstances under which discontinuation of MCS was desired.³⁰ This provides further evidence that simply appointing and signing the proxy form is not sufficient. Along with the assignment of a surrogate decision maker, the clinician should also assure that the person named is aware of the patient's desires for care should the patient become unable to make a decision; this is especially true under circumstances of permanent loss of ability to communicate or interact with loved ones. (For a list of websites, including those allowing on-line completion and state-by-state regulations relating to proxies/surrogate decision-making, see the resources section at www.getpalliativecare.org.)

For those patients who choose to proceed with MCS, palliative care can continue to work with the MCS team to offer support to the patient and family, depending on their individual needs. Patients and caregivers must learn how to manage the device, including tasks such as changing from the power base unit to batteries, troubleshooting alarms, changing batteries, and performing driveline dressing changes using a sterile technique. In addition, patients must diligently maintain the driveline site and avoid trauma to the driveline in order to prevent infection. The way a patient dresses may change in order to accommodate or hide the device, and little is known about changes in patients' self-image and sexuality on MCS, particularly in younger patients. Though the MCS team is primarily responsible for addressing these issues, palliative care can provide additional support longitudinally, particularly for patients having difficulty adjusting to life following device implant. Finally, patients and families awaiting heart transplant describe impatience, as wait times are dependent upon blood group and local availability of organs – factors completely outside of their control. None of these aspects of care have been studied in MCS patients, yet all are potential sources of increased anxiety, a sense of vulnerability, and reminders of potential mortality. While MCS teams are experts at educating patients and assessing their psychological needs, the assistance of the palliative care team in working with patients and their families during the immediate post-MCS transition period may be of additional benefit.

After periods of hospitalization or at the time of a serious complication, the role of MCS may need to be reassessed. While current devices have overall lower rates of adverse events, complications remain significant. Disabling stroke is one of the most feared complications, and recent data from the HeartMate II Investigators demonstrated that patients with continuous-flow MCS devices used as bridge to transplant have an incidence of stroke between 3-12%;³¹ recent data from INTERMACS demonstrate that stroke may be the cause of death up to 14% of the time.³² Events such as these may make bridge to transplant patients no longer eligible for transplant, or may change the benefit-burden analysis for patients with the devices as destination therapy. These types of complications necessitate renewed conversations about achievable goals for care and whether MCS remains valuable in the pursuit of them. Palliative care team members can assist with treatment of symptoms that occur as a result of adverse events, help patients and families reassess goals of care, and work alongside the MCS team to provide emotional and psychological support during and after these potentially life-threatening events.

Finally, palliative care is appropriate at the end of a patient's life regardless of whether the cause of death is related to MCS or to progression of other co-morbid conditions. Reassessment of MCS should be considered during the dying process: does it continue to allow a life of meaning, quality and value for the patient even at end of life, or is it merely prolonging a difficult dying process? The palliative care team may be called to assure that patients' symptoms are controlled when MCS is discontinued as well as to provide additional assistance in supporting the patient's family. In cases where the patient has been referred to hospice, the hospice benefit provides continued grief and bereavement counseling for the family for up to a year after the patient's death.

Improving Communication and Decision Making in MCS Patients

Whether due to time pressures or discomfort with the task, conversations about goals of care are often avoided by physicians despite the high priority given to them by patients and their families.¹⁹ Clinician communication skills can be taught, and better communication improves quality and quantity of life for patients and their caregivers.^{20, 33-35} However, most trainees and practicing physicians have not received training in communication skills.³⁴⁻³⁵ Palliative care colleagues may enhance the multidisciplinary MCS team by providing expertise under circumstances requiring skill with complex conversations about goals of care, family distress, and assuring adequate support for the patient's care needs outside of the institutional environment.

Strengthening communication between health professionals, patients, and their caregivers is a core component of palliative care services. Data from other fields demonstrate mismatches between what clinicians believe they have told patients and what patients actually comprehend.³⁶⁻³⁷ Timely and effective communication is essential to assuring that patients and caregivers understand the nature of MCS, its benefits, and its potential burdens.³⁸

MCS patients and their caregivers will not be able to anticipate all of the possible outcomes and potential complications, nor can they be expected to make complex medical decisions without considerable and detailed guidance from the clinical team. Conversations relating to implantation or management of MCS need to be patient-centered and focus on goals of care instead of driven by the intervention bias characteristic of modern medicine which promotes providing all therapies without first having a discussion about the patient's goals and how the treatment may align with those desires. These discussions should clarify patient and caregiver understanding of HF and its likely progressive course, discuss available treatment options and their corresponding risks and benefits, and explore how the patient balances the desire for quantity of life with quality of life. For patients and family caregivers understandably focused on MCS as the key to survival or to stabilization while awaiting transplant, the progression of comorbid illness despite MCS may be confusing, necessitating repeated discussions of the multiple contributors to well being and the possibility of changing goals for care as disease progresses and function and quality of life decline. This may be especially true for BTT patients, who may experience worsening health due to progression of illness despite MCS, or may develop a complication thereby rendering them ineligible for transplant.

Discussions about Goals of Care

Discussions about matching treatments to patient goals are complex, time consuming, and often emotionally challenging for clinicians.³⁹ Unfortunately under the current payment system, the time spent on these discussions is not appropriately compensated, and it may be difficult for the busy clinician to integrate these conversations into routine practice. Recent legislative efforts aimed at assuring appropriate payment mechanisms for these conversations and assuring they become an element of routine care were met with substantial resistance from major political organizations.⁴⁰ Palliative care consultation may be effective in assisting the MCS team with conversations that may be particularly complex or time intensive. In addition this manuscript provides a conversation guide to help make these discussions easier and more successful. Table 2 outlines a step-by-step plan for communicating with patients and caregivers and provides sample language that can be used at each step in the process. It is not meant, however, to be a comprehensive guide on communication with MCS patients and their families (see for example reference ⁴⁴). The core elements of each step are summarized below:

- Step 1: Elicit what patients and caregivers understand about HF. Data have shown widely divergent patient and physician perceptions on whether a conversation

about diagnosis, disease course, prognosis, and life expectancy have actually occurred.³⁶⁻³⁷

- Step 2: Determine what patient and caregiver understand about MCS, the associated risks and benefits, and goals of device therapy. Conversations with patients being considered for BTT should include a discussion of the likelihood of receiving a transplant, timing of being listed, and probable duration of MCS. Those receiving a device as DT should understand that MCS may be discontinued if no longer concordant with their goals of care.
- Step 3: Determine how much and what information the patient and caregivers want to know. Most, but not all, patients with advanced HF want to know the severity of their disease and what to expect in their future.²⁴
- Step 4: Identify and address misconceptions about the illness and answer specific questions in order to provide for informed decision-making.
- Step 5: Help patients articulate their overall goals of care to better understand how they balance desired outcomes with conditions in which continuation of MCS may be worse than death.
- Step 6: Work with the patient and family to incorporate goals into a treatment plan aligned with the articulated values and desired, medically achievable outcomes.
- Step 7: Ask the patient and family to summarize the conversation (“talk back”) to assure accuracy of patient and caregiver understanding
- Step 8: Create a concrete and legibly written plan for the patient and family to take home and review; arrange for follow-up discussions to address additional questions or concerns as needed.

For MCS patients, these conversations are not one-time events but occur repeatedly over time, as studies in patients with advanced HF have demonstrated that their preferences for life-sustaining treatments may change over time.^{45,46} This may be particularly true of MCS patients, as they may not be able to fully anticipate the reality of living with the device or how it will affect their symptoms until they have experienced it for themselves. Open and ongoing dialogue will help patients and caregivers adapt and cope with changes in health and functional status along the way. Table 3 expands upon the communication protocol by identifying junctures or milestones at which additional conversations might improve care of the patient and family.

The Role of Self-Care for the MCS Team

The care of patients with serious and complex illness can be difficult for clinicians themselves. Unrecognized and unexplored physician distress has a detrimental effect on patient care by reducing physician satisfaction and increasing the risk of clinician burnout.³⁹ Collaboration with the palliative care team can help MCS teams acknowledge their experiences of caring for seriously ill patients and their families. While there have been no studies examining the role of palliative care in preventing clinician fatigue in cardiologists or cardiothoracic surgeons, multidisciplinary team approaches have been shown to decrease burnout and improve satisfaction for clinicians caring for patients with life-threatening illness.⁴⁸⁻⁴⁹

Conclusion

For patients with end-stage HF, MCS is associated with prolonged survival and improved quality of life, whether as bridge-to-transplant or as destination therapy. MCS patients and their caregivers are faced with complex decision-making, may experience ongoing

symptoms or develop new complications, and can have unmet physical and psychological needs unique to device therapy. Based on the beneficial outcomes of palliative care co-management in other cohorts of seriously ill patients, early and continued integration of palliative care into the management of MCS patients will likely lead to improvements in patient and caregiver quality of life. This approach to care involves palliative care specialists working alongside cardiologists and cardiac surgeons to provide comprehensive care to meet the full range of patient and caregiver needs. Research is still needed, however, to better understand the needs of MCS patients and their family caregivers, and to evaluate the impact of palliative care on MCS patient and caregiver outcomes. Our embrace of advanced medical technology must be accompanied by the recognition of the unmet needs of our patients and their caregivers. Partnership between the MCS and palliative care teams is an obvious and feasible approach to assure the most comprehensive care for these patients and their families.

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Table 1

Selected Joint Commission Requirements for MCS Programs and How Palliative Care Meets Standards. The table demonstrates how palliative care can help meet selected elements of the Standards for Joint Commission MCS certification. The “Standards” and “Elements of Performance” are taken verbatim (including numbering) from reference ¹¹. Portions reprinted with permission from The Joint Commission Standards for Disease Specific Care Certification for Ventricular Assist Devices as Destination Therapy.

Standard	Element of Performance	Ways Palliative Care Helps to Meet Standard
DOMAIN: DELIVERING OR FACILITATING CLINICAL CARE		
DF.3 The standardized process is tailored to meet the participant's needs.	7. The plan of care is updated to meet the participant's ongoing needs.	Palliative care team meets with patients / caregivers before implantation to clarify goals of care and patient/family needs. Conversations regarding patient and caregiver needs and concerns continue post-implant and at each follow-up visit.
DF.4 Concurrently occurring conditions are managed, or the information necessary for their management is communicated to the appropriate practitioner(s).	1. Care is coordinated for participants with multiple diseases and/or whom multiple disease-specific care programs manage.	Palliative care teams provide care coordination across settings and while the patient is at home, identifying and preventing crises before they develop. This allows the MCS team to focus on management of the HF and the patient's device. Palliative care clinicians also help communicate and coordinate care with other specialists.
DOMAIN: SUPPORTING SELF MANAGEMENT		
SE.1 The program involves participants in making decisions about managing their disease or condition.	1 Participants are involved in decisions about their clinical care. <i>Signed consent reflects the patient's awareness of preoperative, intraoperative, and postoperative plans and expectations.</i>	Palliative care meets, in conjunction with MCS team, with patient/caregiver before implantation to not only assure understanding of device and its role in patient's health but also that it is consistent with informed patient goals for care. They also assure that patient/caregiver understand nature of future and ongoing care needs and continued requirement for caregiver support for the remainder of the time the patient is on MCS. Palliative care works to assure that patients/caregivers understand implications of non-compliance while providing support and referral to community support mechanisms (e.g. social work, chaplaincy) that will help them follow through with care plan.
	2 Participants and practitioners mutually agree upon goals.	
	3 Participants are informed of their responsibilities to provide information to facilitate treatment and cooperate with health care practitioners.	
	4 Participants are informed about potential consequences of not complying with a recommended treatment.	
	5 The patient's readiness, willingness, and ability to provide or support self management activities are assessed.	
	6 As appropriate, the family's readiness, willingness and ability to provide or support self-management activities are assessed.	
SE.2 The program addresses lifestyle changes that support self-management regimens	1 Lifestyle changes that support self-management regimens are promoted as necessary.	Palliative care assists both patient and caregivers with lifestyle changes necessary after MCS. This includes support for physical, psychological, spiritual and practical care needs. Palliative care teams assist with complex discharge planning and assuring timely and consistent access to home and community support services for patients and their caregivers.
	2 Support structures (family and community) are involved as necessary.	
	3 Barriers to change are evaluated as necessary.	
	4 The participant's response to making the recommended lifestyle changes is assessed and documented.	

Standard	Element of Performance	Ways Palliative Care Helps to Meet Standard
	5 The effectiveness of efforts to help the participant in making lifestyle changes is assessed.	
SE.3 The program addresses participants' education needs.	3 The participant's comprehension is assessed initially and on an ongoing basis.	Palliative care assures patient and caregiver understanding of the need for MCS and continuing care for patient and the device after implantation. Continued follow up with palliative care after hospital discharge assures that patient/caregiver understanding and needs are assessed and supported on an ongoing basis.
	4 Education needs related to lifestyle changes that support self-management	
	6 Education needs related to information about the participant's illnesses and treatments are addressed.	
DOMAIN: PROGRAM MANAGEMENT		
PR.6. The program's leaders and, as appropriate, participants, practitioners, and community leaders collaborate to design, implement, and evaluate services.	1 All relevant individuals and/or disciplines participate in designing the program.	Palliative care specialists provide expertise in patient and caregiver centered metrics including symptoms, quality of life, adequacy of community supports and other key outcomes.
	2 All relevant individuals and/or disciplines participate in implementing the program.	
	3 All relevant individuals and/or disciplines participate in evaluating the program.	

Table 2

Techniques to Improve Communication with MCS Patients and their Caregivers. Examples provided focus on time of device implantation, but the steps apply to any conversation about prognosis or therapeutic options. Adapted from references.⁴¹⁻⁴³ Portions adapted with permission from Wiegand DL, Kalowes PG. Withdrawal of cardiac medications and devices. *AACN Adv Crit Care*. 2007;18:415-425. Portions also adapted from *Arch Intern Med*. 2008;168:1733-1739, Copyright © 2008. American Medical Association. All rights reserved.

Communication Step	Sample Phrases to Begin each Step
1. Determine what patient/caregiver know about the illness	"Tell me what you understand about your heart disease - how have things been going of late? What have the other doctors told you about what to expect and your treatment options?"
2. Specifically ask what patient / caregiver know about MCS	"Tell me what you understand about Mechanical Circulatory Support systems. What is its purpose?"
3. Determine what patient / caregiver wants to know about illness	"Some of my patients like to know many details, and others prefer a more general outline. What kind of person are you? How much information do you want about your disease and the role of MCS in treating it?"
4. Clarify misconceptions about illness or treatment options	"I think you have a pretty good understanding of what is happening with your heart, but there are a few points I'd like to clear up."
5. Determine overall goals of care	"Help me to understand what is important to you in terms of your overall care. Some patients tell me that the most important goal is to be able to continue interacting with friends and family in a meaningful way. Others tell me they want to live as long as possible, regardless of quality of life. Some patients are very worried that they will be in pain or have other uncontrolled symptoms. Do you have any concerns like the ones I've mentioned?"
6. Tailor treatments to goals	"Given what you've told me, I think consideration of MCS does/does not make sense for you."*
7. Ask patient/caregiver to summarize conversation to assure understanding	"We've covered a lot of information. Please tell me in your own words what you understand the plan to be. We can then discuss any questions you might have."
8. Make plan for next steps.	"I will speak with the other members of the MCS team to make sure we are all in agreement about MCS and that they are aware of your goals of care. Members of the team will come to talk with you about this again."

* Phrase chosen here depends on whether use of MCS is in line with the patient's goals of care. If a patient stated that they did not want any further procedures or life-sustaining treatments, then one would proceed with the language explaining that MCS is not in line with the patient's stated goals.

Table 3

Specific Points to Cover at Key Times for Patients with MCS and Sample Communication Techniques for each Time Point. The table provides examples of the kinds of language that clinicians might use when having discussions with patients and caregivers. Adapted from references ^{41, 43, 47}. Portions adapted with permission from Wiegand DL, Kalowes PG. Withdrawal of cardiac medications and devices. *AACN Adv Crit Care*. 2007;18:415-425. Portions also adapted from *Arch Intern Med*. 2008;168:1733-1739, Copyright © 2008. American Medical Association. All rights reserved.

Time Point	Points to Cover in Conversations	Sample Phrases to Use
Patient Being Considered for Mechanical Circulatory Support	Assure patient understands other options, which include continued medical treatments (without implantation) ± hospice	"We want to make sure you understand all of your options. I'm going to outline three possible paths: use of MCS implantation, continued life-sustaining treatments without MCS, and a plan focusing solely on comfort."
	Informed consent includes not only risks of procedure but possible complications of bleeding, infection, device failure, and stroke	"There are risks of putting the device in, but we should also talk about other complications that can happen after the device is implanted. Some of these relate to the device itself, and others relate to the medications we have to give you because of the device."
	Discuss changes that may be necessary in terms of lifestyle and need for assistance from caregivers	"Let's talk some about what it will be like when you're home. Many patients and caregivers have questions about what it will be like in terms of day-to-day activities and what kinds of help they will need from their family and other kinds of caregivers."
	Encourage advance care planning conversations, and in particular have patient appoint health care proxy (durable power of attorney for healthcare)	"Let's talk about who you would want to make decisions for you if at some point in your illness you become unable to make decisions for yourself. Have you had conversations about what kind of care you would want if you were permanently unable to recognize and interact with your loved ones?"
	Explain that device can be disabled at some point in future if patients so desires	"Sometimes patients want to know if they can stop MCS if at some point they feel like they've had enough. I want to assure you that you can. Let's talk some about that now, but what is most important is your just knowing that this is a future option."
	Reassure patient of continued involvement by both MCS team and palliative care team	"We will remain available to assure that your symptoms are well controlled and help support you and your family."
Follow-up appointments after device implanted	Assess physical, psychological, and spiritual needs. Refer to appropriate services when needed (e.g. social work, chaplain)	"I like to check in with patients at each visit to see how they are doing physically, emotionally, and spiritually. Tell me how you are doing."
	Assess caregiver coping to patient's illness and MCS	"MCS has effects on both patients and their caregivers. Tell me how your loved ones are doing."
Periods of Infection, Neurologic Events, or Device Failure	Same points as "follow-up appointments" above PLUS:	
	Provide options for treatment which include both life-sustaining treatments as well as comfort oriented treatment only	"I think that we can help you get over this problem, but that doesn't mean that we have to necessarily continue every treatment that we are now doing. Would you like to talk more about other options?"
	Assess if goals of care have changed and assess if patient continues to benefit from MCS	"Let's take a moment to reassess your overall goals for your healthcare. What are your current thoughts about the pros and cons of the MCS system?"
Determination that Bridge to Transplant Patients are No Longer a Candidate for Cardiac Transplant	Explain to patient and caregiver why they are no longer a candidate for transplantation	"You have been under evaluation for heart transplantation. After speaking with your other physicians, we unfortunately do not have good news today. The cardiac transplant team has determined that you are not eligible for a transplant." <Allow for silence.> "We'd like to review with you how the transplant team came to that decision and what it means for future treatment. Is it okay if I go ahead?"
	Acknowledge that this determination may have a significant psychological or emotional impact and allow for this to be expressed	"I know that this may be upsetting to hear. What are you feeling?"

Time Point	Points to Cover in Conversations	Sample Phrases to Use
	Determine how this does or does not change patient's decision making with regards to MCS	"How does the lack of transplantation as an option influence your thinking about MCS in your overall healthcare?"
	Assure continued emotional and psychological support and availability to discuss these needs on future visits	"This is a lot to discuss in one visit. I want to assure you that the entire team is here to support you and available should you want to discuss this further. I'll be sure to ask about how you're doing at our next visit as well."
End of Life / Disabling MCS *	Assess goals of care and determine whether burdens of device now outweigh benefits	"The MCS system has served you well though it sounds like things may have been more difficult recently. Tell me your thoughts about how things have been going recently. Is MCS still helping you to have the kind of life you want? You may want to take some time to think about this - when you are ready let's talk about your feelings about continuing MCS."
	Assess physical, psychological, and spiritual needs of patients and refer to appropriate services	"I know this can be a difficult time. Let's talk about your physical, emotional, and spiritual needs at this point. If there are things I can't help you with then perhaps we can refer you to someone who can."
	Reassure patient of continued involvement by palliative care	"The palliative care team and the MCS team will remain available to assure that your symptoms are well controlled and help support you and your family. Your cardiologist and cardiac surgeons are still in charge of your care, but palliative care will continue to work along side them to help you in any way we can."
	Assure patient and caregiver understand that disabling MCS will most likely be followed by rapid decline and death	"I know this is difficult to talk about, but I need to make sure you understand what stopping the MCS means. We will make sure you are comfortable at all times. After you have said your good-byes, we will give you medications to help you relax and sleep. We will then turn off the MCS and you will die soon thereafter."
	Explain to patient, caregiver, and staff medications to be used and indication	"I'm going to give you some medications to make sure that you don't feel short of breath or anxious. It is important that you understand that the purpose of the medication is only to make sure you are comfortable after MCS is turned off."
	Determine if patient / caregiver / family have said all they need to say to each other	"Are there any important tasks that are still undone? Have you said everything to your family and friends that you feel you need to? There are five things that many families may consider saying to each other at this stage of life: I forgive you, forgive me, thank you, I love you, and goodbye. I can write these things down and you can think through them later. Do you have questions about other important things to consider at this stage of your life?" [See reference 47]

* At this stage of advanced disease, not all patients may be able to communicate with the clinician. Conversations should occur with the patient whenever possible (assuming he/she wants to be involved in them). The table is written as if the patient is able to communicate, though if he/she is unable, the conversation could occur with the caregiver or surrogate decision maker.