Comprehensive Care for Mechanical Circulatory Support
A New Frontier for Synergy With Palliative Care

Nathan E. Goldstein, MD; Christopher W. May, MD; Diane E. Meier, MD

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, 2680 adults in the United States received a Food and Drug Administration–approved durable MCS device as treatment for end-stage HF. 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), whereas 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. The 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 comorbidities. Within the INTERMACS [Interagency Registry for Mechanically Assisted Circulatory Support] registry, 87% of BTT patients have been transplanted or are still alive on MCS at 12 months compared with 67% of DT patients. By 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 left ventricular assist device as BTT is 83% and 75%, respectively, whereas 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. Although quality-of-life scores, New York Heart Association functional class, and distance walked in 6 minutes are improved after left ventricular assist device implant, 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 HF, 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 HF; (3) review key points in the 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. It is offered simultaneously with other medical treatments. Palliative care teams consist of physicians, nurses, social workers, chaplains, and other clinicians (eg, psychologists, massage therapists) who work together to integrate treatment of medical illness with psychological, emotional, and spiritual support to provide "whole person" care. Palliative care is not synonymous with hospice and should be offered to all patients being considered for MCS as early as possible. Eligibility for nonhospice palliative care is based on patient 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.
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. By partnering with the MCS team, palliative care can help meet the complex needs of patients and their families. Although several comprehensive reviews have been written on the optimal relationship between palliative care and patients with HF, 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 HF; (3) review key points in the 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.

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families. Palliative care augments and supports the work of the MCS team, with 2 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 HF. 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 DT program certification.

### Palliative Care Improves Outcomes for Patients With Serious Illness

To date, there are no intervention studies of palliative care outcomes in HF or MCS populations, but studies of integration of palliative care into the care of patients with serious and complex illnesses (such as cancer) suggest that coproduction of palliative care improves outcomes. Palliative care has been associated with improved symptom control, reduced rehospitalization, increased patient/caregiver satisfaction, and decreased costs in patients with cancer, HF, and critical illness. A recent study of simultaneous palliative care consultation at the time of diagnosis of patients with advanced lung cancer found that whereas patients in both groups received life-sustaining cancer-specific treatments, those who received simultaneous consultation from palliative care consultants had markedly better quality of life, better psychological health, and significantly longer survival as compared with those patients who did not. Similarly, Medicare beneficiaries with HF who received hospice demonstrated an increased mean survival of 81 days as compared with those HF patients who did not receive hospice. Palliative care interventions have also been shown to improve patient and caregiver psychological outcomes, communication, and satisfaction with care. 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 posttraumatic stress disorder and prolonged grief disorder as compared with family members who did not receive palliative care. 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 (eg, 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 HF, see References 4 and 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. For patients receiving devices as either BTT or DT, having a surrogate decision maker (ie, health care proxy) is essential because of the loss of decisional capacity during the perioperative 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
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<th>Ways Palliative Care Helps to Meet Standard</th>
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<td><strong>Domain: Delivering or Facilitating Clinical Care</strong></td>
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<td>DF.3</td>
<td>The plan of care is updated to meet the participant’s ongoing needs.</td>
<td>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 after implant and at each follow-up visit.</td>
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<td>DF.4</td>
<td>Concurrently occurring conditions are managed, or the information necessary for their management is communicated to the appropriate practitioner(s).</td>
<td>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.</td>
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<td><strong>Domain: Supporting Self-Management</strong></td>
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<td>SE.1</td>
<td>The program involves participants in making decisions about managing their disease or condition.</td>
<td>Palliative care meets, in conjunction with MCS team, with patient/caregiver before implantation to not only ensure understanding of device and its role in patient’s health but also that it is consistent with informed patient goals for care. They also ensure 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 ensure that patients/caregivers understand implications of non-compliance while providing support and referral to community support mechanisms (eg, social work, chaplaincy) that will help them follow through with care plan.</td>
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<td>SE.2</td>
<td>The program addresses lifestyle changes that support self-management regimens.</td>
<td>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.</td>
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<td>SE.3</td>
<td>The program addresses participants' education needs.</td>
<td>Palliative care ensures 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 ensures that patient/caregiver understanding and needs are assessed and supported on an ongoing basis.</td>
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<td><strong>Domain: Program Management</strong></td>
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<td>PR.6</td>
<td>The program’s leaders and, as appropriate, participants, practitioners, and community leaders collaborate to design, implement, and evaluate services.</td>
<td>Palliative care specialists provide expertise in patient and caregiver centered metrics including symptoms, quality of life, adequacy of community supports and other key outcomes.</td>
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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.
desired. 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 ensure 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 online completion and state-by-state regulations relating to proxies/surrogate decision-making, see the resources section at www.getpalliativevecare.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 to prevent infection. The way a patient dresses may change 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 after device implant. Finally, patients and families awaiting heart transplant describe impatience, as wait times are dependent on 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. Although 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. Although 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 BTT have an incidence of stroke between 3% to 12%; recent data from INTERMACS demonstrate that stroke may be the cause of death up to 14% of the time. Events such as these may make BTT patients no longer eligible for transplant or may change the benefit-risk analysis for patients with the devices as DT. 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 comorbid 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 ensure that patients’ symptoms are controlled when MCS is discontinued as well as to provide additional assistance in supporting the patient’s family. In cases in which the patient has been referred to hospice, the hospice benefit provides continued grief and bereavement counseling for the family for up to 1 year after the patient’s death.

**Improving Communication and Decision-Making in MCS Patients**

Whether because of 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. Clinician communication skills can be taught, and better communication improves quality and quantity of life for patients and their caregivers. However, most trainees and practicing physicians have not received training in communication skills. 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 ensuring 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. Timely and effective communication is essential to ensuring that patients and caregivers understand the nature of MCS, its benefits, and its potential burdens.

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 must 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...
Table 2. Techniques to Improve Communication With MCS Patients and Their Caregivers

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<th>Communication Step</th>
<th>Sample Phrases to Begin Each Step</th>
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<tr>
<td>(1) Determine what patient/caregiver know about the illness.</td>
<td>“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?”</td>
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<td>(2) Specifically ask what patient/caregiver know about MCS.</td>
<td>“Tell me what you understand about MCS systems. What is its purpose?”</td>
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<td>(3) Determine what patient/caregiver wants to know about illness.</td>
<td>“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?”</td>
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<td>(4) Clarify misconceptions about illness or treatment options.</td>
<td>“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.”</td>
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<td>(5) Determine overall goals of care.</td>
<td>“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?”</td>
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<td>(6) Tailor treatments to goals.</td>
<td>“Given what you’ve told me, I think consideration of MCS does/does not make sense for you.”*</td>
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<td>(7) Ask patient/caregiver to summarize conversation to ensure understanding.</td>
<td>“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.”</td>
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<td>(8) Make plan for next steps.</td>
<td>“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.”</td>
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Examples provided focus on time of device implantation, but the steps apply to any conversation about prognosis or therapeutic options. Adapted from References 41 through 43,41–43 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.

*Phrase chosen here depends on whether use of MCS is in line with the patient’s goals of care. If a patient stated that he or she 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.

Discussions About Goals of Care

Discussions about matching treatments to patient goals are complex, time-consuming, and often emotionally challenging for clinicians.59 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 ensuring appropriate payment mechanisms for these conversations and ensuring 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 report 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).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.44
- Step 4: Identify and address misconceptions about the illness and answer specific questions 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 ensure 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...
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<th>Points to Cover in Conversations</th>
<th>Sample Phrases to Use</th>
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<td>Patient being considered for MCS</td>
<td>Ensure that patient understands other options, which include continued medical treatments (without implantation) with/without hospice. Informed consent includes not only risks of procedure but possible complications of bleeding, infection, device failure, and stroke. Discuss changes that may be necessary in terms of lifestyle and need for assistance from caregivers. Encourage advance care planning conversations, and in particular have patient appoint health care proxy (durable power of attorney for health care). Explain that device can be disabled at some point in future if patients so desires. Reassure patient of continued involvement by both MCS team and palliative care team.</td>
<td>“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.” “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.” “Let’s talk 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.” “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?” 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 about that now, but what is most important is your just knowing that this is a future option.” “We will remain available to ensure that your symptoms are well controlled and help support you and your family.” “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.” “MCS has effects on both patients and their caregivers. Tell me how your loved ones are doing.” “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?” “Let’s take a moment to reassess your overall goals for your health care. What are your current thoughts about the pros and cons of the MCS system?” “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?” “I know that this may be upsetting to hear. What are you feeling?” “How does the lack of transplantation as an option influence your thinking about MCS in your overall health care?” “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.”</td>
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<tr>
<td>Follow-up appointments after device implanted</td>
<td>Assess physical, psychological, and spiritual needs. Refer to appropriate services when needed (e.g., social worker, chaplain). Assess caregiver coping to patient’s illness and MCS. Provide options for treatment, which include both life-sustaining treatments as well as comfort-oriented treatment only. Assess if goals of care have changed and assess if patient continues to benefit from MCS.</td>
<td>“We will remain available to ensure that your symptoms are well controlled and help support you and your family.” “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.” “MCS has effects on both patients and their caregivers. Tell me how your loved ones are doing.” “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?” “Let’s take a moment to reassess your overall goals for your health care. What are your current thoughts about the pros and cons of the MCS system?” “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?” “I know that this may be upsetting to hear. What are you feeling?” “How does the lack of transplantation as an option influence your thinking about MCS in your overall health care?” “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.”</td>
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<td>Periods of infection, neurologic events, or device failure</td>
<td>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. Assess if goals of care have changed and assess if patient continues to benefit from MCS.</td>
<td>“We will remain available to ensure that your symptoms are well controlled and help support you and your family.” “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.” “MCS has effects on both patients and their caregivers. Tell me how your loved ones are doing.” “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?” “Let’s take a moment to reassess your overall goals for your health care. What are your current thoughts about the pros and cons of the MCS system?” “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?” “I know that this may be upsetting to hear. What are you feeling?” “How does the lack of transplantation as an option influence your thinking about MCS in your overall health care?” “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.”</td>
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<td>Determination that BTT patients are no longer a candidate for cardiac transplant</td>
<td>Explain to patient and caregiver why they are no longer a candidate for transplantation. Acknowledge that this determination may have a significant psychological or emotional impact and allow for this to be expressed. Determine how this does or does not change patient’s decision-making with regard to MCS. Ensure continued emotional and psychological support and availability to discuss these needs on future visits.</td>
<td>“We will remain available to ensure that your symptoms are well controlled and help support you and your family.” “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.” “MCS has effects on both patients and their caregivers. Tell me how your loved ones are doing.” “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?” “Let’s take a moment to reassess your overall goals for your health care. What are your current thoughts about the pros and cons of the MCS system?” “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?” “I know that this may be upsetting to hear. What are you feeling?” “How does the lack of transplantation as an option influence your thinking about MCS in your overall health care?” “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.”</td>
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Table 3. Continued

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<th>Time Point</th>
<th>Points to Cover in Conversations</th>
<th>Sample Phrases to Use</th>
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<tr>
<td>End of life/disabling MCS*</td>
<td>Assess goals of care and determine whether burdens of device now outweigh benefits.</td>
<td>&quot;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.&quot;</td>
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|                                                      | 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 ensure 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."
|                                                      | Ensure that 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 goodbyes, 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 5 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)47

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, and 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.

*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.
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 because 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 on the communication protocol by identifying junctures or milestones at which additional conversations might improve care of the patient and family.

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.49 Collaboration with the palliative care team can help MCS teams acknowledge their experiences of caring for seriously ill patients and their families. Although 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 BTT or as DT. MCS patients and their caregivers are faced with complex decision-making, may have ongoing symptoms or develop new complications, and can have unmet physical and psychological needs unique to device therapy. On the basis of the beneficial outcomes of palliative care management in other cohorts of seriously ill patients, early and continued integration of palliative care into the management of MCS patients probably will 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 ensure the most comprehensive care for these patients and their families.

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Disclosures

None.

References


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