

## MEDICINE AND SOCIETY

### Palliative Care for Patients on Mechanical Circulatory Support

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#### Abstract

Palliative care (PC) teams are primed to support patients with advanced illness, including patients with mechanical circulatory support (MCS), and are increasingly being called upon to help care for these patients.

Detailed guidelines for PC engagement are lacking despite key stakeholders' endorsements of collaboration. PC needs to encompass the decision-making period, the duration of therapy, and end-of-life care. PC teams can assist with symptom management, advance care planning, and communication across the continuum of MCS care. However, the current state of MCS and PC collaboration is variable and can be hindered by staffing challenges and clinician discomfort. To best care for patients who receive advanced cardiopulmonary life-sustaining therapies, meaningful engagement of PC during all phases of MCS is essential.

#### Need for Palliative Care Partnerships

Mechanical circulatory support (MCS) is increasingly being used to support patients with advanced heart failure.<sup>1</sup> In many tertiary hospitals, once foreign devices are now common, including left ventricular assist devices (LVAD), extracorporeal membrane oxygenation (ECMO), and total artificial hearts.<sup>1</sup> Initially developed and used as a bridge to other treatment options such as transplantation, advanced heart failure therapies now support patients with diverse goals of care and for variable periods of time, ranging from hours to years. For patients who ultimately progress to end of life with their device in situ or suffer from complications, issues concerning quality of life, mortality, psychosocial needs, and advance care planning can be complex. Palliative care (PC) teams are well equipped to support patients, families, and MCS teams throughout the continuum of MCS care.

In recent years, PC teams have been increasingly engaged in the care of patients with MCS. Collaboration between PC and MCS teams is supported by the International Society for Heart and Lung Transplantation guidelines for MCS, which include a class IIa recommendation for PC consultation during the evaluation or preimplantation phase for patients considering a destination therapy LVAD (DT-LVAD).<sup>2</sup> The Centers for Medicare and Medicaid Services and the Joint Commission further require that a PC specialist be a part of the core multidisciplinary MCS team.<sup>3</sup> Nonetheless, detailed guidelines and

guidance for the logistics of engagement are lacking despite these endorsements. The MCS-PC [partnership](#) could be further complicated by staffing challenges, variable PC clinician familiarity with MCS, and patients', clinicians', and hospital systems' misconceptions about the role of PC.

As guidelines and best practices emerge, individual patients and clinicians, MCS and PC teams, and administrators must wade through a complex collaboration. The intricacies and unknowns of this alliance beg the question of how the system as a whole should best support this unique patient population. In a landscape of highly variable health care and multiteam systems, PC teams, which are armed with [advanced skills in communication](#), shared decision making, psychosocial support, and symptom management, can serve as key partners in the care of patients with MCS. Here, we consider ways in which PC teams can meet the needs of MCS patients.

### **Decision-Making Support**

While candidate selection for emergent ECMO might be outside the scope of practice for a PC specialist, how to elicit and align the patient's goals, preferences, and values with treatment options during a prolonged ICU stay certainly is not. Common themes arise in the care of patients and families considering MCS, regardless of the device type or intent. Patients might feel there is not a choice when they consider advanced therapies such as an LVAD. This perception is likely multifactorial, related to clinicians framing discussions as "life or death" as well as patients' strong desire to live.<sup>4</sup> Furthermore, refractory shortness of breath, fatigue, or volume overload might steer patients towards advanced therapy options with any chance of improving their disease state and symptom burden. These factors underscore that patients require time for deliberation as well as solicitation of their values and goals during the decision-making period. Caregivers have expressed feeling tension during this time as well, wanting their loved ones to live but also wanting to respect their loved one's wishes.<sup>5</sup> PC can play a key role in the decision-making process by offering an additional perspective on treatment options and assisting with the documentation of specific treatment preferences, such as in a honed and disease-specific advance directive.<sup>6</sup> Given the Centers for Medicare and Medicaid Services and Joint Commission mandate, many heart failure centers consult PC teams during the candidate selection process, and some programs have PC professionals present at their MCS selection meetings and fully engaged in patients' ongoing care.

Patient and clinician engagement in shared decision making is ideal for preference-sensitive decision making. This process should be iterative throughout the continuum of MCS care and can be supported by any team or team member with expertise in shared decision making. MCS and PC teams should collaborate to ensure concordance of the plan of care with the patient's values and preferences when considering LVAD therapy, during LVAD support, and when approaching end of life or potential withdrawal of LVAD support. To facilitate shared decision making preimplantation, a decision aid has been

developed for patients considering DT-LVAD to assist with solicitation of patient preferences.<sup>7</sup> Use of this decision aid increased patient knowledge and the concordance between patient values and patient-reported treatment choice.<sup>7</sup> In other words, patients' decisions about treatment aligned with their values and goals. Involvement of PC specialists early in consideration of LVAD placement is thus optimal to ensure the promotion of shared decision making.

### **Collaborative Care for the Duration of Treatment**

Studies exploring the role of PC in supporting the MCS patient population are lacking; however, there have been several studies in recent years describing PC involvement with patients with heart failure (HF). One PC-HF pilot study showed meaningful impact of PC on patient care as assessed by both HF and PC clinicians, especially for patients in a liminal state, such as those awaiting transplantation.<sup>8</sup> More recently, a randomized trial of 150 patients with advanced HF showed that a multidisciplinary PC intervention improved HF patients' "quality of life, anxiety, depression, and spiritual well-being" compared to usual care.<sup>9</sup> Additional large-scale trials of the effect of PC interventions on patient and caregiver quality-of-life outcomes are now ongoing, and hopefully higher-powered data to support the PC-HF collaboration will be forthcoming.<sup>10,11</sup>

Patients receiving MCS can experience high symptom burdens and have multifaceted advance care planning needs and complex end-of-life considerations that would benefit from ongoing PC-MCS collaboration. Patients with advanced illness often face a constellation of quality-of-life-limiting symptoms. For patients pursuing MCS, common physical symptoms may include dyspnea or pain. While the primary focus of symptom management should be addressing the underlying issues precipitating the symptoms, patients with advanced or refractory illness may require PC interventions directed at the symptom burden itself, such as weighing the risks and benefits of opioids for refractory pain or dyspnea, to promote quality of life. Furthermore, during MCS treatment, PC teams can add intentionally redundant layers of support to ensure that patients', families', and MCS team members' psychosocial needs are being met. This redundancy can be especially important for patients receiving prolonged MCS support or for patients facing complications from therapy when their needs escalate. PC clinicians are trained to assess psychological and social burdens of care in part by asking open-ended questions and soliciting social and emotional histories. Assessing both the physical and the nonphysical burdens of care takes time and skill, which may not be a part of a typical medical encounter with a subspecialty MCS clinician whose focus is appropriately on the detailed management of the patient's disease or device. PC social workers and chaplains can directly support the MCS team by offering their time and expertise in caring for both patients with advanced illness and their families in medical settings where patients' device, condition, or length of stay might render them outliers or otherwise in need of special consideration. The ideal of true interdisciplinary MCS-PC collaboration would likely include participation in daily inpatient rounds and embedment of PC clinicians

within the ambulatory MCS clinic, but likely remains a significant challenge at many institutions due to [resource limitations and challenges](#) in gaining clinician buy-in.

Despite limited data on the efficacy of PC in patients with MCS, thought leaders in the care of patients with LVADs have developed and put forth important tools that advance our collective understanding and ability to care for these patients. Preparedness planning toolkits, graphic representations of the clinical pathways from implantation to death with an LVAD, and patient and caregiver decision aids serve as critical pieces to the puzzle in orchestrating collaborative, quality-of-life-promoting care for this population across the care continuum.<sup>7,12-14</sup> Honed advance care planning, maximal symptom support, and addressing the psychosocial needs of patients and families are relevant to all patients with MCS, and perhaps PC involvement in these areas can inspire the development of tools that serve related but distinct populations.

### **End-of-Life Care**

PC specialists are frequently involved in the process of deactivation of MCS devices. Despite recommendations for early engagement of PC teams in patient selection and preimplantation decision-making support, device deactivation unfortunately might be the first introduction to PC of some patients and families. End-of-life care is more intricate in patients with MCS due to the nature of the devices themselves (eg, power cords, implanted hardware) and the close relationships between patients, caregivers, and clinical teams.<sup>15</sup> Patients and caregivers have described the device deactivation process as confusing, complex, and multifaceted. While the legal and ethical principles involved are similar in deactivation of MCS devices and withdrawal of other life-sustaining treatments,<sup>16</sup> patients, caregivers, and MCS team members might still consider MCS device deactivation to be an act of euthanasia or assisted suicide.<sup>17</sup>

PC specialists can support end-of-life care in various ways. As experts in communication, they can help allay concerns about end-of-life matters. Additionally, PC teams can assist with the transition to hospice care, if indicated, prior to a planned withdrawal of MCS support or following the withdrawal of MCS support if a patient's goal is to die outside the hospital and resources are in place to assist with this transition. Indeed, some patients may live up to 26 hours following device deactivation.<sup>12</sup> Furthermore, PC teams can assist with comfort-oriented care and symptom management for patients approaching end of life, including during planned MCS deactivation. Ideally, however, integration of PC specialists would happen prior to device implantation—and thus prior to consideration of device deactivation—in order to foster trust and PC teams' relationships with patients and caregivers as well as clinical teams.

### **Integrating PC Specialists Into MCS Teams**

The intricacies of care for patients being considered for, receiving, or approaching end of life with advanced circulatory support are substantial. The time and workforce required

to meet these needs is not insignificant. It is estimated that nearly 150 000 to 250 000 patients annually may be eligible for DT-LVAD.<sup>18</sup> The ability of PC teams to help support quality of life, excellent communication, and shared decision making cannot, however, serve as a justification for other clinicians and teams to shy away from patient-centered care and primary palliative medicine. Care models and triage systems should be in place that distinguish the need for subspecialty PC consultations and primary PC, with medical specialties such as cardiology and cardiothoracic surgery delineating basic skills of PC and opportunities for primary PC to be delivered by their members.<sup>19</sup> The decision is not about the appropriateness of PC; the decision is about which patients require subspecialty PC clinician consultation and when. Allen et al have outlined the critical role of shared decision making in the American Heart Association scientific statement on decision making in advanced HF<sup>20</sup>; however, they also recognize there is uneven access to clinicians with adequate expertise in HF and PC. Furthermore, there will be significant challenges in implementing true shared decision making without fundamental changes to how the health care system currently values and incentivizes such a model.<sup>20</sup> Questions concerning what the ideal HF-PC collaboration should look like and the perceived value of such a collaboration remain as we move forward in our understanding of the care needs of MCS patients.

DT-LVAD might be one of the most aggressive forms of palliation that we have in medicine. Device implantation and management in this setting are undeniably technical and intricate but fundamentally without curative intent. Rather, they are undertaken primarily to address quality-of-life burdens in advanced illness.

### **Conclusions**

To best care for patients who receive advanced cardiopulmonary life-sustaining therapies, we must finally transcend the idea of PC teams as end-of-life teams and genuinely promote them as quality-of-life teams tasked with helping support patients, families, teams, and systems across the continuum of care. Patients receiving MCS face innumerable challenges—both anticipated and unplanned—that range from surgical and device complications to caregiver catastrophes and intricate end-of-life considerations during the course of therapy. Accordingly, patients and clinicians are best served when we can support the entirety of patients' medical care and their personhood. Hospital policies can help support MCS-PC collaboration as partnerships develop or deepen but would be unlikely to encourage meaningful collaboration if, for example, a PC clinician is only vaguely familiar with MCS technology or a cardiothoracic surgeon is reluctant to allow PC engagement. To bolster patient-centered MCS care, subspecialty PC must be promoted at all levels; time and the development of trust will hopefully allow for increasingly meaningful ongoing collaborative engagement.

The current state of MCS-PC collaboration remains highly variable and ranges from the consistent use of embedded, highly specialized PC teams to general consultation driven

by engagement of a PC team member. MCS and PC teams practicing in settings where any type of MCS can be utilized should seek to collaborate for the best interest of the patient, caregiver, and health care system. PC teams should seek to gain detailed understanding of MCS support, outcomes, complications, and device-specific continuums of care. MCS teams should seek to augment primary PC skills, practice shared decision making, and work to address unmet psychosocial needs. Without true engagement and collaboration, each side risks misunderstanding the other and missing opportunities to deliver high-quality, high-value, patient-centered care.

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**Citation**

*AMA J Ethics.* 2019;21(5):E435-442.

**DOI**

10.1001/amajethics.2019.435.

**Conflict of Interest Disclosure**

The author(s) had no conflicts of interest to disclose.

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