Editorial

Palliative Care Throughout the Journey of Life
With a Left Ventricular Assist Device

Winifred Teuteberg, MD; Mathew Maurer, MD

There is no good death. It always hurts, both the dying and the left behind. But there is a good enough death.
—Ann Neumann, The Good Death

Advances in mechanical circulatory support (MCS) have resulted in improved quality of life (QOL) and survival for the majority of patients implanted for destination therapy (DT).\(^1\) However, some patients will have persistently limiting heart failure (HF) symptoms and poor QOL.\(^2\) Nearly all patients receiving a left ventricular assist device (LVAD) as DT will eventually die with their device in situ. Palliative care (PC) is considered essential for the management of patients who receive a DT-LVAD. Although the clinical course of patients with MCS for DT has been documented,\(^3,4\) there is a paucity of data describing in detail how patients die. Such data can inform how to structure PC services for these patients.

Is There Room for Improvement in the Care of LVAD Patients and Those Who Care for Them?
In addition to the rich descriptive information about location of death and clinical trajectories presented by Dunlay et al,\(^5\) recent qualitative reports shed light on potential areas of improvement for DT-LVAD patients including caregiver experience and patient–provider communication. One study suggests that caregivers experienced a significant amount of confusion about what happened at the EOL for their loved one who died with an LVAD.\(^9\) Another, about the decision to undergo LVAD implantation, demonstrates that there is room for improvement in the process of choosing clinical interventions. Patients reported often being presented with the decision to undergo implantation at a time when they felt that they had no other choice.\(^10\) They also found that expectations for preimplantation QOL were frequently not met postimplantation. Collectively, such data suggest that patients may benefit from iterative goals of care conversations during the time leading up to the decision for implantation that includes clear information about achievable QOL after LVAD that based on existing medical literature.

How Might PC Impact Patient and Caregiver QOL?
In oncology populations, PC has been shown to improve the quality and even quantity of life during the final months of life.\(^11\) Furthermore, oncology patients who die outside of the hospital experience better QOL and their caregivers have a lower incidence of psychiatric illness during bereavement.\(^12\) More recently, increased access to hospice and PC services for patients with HF has led to improved QOL care for these patients.\(^7\) Despite these advances, these data demonstrate that, in contrast to HF patients dying without an LVAD, patients dying with an LVAD most often die not in a peaceful and familiar location surrounded by loved ones, but in sterile hospital rooms and unfamiliar faces. However, it is arguable that death outside of the hospital may not be achievable for all LVAD patients, primary because of the acute events preceding many of these deaths. In those instances, it is possible that early adoption of preimplantation PC consults for patients receiving DT-LVADs\(^13\) at Mayo allowed for more streamlined EOL decision making because of the availability of a thoughtful advance care plan.

How Can We Scale PC Services to Meet the Needs of the LVAD Population?
As evidence for the benefits of PC for HF, LVAD, and other patient populations has grown, the demand for PC specialists

See Article by Dunlay et al

In this issue of Circulation: Heart Failure, Dunlay et al\(^6\) provide a description of end of life (EOL) experiences at the Mayo Clinic, where there is a strong history of collaboration between the PC and MCS teams. The study population, typical of those receiving a DT-LVAD, died an average of 14 months after device implantation, predominately from multiorgan failure, hemorrhagic stroke, and progressive HF. In addition to the three distinct clinical trajectories previously described,\(^8\) they identified a unique trajectory, termed acute, which was heralded by an unexpected event resulting in an abrupt decline and death within 14 days (Figure). Despite initial PC engagement that included a PC consult for preparedness planning,\(^7\) less than half saw a PC provider in the month before their death with most (68%) dying in the intensive care unit. Leveraging their previous data,\(^8\) on EOL care for community-dwelling HF patients, they found that LVAD patients had lower rates of hospice utilization and deaths outside of the hospital. Some of these differences may be attributable to the observation that LVAD deactivation occurred commonly at the EOL (>60%) with decision making often involving surrogates.

The opinions expressed in this article are not necessarily those of the editors or of the American Heart Association.

From the Department of Medicine, University of Pittsburgh School of Medicine, PA (W.G.T.); and Department of Medicine, Columbia University Medical Center, New York Presbyterian Hospital, NY (M.M.).

Correspondence to Winifred G. Teuteberg, MD, Section of Palliative Care and Medical Ethics, 200 Lothrop St, Suite 933W, Pittsburgh, PA 15213. E-mail teutebergwg@upmc.edu

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has increased dramatically. It is unrealistic to believe that there will ever be enough PC specialists to care for the majority of patients who die from serious illness. To respond for this rapidly expanding unmet clinical need, many have advocated for enhancement of primary PC. 14–17 In contrast to specialty PC delivered in a consultative model by PC trained providers, primary PC is care delivered by patients’ primary providers. 14 Primary PC involves the same domains as subspecialty PC, including symptom management and communication about goals of care, but differs in the level of complexity within each domain. For example, management of uncomplicated nausea or adjustment reaction with depressed mood might fall under primary PC, whereas management of a refractory pain or a major depressive episode would fall under specialty primary care. Many discussions about advance care planning and code status would fall under primary PC, such as conversations involving a patient who has clearly thought out wishes for EOL care that are universally supported by family. More complex discussions requiring nuanced mediation of conflicts between family members or patients with high levels of ambiguity about EOL care would require specialty PC. 14

As LVAD technologies continue to advance and outcomes improve, the population with such devices will grow exponentially, requiring investigation on how to enhance primary PC for patients receiving LVADs. Capitalizing on the already existing comprehensive multidisciplinary teams by adding PC educational programs and work flow enhancements could rapidly improve the successful provision of primary PC for all LVAD patients. Because these patients and their caregivers have high frequency of interaction with all members of the MCS team, including nurses, social workers, and advanced practice providers, the engagement and training of many team members, not just physicians, is crucial for the success of this endeavor. In addition to being scalable, it is likely that provision of PC by the LVAD team would minimize patients and caregivers confusion and loss of continuity that has been reported to occur when PC needs are handed off to PC specialists. 9

By enhancing the availability of PC through educating the members of LVAD team to deliver primary PC, comprehensive PC would be available for patients during times of need throughout the continuum for all trajectories. PC could be provided in the form of advance care planning before implementation and regular iterative goals of care conversations over time. Availability of specialty PC would allow for timely and high-quality symptom management during periods of decline and also allow for triggered revisiting of goals of care when a patient suffers an acute event. Finally, knowledge and education in PC domains would allow the MCS team to work with the specialty PC team to ensure caregivers receive bereavement support (Figure). This model would facilitate seamless integration of PC into the everyday care of DT-LVAD patients while allowing appropriate utilization of specialty PC when needed.

In summary, although the survival outcomes for patients with DT-LVADs continue to improve, many will have ongoing PC needs and for many, hospice may not be feasible. To fully realize the potential of PC for patients with LVADs, PC skills and their application needs to occur not only before implantation but also continuously throughout the course of LVAD therapy. Indeed, most poignantly at the EOL, we all hope to receive care that is in accordance with our goals and values, to be spared from suffering, and to never feel abandoned by the healthcare system.

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References


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