Usefulness of Palliative Care to Complement the Management of Patients on Left Ventricular Assist Devices

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Within the last decade, advancements in left ventricular assist device therapy have allowed patients with end-stage heart failure (HF) to live longer and with better quality of life. Like other life-saving interventions, however, there remains the risk of complications including infections, bleeding episodes, and stroke. The candidate for left ventricular assist device therapy faces complex challenges going forward, both physical and psychological, many of which may benefit from the application of palliative care principles by trained specialists. Despite these advantages, palliative care remains underused in many advanced HF programs. Here, we describe the benefits of palliative care, barriers to use within HF, and specific applications to the integrated care of patients on mechanical circulatory support. © 2016 Elsevier Inc. All rights reserved. (Am J Cardiol 2016;■:■−■)

At the most advanced stages of heart failure (HF), many patients are now offered a durable left ventricular assist device (LVAD). A multidisciplinary team is required to shepherd patients effectively through the complex and time-intensive discussions and decision-making processes related to LVAD therapy. Although medical and surgical teams have traditionally addressed the initial evaluation and operative aspects, the integration of palliative care principles, including collaboration with a palliative care specialist, can further help to manage symptoms, set realistic expectations, and facilitate advance care planning. Current practice guidelines and consensus recommendations emphasize the integration of palliative care into the management of patients with advanced HF and mechanical circulatory support (MCS).[1,2] In fact, in the United States, the Center for Medicare and Medicaid Services requires the involvement of a palliative care specialist to be a member of MCS destination therapy programs.[3] This manuscript reviews the current literature on the integration between palliative medicine and HF and provides recommendations on how palliative care may assist the MCS team with specific aspects of patient care.

Benefits of Palliative Care

Palliative care complements disease-modifying therapies, rather than supplanting them. A progressive palliative care management approach directs education and communication equally toward families and caregivers as much as patients, and helps patients better understand their illness, treatment options, and prognosis, and empowers them to make medical decisions consistent with achievable goals of care. To support these goals, a typical multidisciplinary team is composed of physicians, nurses, social workers, chaplains, physical therapists, and psychologists.[4] Notably, there has been a historical misconception that palliative care is synonymous with hospice care. Hospice care is, in fact, the application of palliative services to the terminally ill patient with an expected survival of <6 months. In contrast, palliative care should be offered independent of prognosis and based on patient needs and an ability to offer benefit.[4]

Palliative care has historically been studied primarily in a cancer setting; reliable data for cohorts with cardiovascular disease are in a comparatively nascent stage. When integrated with oncology care, palliative care leads to improvements in quality of life, less aggressive end-of-life care, and even survival.[5,6] An important component has been increased incidences of advance care planning, whereby patients—together with their health care clinicians and family members—make and document decisions about future health care goals and desired therapies.[7] Advance care planning discussions increase the likelihood that the patient's wishes are followed at the end of life.[7,8] Surviving relatives report that these strategies result in improved satisfaction, better communication, and reduced stress and anxiety.[7] Almost 30% of elderly Americans require surrogate decision-making at the end of life; those with documented advance directives will have a higher likelihood of receiving the care they wanted.[8] In patients with HF, pilot studies have suggested similar benefits in quality of life, depression, and symptom control compared with patients with cancer, but results from large-scale studies are still pending.[9] The recent randomized controlled trial of Palliative Care in Heart Failure, sponsored by the National Institute for Nursing Research, will provide empirical

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evidence for the potential benefits of a team-based palliative care intervention in conjunction with usual HF care on patient-reported quality of life.[10]

Traditional Barriers to Use in Cardiology

Palliative care has also been underused in patients with advanced HF compared with oncology, ranging from an estimated 2% to 20% versus over 50%, respectively.[11,12] In HF populations, enrollment into hospice occurs comparatively late in the disease trajectory—a median of only 12 days before death compared with 20 days in patients with cancer.[12] In addition, hospice agencies have fewer options for patients with end-stage HF. Although oral medications and opiates are commonly provided, few agencies can manage the expense of intravenous inotropes and/or diuretics within the limitations of a per diem payment structure.[13] And whether in inpatient or outpatient settings, relatively few hospice agencies around the country have experience managing end-of-life care for patients already on MCS.

There are several considerations that have limited the widespread adoption of palliative care in patients with HF. Two key considerations are related to the uncertainty of disease progression (for both patients and clinicians) and real or perceived patient aversion to end-of-life planning. Unlike cancer, which more frequently follows a trajectory of progressive decline in the latter stages of disease, HF commonly follows a cyclical natural history. Periods of decompensation followed by periods of relative stability make it difficult to recognize when patients with HF are approaching terminal stages. Death from sudden arrhythmia can occur at any time, further compounding perceived unpredictability. As such, less than a quarter of physicians caring for patients with HF are comfortable predicting a patient's 6-month mortality.[14] Patients may not even fully comprehend HF's life-limiting nature.[15] When there is significant uncertainly, timing discussions about advance care planning can be complicated, and as a result, these conversations are routinely initiated too late in the course of disease.[16]

Even when symptoms stabilize or abate, both clinicians and patients may be reluctant to discuss prognosis and life expectancy. Patients' emotions including anxiety, depression, and denial may hamper adequate discussion and understanding. Depression is present in approximately 20% of patients with HF with a prevalence near 40% in those with the most advanced disease.[17] In addition, approximately 40% of patients with HF experience anxiety.[18] In contrast, data suggest that despite the high prevalence of co-morbid mood disorders, patients with HF expect their physicians to initiate discussions on prognosis and have a strong desire to know the realities of their life expectancy.[19] Although physicians may fear that discussing prognosis will cause patients to lose hope, acknowledging these issues has not been shown to adversely affect patients.[19,20] Engaging in these difficult discussions earlier in the disease course aims to ease the difficult decisions of the future.

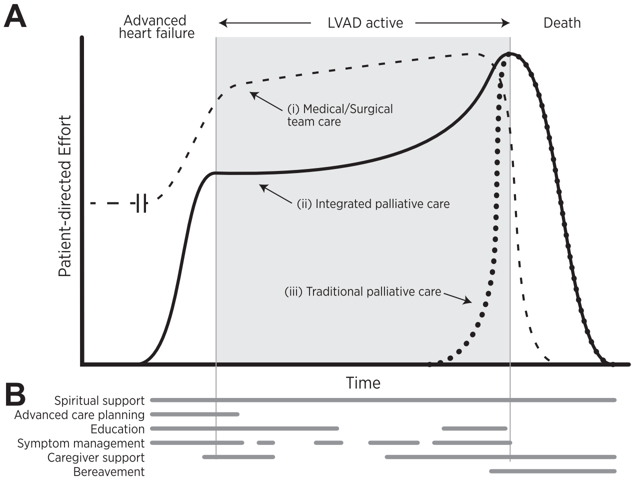

Figure 1. *(A)* depicts (1) effort by medical/surgical team for implantation and symptom management over course of LVAD therapy; (2) integrated approach to palliative care, with emphasis on long-term relationship developed before implantation; and (3) traditional approach to palliative care, with active involvement only close to end-of-life. *(B)* depicts opportunities for a palliative care team to support patients throughout the LVAD process.

Role of Palliative Care in the Management of Patients with MCS

Palliative care principles can help target many aspects in support of patients with MCS, especially in those who may expect to live the rest of their lives on mechanical support. The management approaches of palliative care and practice methods of palliative care specialists integrate well into and reinforce the goals and messages of the medical MCS team. Figure 1 shows a graphical representation of the potential roles for integrating palliative care into the management of patient on MCS. At the initial discussion of advanced HF options, a palliative care team can further guide advance care planning and participatory decision-making. They can explicitly address goals of therapy specific to MCS therapy and discuss care preferences in the event of undesired outcomes such as poor quality of life or progression of a co-morbid condition.[21] After implantation, the team can reinforce symptom management and support for families and caregivers in the early postoperative period. Finally, the team can help the patient and his or her family with transition of care and discussions of device deactivation by defining new goals of care. Although these conversations benefit from consistent reevaluation over the duration of MCS therapy, they are best initiated before surgery.

Empirical evidence and consensus statements suggest that advance care planning is beneficial to patients with HF and an essential part of quality health care.[8,16] Beyond the designation of a health care proxy and the execution of a living will, advance care planning is, ideally, an iterative process that engages the patient, the family and surrogate decision maker, and the medical team. In a best-case scenario, these stakeholders meet to identify health care preferences, values, and goals of care, and document these findings in an advance directive.[21] However, with respect to MCS therapy, most advance directive documents rarely provide concrete guidance for the nuanced and complex medical decisions that arise over the lifespan of an LVAD.[22] Table 1 provides a general overview of the differences between traditional advance directives and one geared specifically for a patient contemplating LVAD therapy. Swetz et al[21] provides a