Brief Report

Pre-Ventricular Assist Device Palliative Care Consultation: A Qualitative Analysis

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Abstract

Introduction. In 2013, the Centers for Medicare and Medicaid Services issued a mandate requiring that all patients undergoing destination therapy ventricular assist device (DT VAD) implantation have access to a palliative care team before surgery. Subsequently, many VAD programs implemented a mandatory preimplantation palliative care consultation for patients considering DT VAD. However, little is known about the quality of these consults.

Methods. All patients undergoing DT VAD implantation at Northwestern Memorial Hospital from October 30, 2013 (the Centers for Medicare and Medicaid Services decision date), through March 1, 2018, were included. Palliative care consultation notes were qualitatively analyzed for elements of "palliative care assessment" and preparedness planning.

Results. Sixty-eight preimplantation palliative care consultations were analyzed. Fifty-six percent of the consults occurred in the intensive care unit, and the median time from consult to VAD implant was six days. General palliative care elements were infrequently discussed. Furthermore, the elements of preparedness planning—device failure, post-VAD health-related quality of life, device complications, and progressive comorbidities—were discussed in only 10%, 54%, 49%, and 12% of consultations, respectively.

Conclusions. One-time preimplantation palliative care consultations at our institution do not lead to completion of preparedness planning or even general palliative care assessment. Further work is needed to determine the most effective way to integrate palliative care into preimplantation care. J Pain Symptom Manage 2019;57:100–107. © *2018 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.*

Key Words

Palliative care, left ventricular assist device, destination therapy, heart failure

Introduction

Destination therapy ventricular assist devices (DT VADs) improve survival, functional status, and quality of life for most patients.[1–3] However, unanticipated adverse events such as stroke and infection can significantly diminish health-related quality of life and shorten survival.[3,4] Owing to the known morbidity and mortality associated with DT VADs, "preparedness planning"—a specialized type of preimplantation advance care planning for DT VAD patients that focuses on complications that might arise after VAD implantation—and goals-of-care discussions are deemed important components of the DT VAD care plan.[5–9] In August 2013, the U.S. Centers for Medicare and Medicaid Services (CMS) issued a new National Coverage Determination requiring that all patients

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Accepted for publication: September 30, 2018.

0885-3924/$ - see front matter
https://doi.org/10.1016/j.jpainsymman.2018.09.023

undergoing DT VAD surgery have access to a palliative care team before device implantation.[10] While not explicit about the expected role of the palliative care team, the text cites the International Society for Heart and Lung Transplantation (ISHLT) Guideline, which states that "palliative care consultation should be a component of the … evaluation phase for mechanical circulatory support. In addition to symptom management, goals and preferences for end-of-life care should be discussed."[6]

As a result of this memo, many U.S. VAD programs, including ours, now require that every patient considering a DT VAD receives a preimplantation palliative care consultation. However, almost five years after the CMS guideline was published, little is known about the content or quality of the interactions between VAD patients and palliative care during these preimplantation consultations. In this article, we describe our institution's experience with palliative care consultation before DT VAD placement after the CMS mandate took effect. Our objective was to better understand the nature and characteristics of palliative care consultations in the preimplantation setting.

Methods

Medical records of 105 consecutive patients who underwent DT VAD implantation at Northwestern Memorial Hospital, Chicago, IL, between October 30, 2013 (the date of the CMS mandate and the date that our institution implemented preimplantation palliative care consultations), and March 1, 2018, were retrospectively reviewed. The Northwestern Institutional Review Board oversaw this study.

All data were abstracted from documentation in the electronic medical record (EMR) and a separate REDCap registry maintained by the mechanical circulatory support team. Characteristics of the preimplantation palliative care consultation were abstracted from the palliative care notes in the EMR. Notes were considered to be preimplantation consultation notes if they were labeled as such in the "reason for visit." Data collected from the preimplantation palliative care notes are shown in Table 1.

Patients were deemed decisional if they were noted to be alert and oriented to self, place, and time and were able to participate in a discussion with the palliative care physician. Patients were deemed not decisional if they were intubated and sedated or had objective documentation of altered mental status. Advance directives at our institution are scanned into the EMR when provided by the patient from home or at the time of completion in the hospital. Information from advance directives was manually abstracted from the medical record. All laboratory data were measured the day before VAD surgery.

Palliative Care Consultation Process

Our hospital's inpatient palliative care consult service is composed of two teams: one team sees patients in the inpatient cancer center and the other team sees patients in the general hospital, including pre-VAD patients. Each team is composed of a palliative care attending physician, a social worker, and several trainees of varying experience (medical student to fellow); one chaplain splits time with both teams. At our institution, palliative care consults before VAD implantation are initiated by the nurse coordinators per protocol as part of the "advanced-therapies evaluation," typically after the decision has been made to pursue DT VAD implantation. These requests are made either after the patient has been admitted (patients may be admitted for planned VAD implantation or may be admitted with acute illness and ultimately deemed candidates for VAD implantation during that admission) or in the outpatient setting if the referral was made before the patient is admitted for VAD implantation. After the initial palliative care visit, the palliative care team remains available to see the patient and family at any point before (or after) the VAD is implanted. To date, we have not instituted a standard "revisit" procedure to ensure follow-up for all patients on a regular basis. Rather, revisits are conducted as needed and at the discretion of the VAD team, palliative care team, and/or patient and family.

Before CMS mandate implementation, the VAD team conducted a short in-service session for the palliative care team on VADs, which recurred on an annual basis. During the in-service, the VAD coordinators met with the palliative care team during a palliative care section meeting. Topics discussed and presented included a description of VAD, lifestyle changes that may come with a VAD, and show-and-tell with the actual device. The in-service did not include a description of what preimplantation visits should include or how they should be conducted. In addition, our palliative care service has not relied on a standardized protocol or template for preimplantation visits.

Statistical Analyses

Qualitative data were analyzed using thematic analysis, wherein the meanings of text from the palliative care notes (i.e., the data) were coded (i.e., categorized), to identify themes.[11] Two members of the research team independently qualitatively coded the palliative care consultation notes. Coders conducted descriptive coding by attaching meaningful labels to blocks of text. Coders looked for general elements (i.e., codes) of two themes, identified a priori, "palliative care assessment" and "preparedness planning."[7–9] To determine reproducibility, both members coded each note. Interrater reliability

Table 1
Elements Addressed During Pre-implantation Palliative Care Consultations

Element (Code)	Coded if Item Was Addressed	n (%), ($N = 68$)	Example Statements From Text
Palliative Care Assessment			
Decision to undergo VAD	Patient and physician discussed the decision to undergo VAD implantation in the context of alternative options (such as hospice or home inotropes)	24 (35%)	"Both patient and family are fearful of experiencing another shock from his defibrillator. The patient's family also fears his life without any advanced intervention, i.e., VAD, and understands that his time and outcome are likely limited without it. They understand the risks of proceeding with VAD procedure and have considered the alternative options such as inotropes."
Current symptoms	Current symptoms pertaining to heart failure or other ailments discussed	41 (60%)	"Patient describes a steady decline in his energy and functional status over the preceding months. He currently denies any symptoms of pain, dyspnea, anxiety, or constipation."
"Limits" or unacceptable states	Patient and physician discussed "unacceptable states," or states of existence or losses of critical functioning that a given patient would want to avoid, such as artificial feeding, mechanical ventilation, and inability to achieve meaningful communication	40 (58%)	"They have discussed unacceptable health outcomes such as conditions where his quality of life is severely impaired, such as a catastrophic stroke. Mr. O would not want prolongation of life sustaining measures if unable to return to independent function. He said he would "not want to be a vegetable" as a way of describing his impression about this topic … He would accept prolonged mechanical ventilation requiring tracheostomy and/or long-term acute care facility so long as it would restore him to independent function." "He discussed not continuing with life-sustaining therapy should he be unable to care for himself at all, interact with his family, or be active in any capacity. Until that point, he is willing to undergo aggressive life-sustaining measures and hospitalizations."
Medications	Physician commented on or made adjustments to medication regimen	3 (4%)	"If stool continues to be hard to pass, would increase MiraLax to twice daily. Would also limit fiber intake to ½ dose or every other day to prevent further hardening in the setting of diuresis."
Spiritual or religious preference	Physician and patient discussed the patient's spiritual or religious preferences	4 (6%)	"Her Christian faith (Baptist tradition) is very important to her and has helped her live all these years with her current medical issues. She cannot think of any state of being wherein she would not want to live because life is so important to her."
Power of attorney identified	Physician and patient identified the person who the patient would want to identify as a power of attorney	57 (84%)	"Mr. B identified his wife as his power of attorney for health care. We discussed the requirements and expectations of a power of attorney to be able to carry out substituted judgment and he agrees. The Power of Attorney form had previously been scanned into the chart."
Advance directive completed by palliative care team	Physician and patient completed an advance directive together and filed it in the medical record	0 (0%)	—

Preparedness Planning			
Situation of device failure	Physician and patient discussed the possibility of device failure	7 (10%)	"We talked about how certain complications, such as pump thrombosis, can cause the VAD to fail and require replacement or reoperation. She and her husband feel comfortable with these risks."
Post-VAD health-related quality of life	Physician and patient discussed hopes for health-related quality of life after VAD implant or potential inadequate health-related quality of life after VAD implant	37 (54%)	"His hope for his VAD is to get back to doing some of the things that give him meaning (golfing, spending time with friends and family) for a few years." "He understands that VAD will not be a panacea for all of his advanced symptoms, but he looks forward to a life where he can spend more time outdoors, go fishing perhaps."
Device complications	Physician and patient discussed catastrophic complication(s) due to VAD-associated factors	33 (49%)	"We discussed the risks associated with VAD and the wishes around care. They understand the following and have no objections to interventions geared to restoring him to a good quality of life: rehospitalization, bleeding requiring transfusion, local or systemic infection, renal failure, stroke, or pump thrombosis."
Progressive comorbid conditions	Physician and patient discussed debilitative comorbid condition(s)	8 (12%)	"We discussed that Ms. L has very 'weak' kidneys already, and the patient wondered if this may get worse, even with the VAD. I acknowledged that her kidneys could get worse, and that there may be a time when dialysis may be considered." "If he was faced with a chronic disease or new life-threatening disease after VAD implant, he would weigh this on a case-by-case basis determining how and whether to proceed with treatment."

estimates, calculated as the percentage agreement for two reviewers blinded to each other's assessments, were assessed.

Descriptive statistics (means and standard deviations for continuous variables, and numbers and percentages for categorical variables) were used to analyze patient characteristics.

Results

Patient Characteristics

A total of 105 patients who were implanted with a DT VAD during the study period were included. Preimplantation characteristics of the patients are described in Table 2.

Table 2
Preimplantation Characteristics of Patients

Characteristic	Overall ($n = 105$)
Age, years (mean ± SD)	60 ± 13
Male, N (%)	84 (80)
Race	
Caucasian, n (%)	58 (55)
African American, n (%)	25 (24)
Asian, n (%)	3 (3)
Other/unknown, n (%)	19 (18)
Latino, n (%)	11 (10)
Primary caregiver relationship to patient	
Spouse, n (%)	53 (50)
Adult child, n (%)	14 (13)
Other, n (%)	38 (36)
Ischemic etiology of heart failure, n (%)	51 (49)
Comorbidities, n (%)	
Hypertension	62 (59)
Diabetes	44 (42)
Peripheral vascular disease	9 (8.5)
Chronic obstructive pulmonary disease	23 (22)
Cerebrovascular disease	11 (10)
Laboratory data before VAD implant, median (interquartile range)	
Total bilirubin, mg/dL	1 (0.7–1.5)
Aspartate aminotransferase, U/mL	27 (18–45)
Alanine aminotransferase, U/mL	21 (13–44)
Albumin, g/dL	3.5 (3.2–3.8)
Platelet count, 1000/μL	183 (138–243)
Blood urea nitrogen, U/dL	25 (18–43)
Creatinine, mg/dL	1.3 (1.0–1.8)
International normalized ratio	1.3 (1.1–1.4)
INTERMACS profile[a] (mean ± SD)	2.1 ± 0.86
Advance Directive completed	34 (32%)
Advance Directive with VAD-specific content	0 (0%)

[a]INTERMACS score stratifies advanced heart failure NYHA class 3B and 4 patients into seven categories, according to the urgency of definitive treatment.[1]

Preimplantation Palliative Care Consultation

Palliative care was consulted on 83 (79%) patients before implantation, whereas 22 patients (21%) did not have palliative care consultations for unclear reasons. For 15 of the 83 patients, palliative care was consulted, but the service team was unable to see the patient due to the patient being off the floor for other clinical testing, undergoing procedures, or undergoing the VAD implantation itself. The remaining 68 palliative care visits were analyzed.

Of the 68 patients who had preimplantation palliative care consultations, one (1.5%) occurred in the outpatient setting, 29 (43%) occurred in the inpatient setting on a general floor, and 38 (56%) occurred in the ICU. Patients who underwent palliative care consultation during their VAD implantation admission were admitted an average of 9.3 ± 8.1 days before surgery. The median time from palliative care consultation to VAD implant was six days (interquartile range 2–21). For all but two of these patients, it was the first time they had seen palliative care in their lifetime. After the initial consultation, the palliative care team saw four patients once more before DT VAD implantation. For each of these follow-up visits, family was not present on the initial visit, and the purpose was for palliative care to follow-up with the patient with family present to answer any additional questions. Family was present for 39 preimplantation visits (57%), including the follow-up visits.

Characteristics of the palliative care consultations are listed in Table 1. The decision to undergo VAD implantation (as opposed to alternative options such as home inotropes) was discussed in 24 (35%) of patients. General palliative care assessment items such as symptom burden, limits or unacceptable states, and spiritual or religious preferences were discussed in 41 (60%), 40 (58%), and 4 (6%) of patients, respectively. The elements of preparedness planning were infrequently discussed, and no patient received complete preparedness planning (defined as discussion of all four elements of preparedness planning). Interrater reliability was 96%–100% for each of the coded elements. Sixty-four patients (94%) were deemed decisional and were able to have a discussion with the palliative care physician during this visit, whereas 4 (6%) patients were intubated and sedated at the time of visit.

Patients and their families occasionally demonstrated appreciation for palliative care consultation: "the patient and his family were thankful for our visit and the support provided. They will continue to reach out if additional questions arise throughout this process." However, there was also resistance to palliative care consultation. This was reflected in the following quotes: "I attempted to speak with the patient and his wife about the risks of VAD and some of the things to be thinking about such as bad outcomes, even though those are rare. Patient did not want to discuss the possibility of bad outcomes and what would or would not be acceptable to his quality of life … He declined having any questions at this time;" "Mr. T was not interested in meeting with palliative care at this time. He and his wife acknowledged having read

information on palliative care and denied having any questions;" "The patient is extremely anxious and having a difficult time coping. She deferred all conversations to her mother and sister present in the room … They acknowledged feeling overwhelmed not only by her clinical situation but by the deluge of information they have received. They wish for some time to process and are open to requesting palliative care information/consultation in the future."

Discussion

Palliative care teams are effective in assisting with shared decision-making,[12] symptom control,[13,14] and advance care planning[15–17] across a number of disease states, including advanced heart failure.[18,19] At our institution, palliative care physicians have an established record of helping to improve and facilitate goals-of-care discussion skills among attending and resident physicians alike.[20–22] We were thus surprised to find that the quality of our palliative care consultations in patients before DT VAD implantation needs improvement. There are multiple reasons why preimplantation palliative care consultations at our institution may not have included documentation of items that are deemed important by International Society for Heart and Lung Transplantation during preimplantation assessment.[6] First, the median time between the palliative care consultation and VAD implant was six days, with 10 consultations occurring the day before VAD implant and 10 consultations occurring on the actual day of implant. Expecting that palliative care consultations that occur within days of the surgical implant will translate into an effective utilization of this important resource may be misguided. At this juncture in a patient's clinical course, the patient is often critically ill and/or has little time or emotional energy for in-depth, potentially difficult discussions because of multiple tests, procedures, and other consultations. This may lead to rushed conversations and overall reduced patient and family engagement with the palliative care team. Furthermore, palliative care clinicians at our institution have shared that they often fear overwhelming the patient with additional information and derailing the process of VAD implantation when the patient has just agreed to proceed with VAD surgery. Second, the palliative care team occasionally remarked that the decision to undergo VAD implant was already made by the patient and the medical team. This was reflected in quotes from palliative care physicians in their notes such as, "he was due to go for a VAD shortly, so we kept our visit short" and "I did not discuss overall goals-of-care with her since the plan to proceed with VAD is already in place." These comments reveal an interesting observation. Perhaps palliative care physicians believe that their role in VAD care is or should be more focused on shared decision-making about whether or not the patient should proceed with VAD, rather than on preparedness planning. If this is the case, the benefits of palliative care involvement may be less recognizable to the palliative care team and by extension to patients and their families, making the patient less likely to engage in goals-of-care discussions and sometimes leading to frustration on behalf of the provider and patient. Finally, although the VAD team at our institution did conduct brief informational sessions for palliative care physicians about living with a VAD and VAD complications, there remained a lack of consensus as to what these consultation visits should entail and the training sessions were neither standardized nor rigorous. In addition, insufficient training on the potential complications of VAD implantation may have led to omission of this information from the initial consultation. These factors, combined with an already strained palliative care service due to high volumes, likely contributed to our study results.

There is a paucity of data on preimplantation palliative care consultations in general. In fact, it is unclear how the palliative care interactions we documented in this study were comparable to those from other centers as, to our knowledge, only a few other institutional experiences have been published following the implementation of the new CMS requirement. A study by Nakagawa et al. in 2018 demonstrated that after the CMS mandate, both DT and bridge-to-transplant patients had more palliative care consults and concomitantly had fewer deaths in the intensive care unit, more deaths in hospice, and fewer aggressive interventions (mechanical interventions and renal replacement therapy) at the end of life.[23] However, it is unclear whether these improved outcomes are due to the palliative care consults themselves or due to other confounding factors (such as an overall greater focus on and attention to end-of-life care in recent years). Furthermore, this study did not address the quality of palliative care consults before VAD implantation.

Studies have shown that certain interventions may make proactive palliative care consultations more effective. Nakagawa et al. (2017) showed that a scripted, integrated palliative care intervention was feasible in both DT and bridge-to-transplant patients before VAD surgery.[24] After the consultation, patients and families expressed an increased awareness of possible complications of surgery and could articulate unacceptable health states. O'Connor et al. (2016) also showed that nurses with basic palliative care skills can conduct scripted preparedness planning conversations, which are well received by patients.[25] These both were single-center feasibility studies that lacked

a control group, thus conclusions cannot truly be made about the effect of the palliative interventions. However, the results do suggest that a semistructured interview script to elicit patients' values and goals with respect to VAD therapy may enhance the ability of palliative care (or other) physicians to identify patient goals and wishes before surgery.

Although limited by the retrospective design and single-center experience, the present study addresses a previously unstudied but important aspect of preimplantation patient management and highlights both potential pitfalls as well as opportunities for improvement with respect to the CMS mandate for palliative care consultation. CMS mandated preimplantation palliative care consultations in a "one-size-fits-all" manner, without providing specific direction for the optimal structure or timing of these consultations. Our institution's experience shows that the acute inpatient consultation by palliative care immediately before implantation is insufficient in delineating patients' preferences or goals. Based on our institution's findings, there are multiple areas for improvement to enhance the quality of these preimplantation palliative care consultations. Implementing the palliative care assessment much earlier in the VAD decision-making process, when patients are not acutely ill and adjusting to the decision to proceed with surgery, may lead to more productive discussions. However, Allen et al. (2018) recently published data demonstrating that a shared decision-making intervention for DT VAD implantation was associated with improved patient decision quality, and nearly a quarter of patients in this study were in the intensive care unit when enrolled.[26] Thus, a patient's critical illness should not preclude a discussion of preparedness planning and goals of care. Establishing agreed-upon goals and protocols[27] for preimplantation palliative care consultation as well as implementing standardized training and scripted interventions are also likely to result in more valuable and thorough discussions among patients, family members, and their physicians. Enlisting other members of the VAD team, such as coordinators and advanced heart failure physicians who may already have relationships with the patient, to have these discussions and complete preparedness planning may also be beneficial. Larger, prospective, multicenter studies to determine the most effective way to integrate palliative care and preparedness planning into the care of patients before DT VAD implantation are warranted.

Disclosures and Acknowledgments

Research reported in this publication was supported, in part, by the Northwestern University Bluhm Cardiovascular Institute (BCVI) Clinical Trials Unit. The authors would like to thank the patients and their caregivers in our VAD program. The authors also acknowledge Duc Thinh Pham, MD, Surgical Director, Center for Heart Failure, and Allen S. Anderson, MD, Medical Director, Center for Heart Failure, BCVI Northwestern University.

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