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Perspectives from Mechanical Circulatory Support Coordinators on the Pre-Implantation Decision Process for Destination Therapy Left Ventricular Assist Devices

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Abstract

Objective—To understand mechanical circulatory support (MCS) coordinators' perspectives related to destination therapy left ventricular assist devices (DT LVAD) decision making

Background—MCS coordinators are central to the team that interacts with patients considering DT LVAD, and are well positioned to comment upon the pre-implantation process.

Methods—From August 2012–January 2013, MCS coordinators were recruited to participate in semi-structured, in-depth interviews. Established qualitative approaches were used to analyze and interpret data.

Results—Eighteen MCS coordinators from 18 programs were interviewed. We found diversity in coordinators' roles and high programmatic variability in how DT LVAD decisions are approached. Despite these differences, three themes were consistently recommended: 1) DT LVAD is a major patient-centered decision: “you’re your best advocate...this may not be the best choice for you”; 2) this decision benefits from an iterative, multidisciplinary process: “*It is not a one-time conversation*”; and 3) this process involves a tension between conveying enough detail

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about the process yet not overwhelming patients: “It’s sometimes hard to walk that line to not scare them but not paint a rainbow and butterflies picture.”

Conclusions—MCS coordinators endorsed a shared decision-making process that starts early, uses non-biased educational materials, and involves a multidisciplinary team sensitive to the tension between conveying enough detail about the therapy yet not overwhelming patients.

Keywords

heart-assist device; heart failure; health-related quality of life; patient-centered care; destination therapy

BACKGROUND

Left ventricular assist devices for destination therapy (DT LVAD) have created a long-term permanent treatment option for patients with advanced heart failure who are ineligible for transplantation.^{1,2} Currently 114 centers across the United States are approved to perform DT LVADs.³ An estimated 150,000-250,000 patients each year could be eligible for DT LVAD from the more than 6,000,000 in the United States with chronic heart failure.⁴⁻⁶ With an increasing prevalence of heart failure,⁵ limited availability of suitable donor hearts,⁷ and ongoing improvements in LVAD technology,⁸ DT LVAD is likely to become an increasingly viable treatment option for this expanding patient population.⁴

For patients and their families, the decision to pursue a DT LVAD is complex. The most common reasons for heart transplant ineligibility, and consequently DT status, are advanced age and non-cardiac medical illness.⁹ Therefore DT LVAD candidates are generally older and sicker than patients being considered for bridge-to-transplant LVAD and heart transplantation. When presented with the option of DT LVAD, patients are typically faced with a decision to pursue an invasive technology with potential risks and burdens in return for the likelihood of prolonged survival.¹⁰ Although the Centers for Medicare and Medicaid Services (CMS) mandate that approved DT LVAD centers have a formal consent process in place and participate in shared decision making,¹¹ the actual process of educating patients eligible for DT LVAD and facilitating patient-centered decision making is largely managed by individual medical centers. The range of consent, decision making, and preparatory processes for DT LVAD has never been characterized across current centers.

Mechanical circulatory support (MCS) coordinators are health care professionals that specialize in caring for the unique LVAD patient population. They are an integral part of a broad medical team that interacts with patients considering this life-changing therapy, and are well-positioned to comment upon the pre-implantation process. Therefore, we systematically solicited MCS coordinators’ perspectives related to DT LVAD shared decision making, including a characterization of the range of informed consent, decision support, and educational preparation currently offered to patients and their caregivers, as well as opinions on how this process could be optimized.

METHODS

Study Design and Participants

A qualitative study design was chosen in order to obtain an expansive and detailed understanding of the MCS coordinator's experience and feedback concerning the DT LVAD decisional process.¹² This design was especially appropriate given the lack of existing data on the topic. The Ottawa Decision Support Framework was used to inform the study design. This prescriptive framework guides the development and evaluation of decision support interventions. It states that participants' decisional needs (e.g. knowledge, values, support) will affect the decision quality—informed, values concordant decisions.¹³ This impacts subsequent outcomes such as emotions, regret, blame, and behavior. The framework asserts that decision support can improve decision quality by addressing unresolved decisional needs. Therefore, we performed semi-structured, in-depth interviews with MCS coordinators located at medical centers across the United States. MCS coordinators who had direct experience with a program's DT LVAD patient population were eligible for this study. Convenience sampling was used to identify participants. Only one coordinator per center was recruited and we sought out a geographically diverse sample. Recruitment was done through a national listserve and study team members' established relationships with MCS programs throughout the United States. Recruitment was complete when thematic saturation was met. Informed consent was obtained from all study participants. A total of 20 MCS coordinators were contacted, of whom 18 agreed to participate. Participation was voluntary and no compensation was provided. The study was approved by the institutional review board at the University of Colorado.

Data Collection

An interview guide was developed (Appendix) which contained both targeted and open-ended questions. The content of the interview guide was developed based on the Ottawa Decision Support Framework¹³ and addressed the role of the MCS coordinator, particularly in relationship to the decision-making process, factors involved in the decision-making process, and suggestions for improvement related to the process. The content validity of the interview guide was established by members of the study team, including two MCS coordinators. Two study team members, who were not MCS coordinators and did not have established relationships with the participants, conducted digitally recorded phone interviews.

Qualitative Analysis

This qualitative, descriptive study used the Ottawa Decision Support Framework as our lens and content analysis as our primary analytic strategy.¹⁴ Qualitative analysis involved an iterative team-based process beginning with transcribing the interview data. The multidisciplinary analytic team consisted of an advanced heart failure and transplant cardiologists, a heart failure and transplant nurse practitioner, two MCS coordinators, a palliative care physician, a social worker, a health communication specialist, and a pre-medical student. Two of the team members had extensive experience in qualitative research. The interviewers recorded each participant's responses in spreadsheet format. Additionally, they included length of interview, reflection on interview process, and a summary of

thoughts and interesting points. Weekly meetings were held to discuss the interviewing process, such as structure and flow of the interview guide and areas requiring further elucidation or probing. The meetings also served to simultaneously begin a reflexive analytic process by discussing emerging themes and patterns, as well as confirming and disconfirming cases. Next steps included two team members listening to the interviews, validating or elucidating the interviewers' notes, and coding for the key themes on which the larger team had reached consensus. To further increase methodological rigor, two team members then reviewed a sample of the recordings and notes, observing agreement, disagreement or areas for further discussion. After a process of team meetings, as well as presentations to other cardiovascular peer groups, we finalized our primary themes.^{15,16,17}

We employed several strategies to assure trustworthiness of the findings.¹⁸⁻²⁰ To assure transferability, we attempted to provide sufficient contextual information about our sample so that others can determine how similar or different populations compare. To assure dependability, an audit trail was kept by CN during the analytic phase of the project. To assure credibility and confirmability, we triangulated our findings using a multi-disciplinary study team.²⁰ Throughout the data analysis, this team met to discuss the analytic process and emergent themes. To ensure the results represented an accurate account of the MCS coordinators' experiences, we conducted a member check, soliciting participant feedback regarding study findings.¹⁷

RESULTS

Overview

From August 2012–January 2013, we interviewed 18 MCS coordinators from 18 programs across the United States. Interviews ranged between 20–55 minutes. MCS coordinators were primarily female (n=15) with varying higher educational degrees (Table 1). MCS programs differed in size, location within the medical center's organizational structure, and hospital affiliation (academic versus private). Fourteen of the centers were associated with established heart transplantation programs. MCS coordinators' job responsibilities varied in regards to specific pre-implantation activities surrounding the therapy. However, all coordinators expressed job satisfaction in helping patients through the decision-making process.

Although existing tactics for decision support varied widely between programs across the country, coordinators consistently expressed optimal strategies for this process. Specifically, three common themes emerged from the coordinator interviews regarding pre-implantation consent, education, and decision making: 1) DT LVAD is a major patient-centered decision, 2) this decision benefits from an iterative and multidisciplinary process, and 3) this process demands a caring and artful approach.

Programmatic Variation in Existing Decision Support

Each coordinator described how his or her institution has developed its own programmatic process, and this overall process differed significantly across programs. MCS coordinators were divided in their opinions of how well the programmatic practices of their own

institutions supported the decision-making process. For example, we found the initial introduction of DT LVAD therapy to patients occurred variably across centers.

DT LVAD is a Major Patient-Centered Decision

Coordinators uniformly endorsed that DT LVAD is a preference sensitive decision. Therefore, patients should ideally have an opportunity to objectively consider relevant factors before making the decision. Often within the context of challenging past experiences, many coordinators emphasized how important it is for patients to see this as a therapeutic option rather than a necessity. All coordinators stressed that the decision to pursue a DT LVAD belongs primarily to the patients and their caregivers. Most coordinators felt that MCS programs should avoid being directional in the decision-making process.

- “I always emphasize that ‘you’re your best advocate, your family is your best advocate...I’m not here to sell you a device, I’m here to be an advocate for you, and this may not be the best choice for you.’”

All coordinators emphasized that earlier introduction to the therapy allows them to build the patient’s knowledge base at a much more reasonable pace and provides more time for multiple, in-depth discussions.

- “Ideally, the decision process is slowed down at all costs.”

It was emphasized that involving the caregiver is an extremely important part of the educational process. Further, coordinators stated it was particularly important that patients and their caregivers fully understand the effects a DT LVAD will have on their lifestyle and quality of life.

- “I think that they need to understand that, yes, this is risky, but it’s also a lifestyle change that they have to modify their lifestyle, and this is going to be a daily thing for them that is going to be their new normal.”

Further, if MCS coordinators were faced with the hypothetical decision to pursue DT LVAD for themselves, the overall consensus was that it would require thoughtful reflection and consideration of multiple factors.

- “My biggest concerns would be the impact on my quality and how am I going to feel after – like what are my responsibilities – is it worth it to go through this huge surgery and hospitalization and pain?”

The DT LVAD Decision Benefits from an Iterative and Multidisciplinary Process

Coordinators consistently emphasized that the shared decision-making process around DT LVAD benefits from an iterative structure involving input from multiple experts. Coordinators described a consent, education, and decision process for which different roles tended to be assumed by different clinician types. In all programs, the coordinators were primarily responsible for the educational process prior to DT LVAD implantation, with the goal of supporting patients and their caregivers in making an informed decision. Despite providing the majority of the education related to the LVAD, MCS coordinators did not feel fully engaged in the informed consent process and felt patients preferred to hear about risks and benefits from physicians.

- “We describe the surgery in general terms...as far as the surgical risks, we don’t get into that. The VAD coordinators focus on the risks for the device and lifestyle choices. We have a whole team that does the surgery piece.”

In addition to meeting with various health care providers, coordinators strongly advocated for patients considering a DT LVAD to meet with a patient currently living with a DT LVAD. Information provided by experts was ideally supplemented by a variety of different resources. MCS coordinators valued hands-on experience as a learning and decision-making tool. When asked how to improve the decision-making process, several MCS coordinators expressed a need for more focus on palliative care, end-of-life discussions, and turning off of the LVAD in the future.

The Decision Process Demands a Caring and Artful Approach

The majority of MCS coordinators discussed the challenges and nuances in educating patients and families about DT LVAD therapy and helping to facilitate shared decision making. While education, consent, and decision making are typically conducted within a framework of contemplating risks and benefits, all coordinators emphasized that the process of DT LVAD decision making is highly emotional and patients are easily overwhelmed.

- “[*The decision*] is a psychosocial nightmare...they have to be willing to live with the VAD forever...[people] don’t realize how long this device is going to affect their lives.”

Almost all coordinators described a central tension between conveying the benefits of DT LVAD without creating panic and anxiety around the therapy. Many felt it was their responsibility to be very honest with the patients about the potential risks and burdens, providing full disclosure to avoid future decision regret.

- “I would rather give the patient more information than they think they need and have them not decide to go forward than to go forward with therapy and regret it.”

In contrast, the majority of MCS coordinators also felt a need to avoid overwhelming patients. Multiple coordinators described the contrast as “*walking a line*,”— finding a balance between the provision of complete, accurate information and a desire to not “*scare*” people away from a potentially life-saving therapy.

- “It’s sometimes hard to walk that line to not scare them but not paint a rainbow and butterflies picture.”

Coordinators described a need for non-biased, high-quality decision support materials to assist with this challenging process. Most programs relied heavily on industry-produced materials. Despite feeling that the industry materials were overly optimistic, MCS coordinators stated they continued to use them because there is “*nothing else out there*”. Several programs have developed their own educational materials and use those in conjunction with the industry resources.

- “The good about the [industry] video is it shows you all the things people can do. The bad thing is it looks like it was a vacation and everything is perfect.”

DISCUSSION

Patients offered DT LVAD are faced with a complicated decision to either pursue DT LVAD therapy, which requires a major surgical operation and the potential for major complications, or continue with medical management, which most often leads to comfort care. Previous work has described the needs of patients when considering DT LVAD^{21,22}; however, there is currently no literature exploring the roles and perceptions of MCS coordinators during the DT LVAD decision-making process. MCS coordinators are central to the care of patients after DT LVAD implant; however, they also play a key role during the pre-implantation decision-making time period. Most importantly, the majority of MCS coordinators come from a nursing background, which focuses on a primary commitment to promote and advocate for the health, safety, and rights of patients.²³ Prior literature has provided insight into the roles of MCS coordinators; however, it does not describe pre-implant roles specifically.²⁴ From the input of MCS coordinators, an optimal pre-implantation process appears to require three central components: 1) decision support with early introduction to DT LVAD therapy and alternative options, 2) an iterative process and multidisciplinary team, and 3) a careful approach balancing tension between conveying enough detail about the process yet not overwhelming patients.

Decision Support and Early Introduction to DT LVAD

Overwhelmingly, MCS coordinators felt that the decision to pursue DT LVAD is complex and should be patient-centered. They also felt that this decision is one that requires thoughtful reflection, including time to consider all options and time to discuss the decision with family and friends. Discussions should be ongoing and patients should have time to process all information before making a decision. Therefore, if at all possible, the initial introduction to DT LVAD therapy should take place early in the disease process. Just as advance care planning and end-of-life discussions are recommended to be initiated at the earliest possible stage, introducing a potentially life-changing therapy should be done in the same context.²⁵

An Iterative Process and Multidisciplinary Team

CMS recently released updated requirements for all DT LVAD centers.¹¹ In this memo, CMS stated that a multidisciplinary team with the appropriate qualifications, training, and experience must manage patients receiving DT LVADs. At a minimum, the team must include at least a cardiothoracic surgeon, a cardiologist trained in advanced heart failure, an LVAD program coordinator, a social worker, and a palliative care specialist.¹¹ These requirements are aimed to standardize the process and care for patients pursuing DT LVAD. MCS coordinators echoed the view that DT LVAD decision-making should involve a multidisciplinary team, including palliative care. Ideally, palliative care within a multidisciplinary team could help address the multidimensional nature of suffering (including spiritual and psychosocial suffering in addition to physical suffering) and enhance shared decision making in chronic end-stage heart failure.²⁶ Some programs have endorsed a palliative care consult for every patient considering a DT LVAD. This would provide an opportunity for patients and their support systems to address goals of care and end-of-life

issues that may otherwise have been only briefly discussed by the DT LVAD medical team.²⁷

A Careful Approach Balancing Tensions

Despite the high variability in pre-implantation programmatic structures and processes, MCS coordinators consistently emphasized the importance of high-quality education, decision-making, and consent. In order to facilitate this pre-implantation process, MCS coordinators recommended a caring and artful approach that recognizes and addresses the difficult nature of this decision and the challenges of performing education and consent within this emotionally charged and easily overwhelming situation.

One tool that may help ensure optimal decision support is the development of non-biased materials that ground the discussion of DT LVAD in an objective set of information. The one constant is that all MCS coordinators we interviewed rely on industry-produced videos and print materials. There is a paucity of research assessing the impact of industry-produced educational materials on patients' decision making, and these materials are often intended to serve marketing purposes and reflect inherent biases.²⁸ Several centers have developed their own DT LVAD educational materials; however, MCS coordinators only use these in conjunction with the industry-produced tools. MCS coordinators felt that independently produced DT LVAD specific educational materials would be beneficial for patients going through this process. Standardized DT LVAD materials should go beyond device introduction, also focusing on the complex decision and alternative options available.²⁵

Communication training may also facilitate optimal decision support. MCS coordinators are not specifically trained in informed consent and end-of-life discussions; regardless, the MCS coordinators we interviewed conducted these discussions with patients considering a DT LVAD on a regular basis. Specific training in communication techniques, shared-decision making, and palliative care may be beneficial for MCS coordinators who guide patients in this complex decision-making process.^{25,29}

According to MCS coordinators interviewed, the decision process can be improved by: 1) introducing the LVAD earlier in the process to allow time for decision making and conversation, 2) engaging palliative care more deeply in the process, and 3) developing educational materials that provide a balanced and thoughtful approach to this complex decision. MCS coordinators are integral to the large team caring for patients with LVADs. Future research should validate MCS coordinator perceptions, perhaps within the context of physician, surgeon, and other healthcare provider perceptions of the DT LVAD decision-making process. This study complements other qualitative studies addressing the needs of patients and caregivers during this complex decision-making process.^{21,22,30} The needs assessments of patients, caregivers, and MCS coordinators have informed our work developing a DT LVAD decision aid, available at www.patientdecisionaid.org.

Limitations

There are several limitations that should be considered when interpreting this data. First, the study was not a true cross-section of United States MCS programs. However, we used purposeful sampling methods to capture a wide range of program types from across the

country. Second, this study only includes the experiences and views of MCS coordinators in the DT LVAD decision-making process. Future work should incorporate the contribution of other clinicians, patients and caregivers' viewpoints to improve this complex process. Third, all but one MCS coordinator in our sample had a nursing background. Some MCS programs employ non-nursing professionals as MCS coordinators and we did not necessarily capture this population; therefore, our results may not be generalizable to those programs. Finally, we chose to focus on the relatively unique scenario of decision making for DT LVAD, and therefore our findings should not be applied to the bridge-to-transplant indication.

CONCLUSION

MCS coordinators provide a unique perspective on the DT LVAD decision-making process and are in a key position to assist with this major decision. Coordinators agreed that the DT LVAD decision-making process is complex; it benefits from early introduction, an iterative process, and a multidisciplinary team; and it requires an artful approach to manage tensions between providing essential information but not overwhelming patients going through this difficult process.

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Appendix: Interview Guide

OVERVIEW

1. First I'd like to learn about your program.

- Where in the hospital structure does your program fit (part of heart failure, CT surg, under transplant)
- Is your hospital part of a University system, community hospital, other?
- What percentage of your patients being considered for DT LVAD are new outside referrals? (For which you don't have long-standing treatment relationship)
- Do you have other duties besides working with VAD patients (i.e. transplant coordinator, heart failure nurse /NP). If yes, what are they?
- What is your educational background? Nurse? NP? CNS? Perfusionist? Engineer?
- How many long term durable VADs did your program implant last year? How many ongoing patients are you currently following? Do you do transplants?

- If not, are you part of the affiliated transplant center's interdisciplinary meeting? Who is included in your meeting? What is your role in introducing the therapy to patients?
- Some coordinators feel that they have a voice in the decision-making process while others do not. How about you?

DECISION MAKING – MEDICATIONS

2. Can you describe for me your general approach to patients when you are considering any treatment for heart failure?

- What do you think are the most important things to communicate to patients (generally for starting medications or considering devices)?

DECISION MAKING – LVADs

3. Now, I have a few questions about the overall process of informing patients about VAD therapy, making a decision, and obtaining consent.

- When and how do you decide to approach a patient about DT LVAD?
- How do you begin your discussion with heart failure patients regarding LVAD therapy?
- Who all is involved? Palliative care consult?
- What information other than verbal is used or given to the patient? What tools do you currently use to explain the therapy? Written, DVD, patient ambassador? Where does that information come from? (who made it)
- How is family / caregiver involved?

4. Understandably, all the potential risks and benefits of a medical intervention cannot reasonably be discussed with a patient. Concerning LVADs, what do you think are the most important aspects that patients should understand before receiving an LVAD? Why?

- If not mentioned, probe for the following: Surgical risks? Quality-of-life? Anxiety/Depression?

5. What are your greatest concerns or challenges about conveying risks to patients? What are your greatest concerns or challenges about conveying benefits? Do you quantify these numbers (and if so, is that helpful? What numbers do you use / where do you get these numbers?)

6. Some patients may approach the decision making process around LVADs differently than you do. Can you tell me about any differences? How about similarities?

7. Assuming you weren't involved with this program, if your doctor just told you that you were eligible for an LVAD, what would you want to know? What would be most important to you?

8. How do you handle it when a patient asks you to make the decision regarding their LVAD for them?
9. What do you think your program might be missing? What would you like to do better? If you could design the ideal educational intervention for you patients considering LVADs, what would that look like?
10. Have I missed anything? That is, is there anything else that is important for me to understand about the decision making process surrounding LVADs?
11. Last question, can you tell me about your most memorable LVAD experience? What was that like for you? What impact, if any, has this experience had on your work with LVAD patients?

ABBREVIATIONS

MCS	mechanical circulatory support
DT	destination therapy
LVAD	left ventricular assist device

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HIGHLIGHTS

- There is high programmatic variability in how DT LVAD decisions are approached
- DT LVAD is a major patient-centered decision
- The DT LVAD decision benefits from an iterative and multidisciplinary process
- There is a central tension between conveying detail yet not overwhelming patients

Table 1

Coordinator Demographics.

Coordinator Characteristics (n=18)	
Female	15 (83%)
Highest Degree / Primary Certification	
Associate Degree in Nursing	1 (5%)
Bachelor of Science in Nursing	7 (39%)
Masters of Science	3 (17%)
Clinical Nurse Specialist	1 (5%)
Nurse Practitioner	3 (17%)
Master in Business Administration	3 (17%)
Program / Center Characteristics	
Region location*	
Northeast	7 (39%)
South	4 (22%)
Midwest	3 (17%)
West	4 (22%)
Transplant center	14 (77%)
Number of DT LVADs, median (range)	30 (4-60)

* According to United States Census Bureau³¹