



## Perspectives from mechanical circulatory support coordinators on the pre-implantation decision process for destination therapy left ventricular assist devices



Colleen K. McIlvennan, DNP, ANP<sup>a,b,\*</sup>, Daniel D. Matlock, MD, MPH<sup>b,c</sup>,  
Madhav P. Narayan, BA<sup>d</sup>, Carolyn Nowels, MSPH<sup>c</sup>, Jocelyn S. Thompson, MA<sup>b</sup>,  
Anne Cannon, BSN<sup>e</sup>, William J. Bradley, RN<sup>e</sup>, Larry A. Allen, MD, MHS<sup>a,b</sup>

<sup>a</sup> Division of Cardiology, University of Colorado School of Medicine, Aurora, CO, USA

<sup>b</sup> Colorado Health Outcomes Group, University of Colorado School of Medicine, Aurora, CO, USA

<sup>c</sup> Division of Internal Medicine, University of Colorado School of Medicine, Aurora, CO, USA

<sup>d</sup> University of Colorado, Boulder, CO, USA

<sup>e</sup> Program of Mechanical Circulatory Support, University of Colorado Hospital, Aurora, CO, USA

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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 to 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 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.

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### 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.<sup>1,2</sup> Currently 114 centers across the United States are approved to perform DT LVADs.<sup>3</sup> 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.<sup>4–6</sup> With an increasing prevalence of heart failure,<sup>5</sup> limited availability of suitable donor hearts,<sup>7</sup> and ongoing improvements in LVAD technology,<sup>8</sup> DT LVAD is likely to become an increasingly viable treatment option for this expanding patient population.<sup>4</sup>

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.<sup>9</sup> 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

**Abbreviations:** MCS, mechanical circulatory support; DT, destination therapy; LVAD, left ventricular assist device.

\* Corresponding author. University of Colorado, School of Medicine, 12631 East 17th Avenue, B130, Aurora, CO 80045, USA. Tel.: +1 303 724 8361; fax: +1 303 724 2094.

E-mail address: [colleen.mcilvennan@ucdenver.edu](mailto:colleen.mcilvennan@ucdenver.edu) (C.K. McIlvennan).

the likelihood of prolonged survival.<sup>10</sup> 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,<sup>11</sup> 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.<sup>12</sup> 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*.<sup>13</sup> 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 listserv 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 Framework<sup>13</sup> 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.<sup>14</sup> 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.<sup>15–17</sup>

We employed several strategies to assure trustworthiness of the findings.<sup>18–20</sup> 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.<sup>20</sup> 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.<sup>17</sup>

## Results

### *Overview*

From August 2012 to January 2013, we interviewed 18 MCS coordinators from 18 programs across the United States. Interviews ranged between 20 and 55 min. 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

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