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Family caregiver-reported outcomes regarding decision-making for left ventricular assist device implantation☆

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ABSTRACT

Background: Family caregivers (FCGs) often participate in the decision for their loved one to receive a left ventricular assist device (LVAD). Little is known about the contribution of FCGs to this complex decision.
Objectives: To investigate family caregiver-reported outcomes related to decision-making for LVAD implantation and their experiences post-implantation.
Methods: Descriptive thematic analysis was used to analyze longitudinal data. Thematic saturation was achieved.
Results: Three key themes emerged from the data. The main theme in the pre-implantation period was: *Not a decision*. The two themes in the post-implantation period were: *More satisfaction than regret* and *Unanticipated situational change*.
Conclusions: Family caregiver-reported outcomes inform clinical practice and future research. FCGs of LVAD recipients did not see viable alternatives to LVAD implantation, were generally satisfied with post-implantation outcomes, and experienced unexpected life changes in the post-implantation period despite feeling prepared preoperatively. Education of both LVAD recipients and their FCGs must be optimized.

Introduction

Family caregivers (FCGs) play an important role in the care of individuals with chronic illness. It is estimated that over a 12-month period, 39.8 million people in the United States provide unpaid care to another adult.[1] The experience of being a FCG has been associated with financial strain, perception of burden, anxiety, depression, stress, poor self-rated health, and increased mortality for the caregiver.[1–3] The additional responsibility of participating in health care decision-making can result in worsening of those issues, particularly stress.[4] The FCG often shares the responsibility of decision-making with the care recipient, whether in an advisory role or in a more active capacity. FCGs may be called on to act as surrogate decision-makers if the person becomes incapacitated. Most people prefer family members to be surrogates when needed, based on the belief that their family knows what they would want.[5]

There are 6.5 million patients with heart failure (HF) in the United States.[6] Despite advances in medical therapy, individuals with HF experience an overall downward trajectory in their health. As they progress to advanced HF, approximately half die within 5 years of diagnosis.[6] Left ventricular assist devices (LVADs) are a life-prolonging technology for select patients with advanced HF as a bridge to transplantation, or as destination therapy when transplantation is not an option.[7,8] More than 2000 LVADs are implanted annually in the United States and this number continues to increase. Many LVAD recipients experience positive outcomes with improvements in health-related quality of life and survival (1-year survival 80%, 2-year survival 70%). However, many also experience complications including bleeding, infection, and increasing rates of hemolysis, stroke, renal dysfunction, and respiratory failure.[9] These complications may result in a prolonged initial hospitalization, repeated office evaluations, and frequent rehospitalizations. Involvement of FCGs in healthcare decision-making for individuals with advanced HF arise throughout the disease trajectory. This may include involvement in decisions about routine care, such as diet and exercise. As HF progresses, it often involves decisions regarding choices about palliative care or aggressive treatments such as LVAD implantation. The FCG

Abbreviations: FCG, family caregiver; LVAD, left ventricular assist device; HF, heart failure

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may participate in decision-making *with* the patient or be required to make decisions *for* the patient.

Negotiating the balance of positive outcomes and complications results in a complex decision that must be made. The importance of patient-reported outcomes to inform decision-making, guidelines, and policy has been acknowledged.[10] Previous studies describe patients' experiences with decisions about LVAD implantation.[11] Yet the patient rarely makes this decision in isolation and family caregiver-reported outcomes have not received the same attention. Shared decision-making has been supported by multiple professional organizations in reference to health care providers and patients.[12,13] Although family members are considered part of the shared decision-making process, less is known about the contribution of the FCG in the LVAD implantation decision. Guidelines primarily address provider decisions but include caregiver burden or lack of an identified caregiver as a relative contraindication to LVAD implantation.[14] Recent studies have begun to describe the experiences of caregivers for patients with LVADs, though do not focus on decision-making implications.[15–19] This study investigated family caregiver-reported outcomes related to decision-making for their family members' LVAD implantation and their resulting experiences post-implantation.

Methods

Study design

A longitudinal descriptive qualitative design was used for data collection and analysis. Qualitative methodology was most appropriate given the complex nature of the phenomenon of interest and the paucity of current data. Use of semi-structured interviews allowed for full exploration of the family caregivers' experiences and therefore, interview content that reflected family caregiver-reported outcomes of most importance to them. The Pennsylvania State University's Institutional Review Board approved the study (PRAMS22307EP-). Written informed consent was obtained from all participants on enrollment. Due to the longitudinal design, requiring up to 24 interviews, participants received a $10 gift card following each interview in compensation for their time.

Sampling and recruitment

This investigation used interview data from a longitudinal study of the palliative care needs of FCGs and patients with Stage D HF[8] and a predicted survival of less than two years as determined using the Seattle Heart Failure Model[20] (NIH/NINR1RO1NRO13419). Stage D HF, as defined by the American College of Cardiology Foundation / American Heart Association (ACCF/AHA), includes persons with refractory HF requiring specialized interventions.[8] Caregivers in the study were identified by the patients as the family member most involved in assisting to meet their care needs. Participants were recruited from an inner city hospital and an academic medical center with a referral base including urban and rural areas in the northeastern United States. The parent study included 100 patient-FCG dyads. Fifteen patient participants had LVADs implanted during the study. Their 15 caregivers were selected as the sub-sample for this secondary analysis.

Data collection

Serial semi-structured interviews were conducted to develop a full understanding of participants' LVAD decision-making and post-LVAD experiences over time. Interviews were conducted by one of the study's principle investigators who is experienced in qualitative data collection, the project coordinator, and a research assistant, both of whom were trained in qualitative interviewing by the principle investigator. Caregivers were interviewed monthly for up to two years or until the LVAD recipient's death using the interview guide developed for the parent study. The timing of LVAD implantation relative to study enrollment varied, as the LVAD was just one potential intervention in HF management. Interviews were conducted in a private area during hospitalizations and clinic visits or by telephone at the participants' convenience.

Interviews conducted prior to LVAD implantation questioned the decision-making process, caregiver role in the LVAD decision, and information received from healthcare professionals about LVAD implantation and other treatment options that may have been discussed. Interviews conducted post-implantation explored changes in LVAD recipient health, changes in caregiving responsibilities, and a retrospective evaluation of the decision-making process. Interviews were digitally recorded, transcribed, de-identified, and verified for accuracy.

Data analysis

Descriptive thematic analysis was utilized.[21] Initial domains, based on the interview guide, were further developed and differentiated based on the interview data. The research team, consisting of the parent study's two PIs and two PhD students, conducted independent coding of caregiver interviews. The findings from the independent analyses were confirmed by group analysis using an iterative team-based approach. Following group analysis, the research team agreed that thematic saturation was achieved as data was consistent across participants and no further themes emerged.

Strict methodological processes were employed to ensure trustworthiness of the data and qualitative analysis. Recorded interviews were transcribed by a professional transcriptionist. Interviewers verified the transcribed interviews, ensuring accuracy. During team analysis, an audit trail was documented to identify any discrepancy in coding. The research team discussed all discrepancies until consensus was achieved, ensuring dependability. All members of the research team agreed on the final codes and thematic description, ensuring credibility.

Results

Demographics

The sample included 15 FCGs of individuals with Stage D HF with a predicted survival of less than 2 years who had LVAD implantation during the study period. The FCG was the person identified by the patient as most involved in assisting to meet their care needs and participated in the decision for LVAD implantation. The indication for LVAD implantation was either bridge to transplant ($n = 10$) or destination therapy ($n = 5$). Five LVAD implantations occurred within one week of initial consultation; none were emergent. The majority of caregivers were female (12/15) and all were white. They ranged in age from 19 to 70 years of age (mean 52). Most were the spouse or partner (12/15); the others were the LVAD recipients' adult children. In addition to their role as caregiver, 11 participants were employed outside the home. One participant experienced the death of their family member LVAD recipient during the study period.

Qualitative themes

Independent and group analysis revealed three themes – one pre-implantation and two post-implantation. Themes were consistent across demographic parameters and regardless of the indication for LVAD implantation (bridge to transplant or destination therapy). Quotations have been selected to illustrate each theme. The main theme in the pre-implantation period was: Not a Decision. The two themes in the post-implantation period were: More Satisfaction than Regret and Unanticipated Situational Change.

Pre-implantation: Not a decision

All participants in the study were caregivers of a family member who underwent LVAD implantation. The basic pre-implantation outcome of the decision-making process, therefore, was a decision in favor of LVAD implantation. There was, however, a consistent theme in how FCGs portrayed that outcome. All caregivers described feeling that the choice of whether LVAD implantation should be accepted was not a decision to be considered. Their family members were increasingly symptomatic as advanced HF progressed. Caregiver participants viewed the LVAD as the next step in the treatment of HF, similar to starting a new medication. Heart transplant had been discussed and participants were aware of whether this was an option for their family member. They also acknowledged receiving information about the option of LVAD, including both risks and benefits, as well as the option of continuing medical management with a goal of symptom management. Most could not recall specific details of any of those options. They interpreted the choice as LVAD or death. Their only consideration was continuation of life, leaving no decision to be made.

"You have no other choice, have no other options once medications don't work."

"Could offer five years of quality time yet."

"It's what he needs if he wants any kind of life or he's not going to have a life."

The caregivers did not hesitate to express their opinions to their family members during the decision-making process. They did, however, make clear that the LVAD recipient made the final decision, except in those few circumstances in which they were critically ill and unable to participate so the caregiver acted as a surrogate.

"I know he feels you might as well take a chance and do it."

"It's his decision. But I think we'll probably pursue it."

Post-implantation: More satisfaction than regret

Caregivers expressed satisfaction with the decision for LVAD implantation. They identified decreased symptom burden and improved quality of life for the LVAD recipient following recovery from surgery. In comparison to the steady downward trajectory experienced prior to LVAD implantation, FCGs interpreted the stability of symptoms in the post-implantation period as a great improvement.

"I hope she stays stable and doesn't get worse. I'm optimistic."

"There hasn't been too much change, which is good."

Caregivers of LVAD recipients who experienced ongoing complications were not as satisfied with the decision. One caregiver of an LVAD recipient who experienced multiple hospital admissions due to gastrointestinal bleeding said, "Once he got that (LVAD), we thought his trips to the hospital would end." Satisfaction with the decision fluctuated with the severity of complications. The same caregiver, during several months without a hospital admission, said "The LVAD – there's no problem with that."

Post-implantation: Unanticipated situational changez

All caregivers felt that they received adequate information prior to LVAD implantation regarding the procedure, the device, and what to expect post-implantation. Education was provided by a combination of the cardiologist, cardiac surgeon, LVAD nurse coordinator, palliative care consultant, and others. Except for the primary cardiologist, caregivers could rarely recall the specific people that they spoke with during the pre-implantation period. They described the pre-implantation period as busy and overwhelming. Despite this, they felt prepared and confident in their ability to make the decision about LVAD implantation.

In the post-implantation period, however, caregivers provided a detailed description of feeling unexpectedly unprepared for the situational changes they faced after discharge. They experienced stress related to new daily routines even though the patient's health status had improved.

"Every day is something." (therapy, doctor visits, blood work)

"He has physical therapy 3 days a week so I go with him because nobody's trained in there to take care of his LVAD."

"Not being able to shower; not being able to swim; we're selling our boat because it's dangerous with him getting wet."

Over time, caregivers described a gradual adjustment to the new routine and responsibilities. They expressed pride in technical skills such as dressing changes and maintaining the LVAD. When asked what they would pass on to future caregivers of LVAD patients, the overall message was that the experience improves with time.

"Very, very scary. . .because of all the things you need to know. Once you get used to it and it becomes your new normal, it gets easier."

Discussion

This is one of the first studies to specifically examine family caregiver-reported outcomes related to the decision-making process for LVAD implantation. The caregiver perspective is different from, though related to, the patient perspective. Previous investigations have focused on provider and patient decision-making. The few studies including caregivers collected data on the decision-making process only after LVAD implantation.[22,23] This study documents the caregivers' involvement with the decision and its consequences for the FCG with longitudinal follow-up. It also highlights the importance of including family caregiver-reported outcomes when evaluating overall LVAD outcomes. Physiologic outcomes are important, but it is just as vital to understand that family caregivers did not feel that there was another option to the LVAD; that they were satisfied with the decision; and that despite having adequate education, they were not prepared for their experiences following LVAD implantation.

All participants in this study described the decision for LVAD implantation as not really involving a decision; this life-prolonging technology was the next step to extend their family member's life. This finding is consistent with the literature.[22,23] Of note in this study, caregivers expressed the same ideas of "not a decision" whether the choice was made in the intensive care unit or under controlled circumstances. Those who had multiple discussions with providers over a period of months described details of the procedure, the device and its management, risks and benefits. They did recall that the option of ongoing medical management and treatment of symptoms was discussed, though they did not recognize the term palliative care. Ultimately, they maintained that there was not a decision to be made as the only significant consideration was preserving life for their family member.

The issue of caregivers not seeing any viable option to LVAD implantation raises ethical concerns about informed consent. Patients with LVADs from this parent study described similar feelings of not having a choice.[11] When both partners express this same perspective,

one wonders whether they truly understand all of the treatment options, even when they have been discussed. The decision remains complex, even when it is not seen as such. Clinicians are obligated to discuss all of the treatment options, from device implantation to ongoing medical management to transition to palliative care, along with the risks, benefits, and consequences of each. Currently available educational resources for patients and caregivers are often suboptimal.[24] Development of tools to assess standardized knowledge[25] and decision aids[26–29] prior to LVAD implantation could be helpful but should also address knowledge of alternatives to LVAD. These mechanisms must also include the FCG as support or surrogate of the patient. In the end, it is the responsibility of the involved clinicians to ensure that both patient and caregiver understand all available alternatives and consent is truly informed.

Overall satisfaction of caregivers with the decision for LVAD implantation with minimal decisional regret is a new finding. Previous studies of FCGs for LVAD recipients have identified those who regret the decision.[18,23] In this study, even the caregivers of those with complications expressed satisfaction with the LVAD. In comparison to the patients in the parent study,[11] the caregivers clearly identified improvement in the LVAD recipients' physical health and quality of life following LVAD implantation even when the recipient did not perceive changes. Caregivers perceived stability as a positive effect after observing years of declining health, whereas LVAD recipients may not have improved as much as they expected. During one interview, a caregiver reminded her husband, who was in the room, "*But before the LVAD, you were really bad!*" This difference in perspective likely accounts for the differences in satisfaction with the decision for LVAD implantation.

Caregivers were not prepared for their role following LVAD implantation. Though they felt they had adequate information to make a decision during the pre-implantation period, the reality of the situation following discharge was a shock. Assuming responsibility for the LVAD from a technological standpoint was stressful. Caregivers took on this responsibility to a much greater degree than the LVAD recipients. Though all FCGs had other family members who could assist, they took primary responsibility upon themselves. They felt unprepared for the workload of doctor visits, therapy sessions, and the need to be almost constantly available to their family member. Restrictions related to the LVAD resulted in changes to even the simplest of routines, e.g., their family member could no longer use the shower to bathe and therefore needed more assistance.

The unanticipated situational change has been previously described in the literature.[11,16,17,19] What is concerning is that the findings have not changed over more than a decade. Despite advances in LVAD technology, patients and FCGs remain unprepared for the life changes LVAD implantation entails. Pre-implantation education is evaluated as adequate by caregivers. It may be adequate to meet their decision-making needs, but does not prepare them for life after discharge. The long-term effects of stress on caregivers of persons with heart failure are well described,[30] including development of post-traumatic stress disorder in caregivers of LVAD recipients.[31] Preparation of LVAD recipients' caregivers for the situational change that occurs in the post-implantation period must be optimized to minimize these negative outcomes for caregivers.

Several study limitations are noted related to the sample. The sample in this study was comprised only of FCGs of individuals who underwent LVAD implantation. Findings about the decision-making process might be different among those who declined LVAD implantation. Identification of those who decline LVAD may be more difficult, but this population should be included in future studies. Since timing of LVAD implantation relative to study enrollment varied, timing of specific interviews relative to implantation also varied. This could potentially result in recall bias. Finally, the homogeneity of the sample is a further limitation, comprised primarily of white females. Though participants were recruited from both an inner city and academic medical center with urban and rural patient bases, diversity was not achieved. Future studies must include diverse participants from multiple sites with LVAD programs.

Conclusions

This study has implications for all clinicians involved in the care of individuals with HF and LVADs. The implications are three-fold, based on the three major themes expressed by the caregiver participants: alternatives for management of advanced HF, changes in health post-implantation, and situational changes post-implantation following discharge.

Family caregivers must be involved in decision-making for the patient with advanced HF. They should be encouraged to be present for clinic visits and hospital rounds. Clinicians should arrange to have any significant discussion about treatment decisions with both the patient and FCG with a goal of shared decision-making. All alternatives for management of advanced HF should be discussed, including eligibility, risks and benefits. Alternatives include mechanical circulatory support (including LVAD), heart transplant, and ongoing medical management. Though these options are currently discussed, our findings suggest that FCGs do not always 'hear' what clinicians believe they say. These discussions should occur over the long course of the heart failure trajectory. The entire healthcare team should provide consistent information. Further research on optimal educational materials and decision aids is warranted.

In a previously published report, we noted that LVAD recipients' expectations of health and well-being following implantation were unmet.[11] In the current study, caregivers expressed a more positive view of LVAD recipients' health status, resulting in greater satisfaction with the decision for LVAD. Further exploration of the underlying reasons for the discrepancy is recommended. Clinicians should provide realistic health and quality of life goals for the post-implantation period.

Despite pre-implantation education, caregivers experience shock and distress related to post-implantation situational change, particularly following discharge. Further studies are needed to develop and test interventions to minimize the negative effects of this on caregivers. Potential interventions could include varying types and timing of education, meetings with current FCGs of LVAD recipients, online or live support groups, or other creative options.

Identification of family caregiver-reported outcomes surrounding LVAD implantation in this study informs our future practice and research. Inclusion of FCGs of advanced HF patients in decision-making for potential LVAD implantation is vital. Discussion of available options and their implications for health and health related quality of life should be ongoing throughout the HF trajectory. Further study is needed to examine discordance between patients and caregivers and to develop interventions that assist the caregiver in managing their new role as caregiver to a family member who is living with an LVAD.

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