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Research Article

Patient decision-making regarding left ventricular assist devices : A multiple case study

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ABSTRACT

Objectives: To understand how patients make decisions regarding a left ventricular assist device (LVAD).
Design: A qualitative multiple case study design was used to explore the context and influence of individuals regarding patients' decision-making processes through: 1) detailed, in-depth interviews of those mostly involved in the patient's decision and 2) pertinent data including observations, medical records, educational information and physical artifacts. Data clusters and patterns of co-occurring codes were examined using thematic analysis.
Main outcome measures: Themes were extrapolated from individual case summaries to provide an in-depth analysis of each case and a cross-case analysis across the multiple cases. The predominant theme, consistent with other studies, was the salience of survival.
Findings: This case study approach revealed new themes beyond those of prior studies. Patients considered: 1) self-care management for patients without a caregiver, 2) acceptability and future expectations of the LVAD and 3) the role of nurses in eliciting patients' fears, values and preferences.
Conclusion: The patients' decision-making processes regarding an LVAD involve a cost-benefit analysis of the anticipated needs and consequences of the LVAD. Acceptability of the device is relevant to clinical practice and public policy. Nurses have a unique role in seeking patients' concerns, an essential component of shared decision-making.

Implications for clinical practice

- Decision making was not automatic, but involved a thoughtful and complex process.
- Self-care management needs to include technological devices, particularly in the absence of a caregiver.
- Further education is needed to increase knowledge and sensitivity of all nurses and the public about evolving technological options in medicine, including LVADs.
- Intensive care nurses have an important role in eliciting patients' fears, values and preferences as a part of shared decision-making.

Introduction

Heart failure (HF) affects approximately 6.5 million adults in the United States (Kirklin et al., 2017) with more than 915,000 new patients diagnosed each year. (Benjamin et al., 2017; Yancy et al., 2013). The left ventricular assist device (LVAD), a means of mechanical circulatory support, is an increasingly used treatment option for patients, who are no longer responsive to maximal drug therapies and either ineligible or awaiting heart transplantation. The dramatic increase in recipients of LVADs over the past nine years suggests that more patients will be making decisions regarding this device (Kirklin et al., 2017).

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Previous research regarding the decision-making process of patients with advanced HF who were offered an LVAD has involved interviews of predominantly white male patients, months after they received an LVAD for either destination therapy (DT) or as a bridge to transplant (BTT). Patients often recalled that they "had no choice" in the decision (Kitko et al., 2016; Ottenberg et al, 2014). Blumenthal-Barby et al. (2015) similarly reported this decision as being "quick and reflexive" for both patients and caregivers, as did Bruce et al. (2015), who concluded that patients initially declined the LVAD until their condition worsened and had more information regarding the LVAD. In general, the perspectives of caregivers and physicians were limited.

Reported here is the first multiple case study conducted to understand the complexity of the patient's decision-making process regarding LVADs. Multiple case studies typically consist of a small number of cases to obtain the greatest possible amount of information and an in-depth analysis of factors beyond the individual cases (Creswell, 2013; Flyvbjerg, 2006). In this study, we obtained individual patient's perspectives, and the perspective of individuals (caregiver, physician, nurse, others) who had a role in the patient's decision to accept or decline an LVAD.

Methods

Study design

The case study method is used to explore and examine relationships through detailed, in-depth data collection involving multiple sources of information and reports a case description and case themes (Creswell, 2013). A case is a unit of analysis consisting of actual sources of information which are closely aligned with the purpose of the study (Yin, 2009). Yin recommends that six sources of evidence: 1) direct observations, 2) participant observation; 3) interviews, 4) documents, 5) archival records and 6) physical artifacts be considered to provide multiple perspectives and opportunities for triangulation as data collection occurs. While qualitative data are generally used for case studies, quantitative data may also be included (Creswell, 2013). These multiple sources of evidence all strengthen the credibility, dependability and confirmability of the study (Yin, 2009). Four to six cases are typical of multiple case study and are carefully selected to predict similar or contrasting results for their informational representativeness. Diverse cases are considered representative of relevant variation (Sandelowski, 2011; Yin, 2009). This research employed a qualitative multiple case study design to examine the patients' decision-making process through: 1) detailed, in-depth face-to-face interviews of those mostly involved in the patient's decision and 2) multiple data sources, including medical records, educational aids, field notes and physical artifacts. In this study, each "case" consisted of a patient with HF who accepted or declined an LVAD and at least three other individuals recommended by that patient for interviewing. Purposive sampling was used to obtain perspectives from individuals of diverse ages, genders, educational backgrounds and marital status (Creswell, 2013).

Setting

The study was conducted at an academic medical centre in New York City known for serving a culturally and socioeconomically diverse patient population.

Ethical approval

The study was approved by the medical center's Institutional Review Board (i14-02044). All interviews of the patients who accepted an LVAD were conducted in the hospital and the remaining interviews were held at the participants' convenience, in a variety of settings (e.g. hospital, residences).

Participants

Criteria for participant eligibility included English speaking patients, age 18 and older, with a confirmed diagnosis of advanced HF (NYHA class IIIb or IV, Stage C or D HF or INTERMACS 3) and who had decided to accept or decline an LVAD. The inclusion and exclusion criteria are provided in Table 1. Members of the VAD team identified and recruited patients who were eligible for the study.

Purposive sampling was used to obtain seven patients who chose to have an LVAD (as a BTT, DT, or bridge to decision [BTD]) and patients who declined an LVAD. The patients displayed great heterogeneity, including males and females, with varying clinical issues, co-morbidities, ages, family structures and supports, cultures and ethnicities, previous experiences with healthcare, socioeconomic status and professions. Establishing this range provided deeper insight into the influencing factors and different decision-making processes used by patients presented with the option of an LVAD. These and other factors contributed to the maximum variability sampling and facilitated informational representativeness (Creswell, 2013; Sandelowski, 2011; Yin, 2009).

Additionally, patients were asked to identify: 1) their care partner (a designated individual anticipated to assist with the care of the patient post-LVAD implantation or the person responsible for assisting with the patient's care if the LVAD was declined), 2) a physician, 3) nurse most influential in the decision-making process and 4) other individuals who had a role in their decision, and who were willing to be interviewed. In other words, a minimum of four participants was included in each case.

Over a 6-month period of recruitment and data collection, a total of 26 individuals were recruited to achieve maximum varia-

Table 1
Inclusion and exclusion criteria for patients participating in the study.

Inclusion Criteria	Exclusion Criteria
Adults age 18 years of age or older	Patients under 18 years of age
NYHA class IIIb, NYHA class IV, Stage C or Stage D HF or INTERMACS 3	Patients too ill to participate
Recently made a decision to: 1. accept an LVAD as a BTT 2. accept an LVAD as a DT or 3. accept an LVAD as a BTD (bridge to decision) 4. decline an LVAD	
Able to speak and understand English	Unable to speak and understand English
Able and willing to engage in a 60-minute interview	Unable or unwilling to provide informed consent
Able to identify referring physician, care partner (or significant other), nurse practitioner (NP) or primary nurse and others who may have assisted or influenced the decision	Unable to identify others who would be willing to participate in the study and could speak and understand English

tion sampling: one key informant, seven patients, four caregivers, three family members, four physicians, five nurses, a social worker and a clergy member (e.g. deacon). Several of the health care professionals were identified and interviewed more than once, resulting in a total of 31 interviews. In order to schedule the interviews with the appropriate coordination, it was essential for the researcher to be sensitive to each participant's time, be creative, flexible and adaptable. The researcher constantly communicated with both patients and members of the health care team (e.g. clerical staff, nurse manager, primary nurse, VAD coordinator). This was critical to ensure that the time and setting of the interview were appropriately planned to maximise the patients' trust, comfort, confidentiality and willingness to respond to questions with minimal interruptions. Further, the researcher, being very comfortable interacting with critically ill patients and families, quickly developed a rapport and created a safe environment for them to share their personal experiences. Both patients and families took the liberty of "teaching the researcher" about their decision-making process.

Instrument development

An interview guide was developed, pilot tested with a key informant and amended after consultation with experts in qualitative research and cardiac nursing. This guide was scripted with a series of open-ended questions and probes regarding the patients' symptoms, information patients received, their understanding of the LVAD and other options offered, concerns, specific factors considered and the role of others in the decision. Corresponding interview guides were developed for the non-patient participants.

Data collection

Informed consent was obtained prior to each interview. Precautions were taken to ensure privacy, confidentiality and reduce the likelihood of any participant influencing the responses of others. Between May and November 2015, patients who chose to have an LVAD were interviewed for an average of 60 minutes. Interviews were post decision and 15–44 hours pre-operatively.

The patients' medical safety was of paramount importance particularly since the face-to-face interviews occurred during a critical period. The researcher, an expert critical care nurse with strong clinical assessment skills, was cognisant of the patients' health and ability to participate in the interview. She ensured that the patients were at ease and comfortable sharing sensitive information, offering to stop the interview at any time. Some of the patients were monitored and all of them required medicated infusions, including intravenous (IV) inotropes.

Following each interview, patients provided the names of at least three additional individuals who were willing to speak about the patient's decision-making process. Patients unable to name a care partner were asked to identify individuals who provided support. Most of the interviews were face-to-face except for two physicians' telephone interviews. These interviews ranged from 31 to 145 minutes. All participants' identities were protected and all documents were de-identified using a numeric code and case number. Following their surgery, patients were given a gift card to thank them for study participation.

Data were filed by case number and organised using a case study database. De-identified audio-recordings were downloaded to a password-protected Dropbox™ file. Files were accessed and transcribed verbatim by a professional transcriptionist. Text was then compared to the audio-recording to ensure transcription accuracy. Information obtained and corresponding sources of evidence are summarised in Table 2.

Data analysis

The decision-making process was explored through Braun and Clarke's (2006) process of thematic analysis, which involved the following steps: 1) familiarisation with the data, 2) coding, 3) searching for themes, 4) reviewing themes, 5) defining and naming themes and 6) producing a report. Open coding systems embedded within the atlas ti7 software were initially used to assign codes (Creswell, 2013) and were followed by hand coding. The codes were organized and categorised into a codebook. The transcription of the pilot interview and coding were reviewed with another qualitative researcher to check for inter-coder reliability of at least 80% congruency. The codebook was amended as new codes were identified. To ensure dependability and reliability, periodic peer debriefing sessions occurred wherein coding schemes and findings were discussed with colleagues knowledgeable about qualitative analysis, HF and LVADs. An audit trail of coding decisions was maintained. Using an iterative process, data were reviewed for

Table 2
Sources of Evidence.

Type of information	What is needed	Sources of Evidence	Informant
Contextual to provide context and background	Organizational background and culture	Archival records, VAD team meetings	Members of LVAD team
	Site description	Observations, Medical records	Researcher, VAD coordinator
	Patient background	Interviews	Participants
Demographic	Patients' age, gender, marital status, race/ethnicity, education, religion, medical insurance information	Medical record	Entries by medical personnel accessed by VAD coordinator
		Interview	Participants
Perceptual	Participants' experiences	Interview	Participants
Relational	Clinic visits	Direct observations of individuals and interactions	Patient-care partner; Patient-VAD team; Patient-VAD coordinator-care partner-others
	Multidisciplinary team meetings		Between VAD team members
	Interviews	Body Language, Tone of voice, Emotions expressed	Researcher with participants
Physical	Educational material, LVAD device	Physical artifacts (handbook, DVD)	Patient/Care partner
	Patient's physical appearance (body image), self-image, perception	Observation Interview	Participants
Reflective	Formal and informal meetings	Field notes, memos, reflective notes, Research diary, Recorded reflections	Researcher

emerging meaningful patterns in order to develop a rich explanation and interpretation of each case (Yin, 2009). Further, recurrent themes and differences between cases were identified.

The following strategies enhanced trustworthiness: 1) rich individual case descriptions of the decision-making process, context and people in the study, 2) multiple methods of triangulation 3) member checking 4) all data were de-identified, appropriately filed and stored, and 5) reflexivity. Methods triangulation was used to collect data (e.g. interviews, educational materials, observations, meeting reflections), identify meaningful patterns and validate that data were consistent. Triangulation of data sources involved comparing and crosschecking various data at different times by different means. For example, observational data were compared with interview data and educational materials. Perceptions of the different participants in each case were compared. Lastly, the consistency of information was checked multiple times. This redundancy of data collection procedures from different sources was part of the triangulation process designed to clarify meaning and increase our confidence in the findings. This application of multiple methods of triangulation enhanced the reliability of the results and attainment of data saturation (Fusch and Ness, 2015). Feedback was obtained from the participants in order to verify interpretation of the data. Also, clarification from the HF specialist and VAD coordinators was obtained regarding current policies and recommendations for LVAD eligibility and social supports. The researcher maintained a diary and field notes, used to reflect personal perceptions and biases.

Table 3
Patient Characteristics.

	Mean	Median	Minimum	Maximum
Age (years)	57.6	51	46	76
EF	20.7%	18%	12%	40%

		N
Sex	Male	4
	Female	3
Decision Type	Bridge to Decision	3
	Bridge to Transplant	1
	Destination Therapy	2
	Declined LVAD	1
HF Etiology	Ischaemic Cardiomyopathy	3
	Non- Ischaemic Cardiomyopathy	4
Stage of HF	NYHA II B	1
	NYHA III	1
	NYHA IV C	1
	NYHA IV D	1
	INTERMACS 3	3
Race/ethnicity	Caucasian	2
	Asian	1
	African American	2
	Haitian	1
	Jamaican	1
Marital Status	Married	3
	Divorced	1
	Separated	1
	Single	2
Education	High School	3
	Some College	1
	Bachelor's Degree	1
	Master's Degree	1
Employment status	Working	1
	Unemployed	4
	Retired	2
Insurance	Medicare	3
	Private	2
	Medicaid	2
	Interrupted	4
Religion	Catholic	1
	Baptist	3
	Episcopalian	1
	Lutheran	1
	Unknown	1

Findings

Table 3 provides the demographic characteristics of the patients interviewed. There were seven cases: six patients accepted an LVAD (one BTT, two DT, three BTD); one patient declined an LVAD for DT. Table 4 provides the characteristics of each case. A total of 31 interviews were conducted with 26 individuals, as some patients identified the same physician or nurse.

Decision summaries provided the themes used in the analysis of data collected from the participant interviews for each case, as well as the medical records and field notes containing the researcher's observations and reflections. Themes consistent with those identified in prior studies (Blumenthal-Barby et al., 2015; Bruce et al., 2015; Kitko et al., 2016; McIlvennan et al., 2014; Ottenberg et al., 2014) include: 1) perceived severity of illness, 2) need for information, 3) importance of the LVAD coordinator role, 4) supportive role of family, 5) value of speaking to patients with LVADs and 6) perception of the LVAD as experimental by African-American patients.

Previous themes have been used to develop decision aids for patients and caregivers (McIlvennan et al., 2016; Thompson et al., 2015). However, the current investigation revealed themes not previously identified. These warrant attention. They are: 1) the salience of survival and complexity of the decision-making process, 2) imperative of self-care management as not all patients have a caregiver, 3) acceptability and future orientation with the LVAD and 4) the role of bedside nurses in shared decision-making.

Themes

The salience of survival and complexity of the decision-making process

The overarching theme that emerged from the patient and family member interviews was the salience of survival. All patients, including the decliner, emphasised that they wanted to live. Patients vividly recalled conversations with their physicians concluding "*I wasn't going to live long*" and "*I have three to six months* (to live) *or several years with an LVAD*". Others remembered the information being less explicit such as, "*he told me I should take a long vacation*". Most patients were initially surprised with the diagnosis, had difficulty processing the information, and took several days "*to sink in*". One patient focused on the LVAD's benefits, saying "you don't want to read that you could die. *You don't want to know*". While patients identified the LVAD as the key to survival and improved quality of life, they carefully thought about the decision. It was not "automatic" as suggested by previous studies.

All patients described debilitating physical symptoms caused by HF. Family members concurred that patients "couldn't walk without stopping to catch a breath" and specified how co-morbidities (e.g. diabetes, asthma, stroke, kidney disease) contributed to the patients' limited activity, complex management of medications and restricted diet. Paradoxically, patients described "*having to be strong*" as they prepared for this "*huge life-changing procedure*". Patients unanimously were concerned about "*having to carry batteries*" and "*being careful not to get the device wet*". Both patients and families hoped the improved circulation of the heart would improve patients' overall health. While patients concurred that they would "*get the LVAD to save* (my) *life*", they carefully considered the risks of surgery and alternatives. One patient said," *it's sort of a risky alternative when you can wait for the transplant but there is no guarantee that you'll be alive...or go for the LVAD*". The patient in the sample who declined, believed that his risk for complications during and after the surgery would be greater due to his extensive

Table 4
Characteristics of each patient and case participants.

Case	1	2	3	4	5	6	7
	Patient Characteristics						
Sex	Female	Male	Female	Female	Male	Male	Male
Age	>65 yrs	<65 yrs	<65 yrs	<65 yrs	<65 yrs	>65 yrs	<65 yrs
Decision	BTD	BTD	BTT	BTD	DT	Declined DT	DT
	Other participants interviewed						
Care Partner	Husband	*None*	*Sister*(not interviewed)*	Husband	*None*	Wife	Neighbour
Other		CSW	Daughter*	Deacon	Mother in-law		Mother
Physician	HF Spec	HF Spec.	HF Spec.	Cardiologist	HF Spec.	Cardiologist	Electro- physiologist
Nurse	NP #1	NP #2	NP #1	NP #3	ICU RN	NP #1	Cardiology RN

BTD = Bridge to decision; BTT = Bridge to transplant; DT = Destination therapy; * = daughter was interviewed instead of the sister, the designated care partner; NP = nurse practitioner (VAD coordinator).

surgical history. He feared exacerbation of pre-existing conditions and was unwilling to accept the device.

Imperative of self-care management as not all patients have a caregiver

When patients were offered an LVAD, they were expected to identify a care partner who would care for them post-implantation. Some voiced discomfort with this expectation, finding it embarrassing to discuss personal issues and living arrangements with the VAD team.

All patients and family members found the LVAD information frightening. Some family members voiced the "*need to learn*", and assumed the care partner role. This was comforting to older patients with arthritis who were concerned about "*shaky hands*", maneuvering the equipment and changing the battery clips. However, it appeared that exhaustive information caused concern and reservations for some in accepting the caregiving role. Some individuals required "*coaxing*", as described by patients and VAD team members. These individuals only agreed to help the patient short-term, while seeking other options long-term. One family sought a neighbour's assistance. Patients accepting the LVAD anticipated post-operative needs such as dressing care, and also daily activities such as house-cleaning. Several patients doubted their caregiver's long-term commitment. They hoped to learn and adapt quickly and become independent with self-care.

One patient pursued the HF specialist of a second center and convinced the VAD team that he could perform his own self-care with the LVAD, thereby improving his eligibility for the a heart transplant. Some of the patients thought that they had to "*prove*" to the VAD team that a caregiver was not essential and could perform their own care. They participated in education sessions, kept hospital appointments, managed their perpherally inserted central catheter (PICCs) and IV milrinone. All patients perceived this routine analogous to the lifestyle and care that would be required with the LVAD. The members of the VAD team reiterated this perception. Additionally, patients identified contingency plans in the event of a power loss, expected to use educational materials for reference, and relied on the VAD team's continued support. Regardless of the degree of commitment of a care partner, those receiving the LVAD informed and educated neighbors and the police/fire departments about the device, with a "*back-up plan*" for power emergencies. One patient added, "*I have a whole village, my daughters, my nephews, my sisters, neighbours, friends. I have a whole team of support*". In contrast, the decliner explored his options solely with his wife, also a nurse and dedicated care partner. In spite of her promised support, he was unable to accept the anticipated disfigurement associated with the LVAD.

Acceptability and future orientation with the LVAD

The invasiveness, alteration in body image, acceptability of the LVAD and adaptations required for patients to "*live normally*" were identified across all interviews. Patients and family members were averse to the size, weight and appearance of the LVAD. Patients anticipated changes to their lifestyle, relationships and environment.

All patients had difficulty imagining the device "*sticking out of their stomach*" and "*carrying batteries*". Similarly, families had difficulty comprehending what it would be like to have an LVAD. One family member said, "*For me, I don't want cables coming out of my body. You've assaulted the image. Everyone has a perfect image of themselves*". Patients unanimously were concerned about how the public would perceive them with the device. While some patients were pleased to hear that the LVAD could be camouflaged, they were still troubled by the public's reaction to them. The men were concerned that police officers would mistakenly view the LVAD and batteries as weapons. Men and women alike were worried about being "*stopped and questioned*" and prevented from travelling because of the device. On the positive side, one patient was thrilled to meet "*another black, heavy person*" who explained how he "*lived with the LVAD*" and concealed the device. Other participants had similar encounters, which helped alleviate their concerns about altered body image and lifestyle.

Patients assessed the acceptability of living with the device in their decision-making process. They were willing to adapt to the undesirable characteristics in order to survive and enjoy an improved quality of life. Even so, all patients were hopeful that newer generation devices would become smaller, less invasive and more efficient with time. To them, the LVAD was not an endpoint, but a bridge to an improved LVAD or heart transplant. This possibility of future options clearly influenced decisions.

The role of bedside nurses in shared decision-making

Unlike earlier studies, which solely reference the VAD coordinator's role (Blumenthal-Barby et al., 2015; Ottenberg et al., 2014), patients identified the bedside nurse as instrumental in the decision-making process. Thus, the intensive care unit (ICU) nurse, cardiology nurse and three nurse practitioners (NP) or VAD coordinators were interviewed. Patients remarked that nurses who provided direct patient care were active listeners, providing "*therapeutic presence*", empathy and support. Patients explained that the bedside nurses "*were there for them*" every hour of the day, making them comfortable expressing their concerns regarding "*living with the LVAD*". Bedside nurses helped them to discuss their fears regarding activities such as cooking, gardening and having sex with the LVAD.

Table 5 provides illustrative quotes of the above four themes.

Discussion

The salience of survival was identified across all patient cases. Their expectation of the LVAD was to live longer with an improved quality of life (e.g. relief of symptoms, spend more time with fam-

Table 5
Theme characteristics of Participants.

Theme	Subtheme	Quote
Decision-making was not automatic	Complex process involved thought	Patient said, “*I have a valve, I take blood thinners. So, because of the blood thinner*. . .*because of all the issues with that*. . .*my blood pressure*. . .*uh possibly not being stable. There’s a lot of risk involved for the doctors*”. Another patient went to the Doctor’s office and saw “*back to back LVAD patients*”. She could barely see the LVADs and said, “*You have to look for it under clothes, a belt holds the batteries, but you have to carry the stuff* (batteries) *and a raincoat. All the patients I saw were doing much better; they could do everything except football and swim.“I switched from I don’t want it to I can’t wait for the surgery*”.
Caregiver role Situations where there is no caregiver	Information	Spouse said, “*It was a lot for her to hear, that she was anxious and overwhelmed*”.
	Peer support	The NP said, “*when she* (significant other) *really learned what it entailed, she was no longer interested*”. After seeing another patient with an LVAD, a patient said, “*If he can do it, so can I*”
	Need for Family support	Mother-in-law said that he (patient) wanted to hear, “*okay, go ahead. I agree. Let’s do it*”.
	Self-care	Patient said, *“it’s a huge sacrifice for me*. . .*carry this box around, changing the bandages, being prepared for the alarms*. . .*but eventually I will learn*”
Acceptability of the device	Personal acceptability	Decliner said, “*what stuck out in my mind more than anything else is the tube coming out of my side, then to change the battery. I said‘Oh God’. It was not a pretty sight at all*. . .*this was not a lifestyle I want to live with*” Another patient said, *“It’s a“huge life changing procedure*. . .*you have to carry batteries and I’ll be plugging myself in the wall at night, like a recharging car*”
	Family Acceptance	Patient said, “*it will be hard to go to Florida* (with my family) *and not be able to go in the pool or to take a shower*” Family member said, “*I don’t want her to die*”. Another family member said, “*You can’t go back. You’ve either got to get a heart transplant or live the rest of your life with this gadget connected. Those are the options*”.
	Public acceptance	Female patient said, “*I will be self-conscious for a while*. . .*going out in public*”. Male patient said, “*all I keep thinking is with the battery packs, I’m afraid*. . .*the cops are going to shoot me because it looks like guns*”.
Role of nurses in decision-making	VAD coordinator	Patient said, “*they* (the NPs) *that just left*. . .*there’s a whole team. They tell me. They show me. They teach me. They prepare me*. . .*alot about the surgery and everything*. . .*And tomorrow’s my surgery*. . .*Once I come out of surgery, they’re gonna be there*. . .*to teach me how to change the bandage, and I’m gonna learn all about it*”. VAD coordinator said, *“if we had not been receptive to all their questions*. . .*and explaining everything. If the family did not feel they had a good handle on it, then they wouldn’t have encouraged their wife, their mother to have this and it wouldn’t have happened*”.
	Bedside nurse	One patient said the nurse told her to “*notify a lot of people of what is my plan, because these are the people who would support me*. . .*But I used to be secretive. I don’t like people to know my business, my personal life*”. A Family member said, “*if the nurse observes a couple holding hands*. . .*the nurse needs to know that one of the concerns that is passing between these two people is,‘will I ever be able to have intimate relations again, the way they were?’*. . .*the nurse has to be astute enough to know that that (sex) is one of their concerns, even if they are not voicing it*”.

ily, return to work). Patients sought relief of symptoms despite the inconvenience of wearing an external device. The patients in MacIver’s study (2008) identified the anticipated mode of death to be a contributing factor in their decision. While patients and caregivers in this study said they “*focused on the positive*” attributes of the LVAD, several of them anticipated how they would respond to negative consequences of the LVAD. Patients worried about the possibility of becoming incapacitated with the device and a burden to their loved ones. Indeed, patients considered what their future would be like post-LVAD. Patients performed a cost-benefit analysis of the attributes of the LVAD. They assessed its acceptability, including anticipated needs and potential consequences of living with the LVAD.

Patients are inundated with new knowledge and technological skills that need to be understood and mastered. Preferably, care partners are identified, become competent with this new technology and are committed to supporting patients. Our research has shown, however, that potential care partners display various degrees of involvement in the decision-making process. McIlvennan (2015), Thompson et al. (2015), Wingate (2016) et al. conducted their studies with the premise that a caregiver is required. However, per International Society of Heart and Lung Transplantation (ISHLT) and Centers for Medicare & Medicaid Services (CMS) guidelines for Mechanical Circulatory Support (MCS) devices, social support is recommended; lack of a caregiver is a relative contraindication to having an LVAD (Feldman et al., 2013; Peura et al., 2012). The VAD team in our study described rare but extenuating circumstances wherein patients without a caregiver would be offered an LVAD. These patients: 1) had prior experience with self-care, 2) demonstrated an ability to perform self- care by successfully managing their medications, monitoring lab values and following up with physicians and 3) anticipated self-care needs with the LVAD. These patients described self-management of IV milrinone to validate their ability to monitor a site for infection, perform dressing changes and respond to pump alarms. Except for Bruce et al.’s (2015) study, the correlation to IV milrinone has not been previously discussed. Additionally, patients understood the ramifications and lifestyle adaptations required for this permanent device. Particularly in the absence of a care partner, patients intended to become proficient with their self-care, including how to recognise and seek medical attention as needed.

There are multiple inherent issues regarding the acceptability of an unnatural device and adaptations required for patients to “*live normally*”. Another key finding was the need for patients and caregivers to express concerns regarding the attributes of the LVAD and how these attributes would be consonant with their sense of well-being. Patients anticipated how the device would change their lifestyle, relationships and environment. Acceptability of the device has been addressed in two recent publications. Bruce et al.’s (2015) described disfigurement as a reason for patients to delay or refuse the LVAD. Magid et al. (2015) whose hypothetical study involved young people without HF, suggested that technology would become more acceptable if it were associated with fewer complications and side effects. Participants in our study also were apprehensive about disfigurement, altered body image, and how patients would be perceived in public. Acceptability of the LVAD's characteristics was important in their willingness to adapt to the device and an important factor in decision-making.

The current study is critically important because it engaged both the VAD coordinators and bedside nurses of different settings. Supporting different aspects of the decision-making process, all nurses had a critical role in providing education and understanding what was important to patients and their quality of life. The ICU and cardiology nurses detected tensions in family relationships and facilitated communication regarding patients' fears and concerns regarding: 1) the surgery, 2) the attributes of the LVAD, 3) their willingness to accept the device and 4) the adaptations needed to live normally with the LVAD. By observing the patients' verbal and non-verbal behaviour, these nurses provided emotional support and fostered expression of the patients' values, which became apparent as patients discussed the activities they enjoyed and concerns they had regarding their future orientation.

Much of the literature argues that patient-physician communication be improved and that patients' understanding of information is an essential part of the decision-making process (Thompson et al., 2015). However, it seems that patients do not share their ideas, concerns and preferences (Fagerlin et al., 2013). Nurses therefore, have an important role in exploring the patients' "unspoken words" to address their needs. While some of these topics (e.g. sex, hospice) may be difficult to discuss, nurses have the unique opportunity to provide a non-judgmental environment for patients to express their concerns.

Study strengths and limitations

The most notable strengths of this study involve the sample and data collection methods which differ from prior studies. This research represents the first multiple case study conducted to understand the decision-making process of patients with HF regarding LVADs. The sample consisted of a heterogeneous population of which variability in age, gender, education and marital status were evident. The sample of seven cases (31 interviews) was robust for a qualitative case study. Even though six of the patients chose to have an LVAD and there was only one decliner, the process of decision-making was examined from various perspectives, which provided for rich data analysis. In addition, it is important to note timing of interviews in that patients were interviewed at a critical juncture after a decision and before the LVAD was implanted.

Another strength of this study was the use of multiple sources of data to verify, validate and amplify the information obtained from the interviews and a rigorous chain of evidence was maintained. Multiple measures were used to objectively collect, review and interpret the data, including a research diary to capture the researcher's ongoing reflections and maintain an audit trail of data collection. A key informant provided clarification and feedback regarding the findings. Experts in the field of decision-making, LVADs, HF and palliative care were consulted throughout the study to validate this study's findings and they provided invaluable comments and suggestions regarding areas which required further investigation and clarity.

The literature reinforces the notion that patients with end stage HF have no other option than to have an LVAD. This study further explored this initial perception of patients and found that the decision-making process is far more complex and involves a multitude of factors. Most fascinating was the patients' perceptions and expectations for existing and future technologies.

There were also a number of limitations of this study. First, there were limitations related to patient recruitment. Patients were recruited from a single academic medical center, which was not a designated heart transplant center at the time of the study. Regardless, a patient for BTT was recruited for this study. The Medical Director and VAD coordinators identified and facilitated the recruitment of all the patients in this study. While a diverse patient population was selected, there was a potential for response bias in which the perceptions of the patients who were selected and agreed to participate could be different from patients who were not selected to participate. More research is needed to include LVAD decliners and patients of cultural and ethnic minorities to better understand and differentiate their attitudes and beliefs regarding decision-making. We can learn from patients who decline the LVAD and the optimal way of planning goals of care, including transitional, palliative and hospice care.

It is not the intent of qualitative research to generalise, but the results were useful in the building of theory (Yin, 2009). A conceptual model was developed and revised based on the responses of those interviewed and there may be applicability to other patient populations who are faced with technological options.

The interview guide was used as a reference, particularly during the interviews with patients and their care partners/designees. Because these participants were so willing to share, they were encouraged to tell their story with minimal interruption so that the most important issues related to the decision-making process would be revealed. The interview guide was used to ensure that all the main topics were addressed. Similar questions were asked in a consistent manner for each interview so that responses could be compared across cases. It is possible that some of the researcher's perceptions and beliefs prevented the probing of sensitive issues which could potentially upset the participants, particularly the patients (e.g. thoughts about palliative care and end-of-life). However, some patients raised sensitive issues themselves. Caution was used when patients responded with emotion since they were having surgery the following day.

Conclusion

Consistent with other studies, the following themes were identified: Salience of survival, quality of life, importance of family in the patients' decision. While the salience of survival was a prominent theme, most patients in this study made the decision to accept or decline an LVAD after a thoughtful process, contrary to prior studies which suggest that these decisions are automatic. Instead, the decision-making process involved a rigorous exploration of each of the anticipated needs and consequences of the LVAD, of which acceptability of the device was a major focus. The current investigation generated new knowledge regarding acceptability of the device, future expectations for living with an LVAD, the importance of self-care management and the role of nurses in eliciting patients' concerns and preferences, which have implications for practice.

This study highlighted the concerns of patients regarding the acceptability of the device and acceptance by society. Nurses working in different specialty areas need to be particularly aware of their personal attitudes and beliefs regarding technology when they interact and care for patients with LVADs, who are particularly sensitive to their alterations in body image. Additionally, as indicated in this research and other literature, racial, cultural and ethnic disparities still exist and affect patients' help seeking behaviours and choices for treatment. Further research is needed to explore how these disparities contribute to patients' distrust in physicians and health care, and how nurses can assist in mitigating those factors.

Current practice relies on the extensive role of the VAD coordinator in the care of patients with LVADs. According to the patients and families in this study, a major component of the VAD coordinator role was to provide education about the LVAD and continuously reinforce that information. Nurses have a critical role in providing education, ensuring patients' understanding of the information and empowering patients to broaden their self-care management skills to include management of the LVAD.

While patients recognised their need for the VAD coordinator, they identified the primary care nurses (including Critical Care nurses) as having a unique and pivotal role, while giving direct patient care, in providing information and helping patients express their thoughts and concerns. In addition to providing emotional support, nurses are important members of the transdisciplinary health care teams and can identify and seek additional consultation and services when needed (e.g. VAD team, chaplain, social work, palliative care). The primary nurses' role is therefore critically important in addressing the gap identified in shared decision-making of eliciting patients' values and preferences.

As more patients have LVADs implanted and live longer, increasing awareness and acceptance by the public is important. At a minimum, education of the public regarding the identification of patients with the LVAD and how to respond in emergencies is needed.

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Clinical trial registry number

Not applicable.

Conflict of interest

None.

Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.iccn.2018.10.004.

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