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LVAD patients' and surrogates' perspectives on SPIRIT-HF: An advance care planning discussion

Maureen Metzger, PhD, RN [a,*], Mi-Kyung Song, PhD, RN, FAAN [b],
Stephanie Devane-Johnson, PhD, RN [c]

[a] *University of Virginia School of Nursing, VA, USA*
[b] *Emory University, Atlanta, GA, USA*
[c] *University of North Carolina at Chapel Hill School of Nursing, NC, USA*

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ABSTRACT

Objectives: To describe LVAD patients' and surrogates' experiences with, and perspectives on SPIRIT-HF, an advance care planning (ACP) intervention.

Background: ACP is important for patients with LVAD, yet little is known about their experiences or those of their surrogates who have participated in ACP discussions.

Methods: We used qualitative content analysis techniques to conduct a secondary analysis of 28 interviews with patients with LVAD ($n = 14$) and their surrogates ($n = 14$) who had participated in an RCT pilot study of SPIRIT-HF.

Results: Main themes from the data include: 1) sharing their HF stories was very beneficial; 2) participating in SPIRIT-HF led to greater peace of mind for patients and surrogates; 3) "one size does not fit all" when it comes to timing of ACP discussions.

Conclusions: An understanding patient and surrogate perspectives may inform clinicians' approach to ACP discussions.

Introduction

Recent advances in medical technology have greatly influenced the management of late-stage heart failure. Left ventricular assist devices (LVADs) in particular, have become an option for prolonging survival[1] and ameliorating the symptoms[2–4] of heart failure in both heart transplant candidates (bridge to transplant (BTT)), and in some patients who are not destined for transplant (destination therapy (DT)). These devices however, are not curative, and advance care planning (ACP) is essential.[5–8] The majority of patients and their families do not have detailed conversations about end-of-life treatment preferences until complications arise.[5,7,8] Consequently, the care that is ultimately delivered, may be inconsistent with patients' goals and values.[5–8] To address the lack of preparedness for end-of-life decision making, an ACP intervention, entitled Sharing the Patient's Illness Representations to Increase Trust in Heart Failure (SPIRIT-HF), was pilot-tested in a sample of patients with LVADs and their surrogate decision-makers. Results, which are reported elsewhere,[9] indicated that SPIRIT-HF was feasible and acceptable. Specifically, participants were unanimous in their characterization of the SPIRIT-HF ACP discussion as beneficial, with the most positive aspects including opportunities to: review their experiences with the LVAD, clarify end-of-life treatment preferences, and increase their knowledge about possible future treatment-related decisions.[9]

In the original study, acceptability was assessed via semi-structured interviews. As expected, during the interview process participants provided information pertinent to their experience of the intervention. In addition, and wholly unsolicited, they shared quite intimate thoughts about their experiences of either having advanced HF or being the loved one of someone with advanced HF. They described in detail *how* and *why* engaging in ACP discussions are so beneficial to patients and families. Researchers were impressed by the volume and richness of information voluntarily offered, and by participants' explicit desire to share their observations and recommendations in a way that would inform other patients, families and clinicians.

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[*] Corresponding author. University of Virginia School of Nursing, P.O. Box 800782, 5038 McLeod Hall, Charlottesville, VA 22908-0782, USA. Tel.: +1 434 924 0112.

E-mail address: mjm9@virginia.edu (M. Metzger).

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This provided the foundation for conducting a secondary analysis on the interview data, the purpose of which was to increase our understanding of patients' and surrogates' experience of engaging in ACP discussions, specifically how and why these discussions may benefit patients with LVADs and their families. If clinicians have a better understanding of the patients' and surrogates' experiences, then they will be better equipped and perhaps more inclined to incorporate ACP discussions into patient care.

Methods

Design and sample

This was a secondary qualitative descriptive analysis of interview data from a pilot study of SPIRIT-HF. Participants were recruited for the pilot study from an LVAD outpatient clinic at the University of North Carolina Medical Center. All research team members successfully completed training in the ethical conduct of research with human subjects, and the university's Institutional Review Board approved all aspects of the study protocol. Written, informed consent was obtained from all participants.

Eligible patients were English-speaking, had an LVAD for either DT or for BTT, were medically stable, at least 30 days post-LVAD placement, with a designated surrogate decision-maker who was willing and able to participate with the patient. The total sample of the original study was 29 patient/surrogate pairs (58 participants). Of those, 14 patient/surrogate pairs (28 participants) were randomized to the intervention or SPIRIT-HF group, and completed separate, semi-structured follow-up interviews.

These 28 participants, 14 patients and their 14 surrogate partners, comprised the sample for this secondary qualitative descriptive study (See Table 1.). In general, the patient participants were married or partnered ($n = 13$, 92.8%), caucasian ($n = 9$, 64.3%), male ($n = 12$, 85.7%), with an average age of 62.6 years (SD = 7.6), and at least a high school education ($n = 14$, 100%). The majority of patients had multiple co-morbidities, such as COPD and kidney disease and were designated DT, meaning not transplant eligible, at the time of LVAD placement. The range of time on support was from 2 to 20 months, with an average of 11 months (SD = 5.4). Surrogates tended to be caucasian ($n = 9$, 64.3%), female ($n = 12$, 85.7%), with an average age of 56.2 years (SD = 12.4), and the spouse or partner of the patient ($n = 12$, 85.7%).

Table 1
Sample characteristics.

Characteristic/variable	Patient ($n = 14$)	Surrogate ($n = 14$)
	n (%) M ± SD (range)	n (%) M ± SD (range)
Gender		
Male	11 (78.6)	2 (14.3)
Female	3 (21.4)	12 (85.7)
Age	62.6 ± 7.6 (44–74)	56.2 ± 12.4
Race		
African-American	10 (71.4)	10 (71.4)
Caucasian	4 (28.6)	4 (28.6)
Patient/surrogate relationship surrogate is …		
Spouse or partner	–	12 (85.7)
Adult child	–	2 (14.3)
Educational background		
High school	6 (42.9)	5 (35.7)
Associates level college/trade school	4 (28.6)	6 (42.9)
Bachelors level college	1 (7.1)	3 (21.4)
Graduate school	3 (21.4)	–
Employment status		
Full time	1 (7.1)	6 (42.9)
Unemployed	–	1 (7.1)
Retired	6 (42.9)	5 (35.7)
Disabled/unable to work	7 (50)	2 (14.3)
Total gross annual household income		
< \$10,000	1 (7.1)	–
\$10,000 – \$19,999	1 (7.1)	1 (7.1)
\$20,000 – \$29,999	3 (21.4)	3 (21.4)
\$30,000 – \$49,999	–	1 (7.1)
≥ \$50,000	9 (64.3)	9 (64.3)
Months on VAD support	11 ± 5.4 (2–20)	–
LVAD purpose destination therapy	11 (78.6)	–
Advance directives in health record	6 (42.8)	–

SPIRIT-HF intervention

The intervention, SPIRIT-HF is described in more detail elsewhere.[9] Briefly, SPIRIT-HF is the result of modifying SPIRIT,[10] an ACP intervention, based on the Representational Approach to Patient Education, targeting dialysis-dependent patients with chronic kidney disease, for use in advanced heart failure (HF) patients, on LVAD support, and their surrogates. The SPIRIT-HF intervention was an approximately one-hour long structured discussion, with patients with LVADs and their designated surrogate decision-makers. The SPIRIT-HF discussion intervention was facilitated by the PI (the interventionist), a PhD-prepared nurse who had completed the formal training program developed by the original SPIRIT research team. The interventionist began the discussion by eliciting the patient's and surrogate's understanding of the patient's heart failure, the LVAD, the impact of HF and LVAD on daily life, prognosis, life-sustaining treatment in general, and life-sustaining treatment in the context of an acute event superimposed on the LVAD/heart failure. Then, using this understanding as a foundation, the interventionist facilitated a discussion between the patient and surrogate about the patient's thoughts about outcomes of life-sustaining treatment, and goals of care in various end-of-life scenarios. The goal of SPIRIT-HF was to introduce an ACP discussion during a time of relative medical stability to allow the patient and surrogate to begin, or in some cases continue conversations designed to provide a foundation for patient-centered end-of-life decision-making.

Data collection

At the end of the SPIRIT-HF discussion, the nurse interventionist arranged dates and times for separate patient and surrogate interviews. At 2 weeks post-intervention, a trained research assistant, using an interview guide that was developed by members of the research team with expertise in qualitative interviewing, conducted individual, semi-structured phone interviews with patients and surrogates separately. The interview guide covered only questions focused on participants' perceptions about the discussion intervention, and included questions such as: Overall, how would you describe your experience of the SPIRIT-HF discussion? What (if any) were the most positive/helpful aspects? How was it helpful/positive? Can you say more about that? What (if any) aspects were negative or not helpful? How was it negative or not helpful? What, if anything could we do to improve the discussion? Do you think this type of discussion should be a part of the care of patients with LVADs? Why or why not? If so, when do you think a discussion like SPIRIT-HF should be introduced? Why then? Based on your experience, would you recommend SPIRIT-HF for other patients with LVADs (and/or loved ones)? Why or why not?

Data management and analysis

Interviews, which lasted between 10 and 45 min, with an average of 36 min, were audio-recorded and uploaded to a folder on a secure study drive. They were then transcribed verbatim by a professional transcriptionist. Interview transcripts were reviewed by the first