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Quality of life with an LVAD: A misunderstood concept

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ABSTRACT

The present study aims to synthesize current evidence on the impact of LVAD implantation on quality of life. Current evidence was systematically reviewed to obtain relevant quantitative and qualitative articles published after 2007. Sandelowski's recommended steps for meta-summary were used to analyze the 19 studies that met the inclusion criteria. LVADs can improve HF symptoms and some aspects of QoL. Emotional and physical adaptation involves many changes and learning to manage the device takes time. Functional limitations still exist and patients still lack independence. LVAD-related complications significantly impact QoL. Psychological distress remains high after implantation. LVADs significantly impact the caregiver as well and their perspective is not well heard in the existing evidence. It is important for providers to have ongoing, in-depth discussions with patients and their caregivers regarding treatment options, goals of care, anticipated end-of-life trajectories with an LVAD, possible LVAD-complications, and the caregiver burden associated with an LVAD.

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Introduction

Cardiovascular disease is the leading cause of death globally.¹ In the United States, the American Heart Association estimates approximately 6.5 million citizens greater than 20 years old live with heart failure; ten percent of those cases are considered to be in advanced heart failure (AHF).² Heart transplantation is one of the most promising treatment options for AHF patients with a one-year survival rate of 90.8 percent and a five-year survival rate of 77.5 and 75.6 percent for male and female patients, respectively.² However, organ scarcity and strict heart transplant eligibility standards have made this option unlikely for many patients.

Left ventricular assist devices

A left ventricular assist device (LVAD) has been developed as an alternative therapy to conservative medical management in the treatment of AHF patients. LVADs were originally developed as a bridge to transplantation (BTT) for patients awaiting heart transplant; however, they are now being used as destination therapy (DT) for patients who are not eligible for heart transplant due to advancing age and/or comorbidities.² As this patient population grows, it is imperative that clinicians understand the impact of LVAD

implantation on quality of life (QoL). LVAD implantation is an invasive procedure that drastically alters the life of a patient and affects QoL. LVAD implantation is increasing rapidly, with 98 placed in 2006 compared to 2,423 placed in 2014.² There are an increasing number of patients with AHF receiving LVADs as DT with the goal of not only extending life, but also improving QoL.

Impact of LVADs on QoL

LVADs can be lifesaving, but they come with dramatic changes in lifestyle, need for caregiver support, and a high likelihood of significant complications.³ QoL can be adversely affected in some patients by infections, neurologic complications, and device malfunction.^{4,5}

There is a limited amount of research conducted on the perspective of the patient living with an LVAD.⁶ Sandau et al.⁷ report that existing QoL measurement tools cannot adequately assess QoL in LVAD patients. Modica et al.⁸ found that psychological distress did not improve after implantation, as documented by higher average anxiety and depression scores. Focus interviews revealed that many patients still did not feel independent due to the complexity of managing an LVAD and the dependence on caregivers.⁸

Impact on caregivers

LVAD implantation also places a significant burden on caregivers.⁴ LVAD management is complex and requires a significant

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commitment from a designated caregiver. In a study investigating the caregiver experience,⁹ caregivers reported overwhelming fear and anxiety after implantation regarding their ability to care for their spouse, the continued survival of their spouse, and fear of what life would be like when they went home.

Realistic expectations and goals of care

Information on the impact of LVAD implantation from the patient's perspective helps patients and families determine whether life with an LVAD would be congruent with their goals of care and individual definition of QoL.⁶ The participants in Kitko et al.'s study¹⁰ expressed feeling they had no choice and that they were too ill to participate significantly in the decision-making process during the pre-implantation phase. Ongoing discussions about goals of care in the pre- and post-implantation phases should include realistic expectations regarding QoL with an LVAD.¹⁰

Methods

Study design

The research question that guided this review was: In patients with AHF, what is the effect of LVAD implantation upon QoL? The purpose of this metasummary was to synthesize the quantitative and qualitative evidence related to the effect of LVAD implantation on QoL outcomes in order to aid the healthcare team in effectively educating patients on the treatment options. As QoL is an individually defined concept, this metasummary includes multiple aspects of QoL in order to help guide goals of care. A deeper understanding of the impact LVAD implantation has on QoL provided by this metasummary will also aid LVAD teams, social workers, and nurses in supporting patients and families navigate their journey of living with an LVAD.

Sample

A literature review was conducted by searching the Simmons online library using the following key terms: "LVAD", "LVAD AND quality of life", "mechanical circulatory support", "mechanical circulatory support AND quality of life", and "advanced heart failure AND quality of life". Simmons library searches multiple databases including PUBMED, CINAHL, and MEDLINE. The ancestry approach was also utilized to identify two articles. Inclusion criteria consisted of articles pertaining to LVADs, AHF, and QoL from peer-reviewed journals. Exclusion criteria consisted of studies published before 2007, non-English language studies, literature reviews, studies on heart failure only, and studies that included non-continuous flow LVADs. A total of 43 articles were found on the initial search and 18 articles were excluded based on exclusion criteria, leaving 25 articles. Six literature reviews were excluded leaving 19 studies. The 19 studies in our sample included ten quantitative studies, eight qualitative studies, and one mixed-method study. The ten quantitative studies in our sample consisted of one systematic review, one randomized controlled trial, one quasi-experimental study, four prospective studies, and three retrospective studies. The eight qualitative studies in our sample consisted of one meta-synthesis, one grounded theory study, three phenomenologic studies, two thematic narrative analyses, and one content analysis study. The research team consisted of two members enrolled in Simmons Masters of Science in Nursing (MSN) online program. One investigator is a practicing nurse with four years of experience caring for LVAD patients. Articles in the sample were individually read by both investigators and evaluated for quality (see [Table 1](#)).

Data analysis

Data analysis followed the recommendations of Sandelowski, Barroso, and Voils.²⁴ Both investigators carefully read each study multiple times to extract findings. The investigators compared findings, discussed, and agreed upon the extracted findings. Next, the investigators individually grouped the findings based on topical similarity in order to recognize how they related to one another.²⁴ The investigators discussed and agreed upon the final grouping of topically similar findings. The grouped findings were then formatted into brief but comprehensive representations in order to remove redundancies while still maintaining the complexity of findings.²⁴ Again, the investigators discussed and agreed upon the formatted findings, which are presented in [Table 2](#).

Effect sizes were then computed for each formatted finding by dividing the number of studies containing that finding by the total number of studies in the sample (19), which are included in [Table 2](#). Sandelowski et al.²⁴ recommends calculating intensity effect sizes to determine how many findings each study contributed. Many of the qualitative articles aimed to investigate the lived experience of their sample and asked more open-ended questions, which allowed for a diversity and larger number of findings. The quantitative articles often focused on a single topic, which implicitly yields a limited number of findings. We attempted to calculate intensity effect sizes; however, due to the lack of meaning this measure provides for our sample, intensity effect sizes are not reported.

Reliability and validity

An audit trail was maintained throughout this study. When collecting and analyzing the data for our study, we followed established guidelines of Sandelowski et al.²⁴ to ensure the validity and reliability of our data and findings. In order to ensure construct validity, multiple databases were searched and multiple data collection methods were used, including literature search and ancestry approach. Extensive analysis and evaluation of each study was performed to strengthen validity. Prolonged engagement with the data and investigator triangulation were implemented to enhance credibility.

Results

Data collection and analysis resulted in 30 statements of findings. While grouping the topically similar findings extracted from the data, five categories emerged to organize our findings: the impact of LVAD implantation on physical functioning and daily life (Findings #1–6), the psychological impact of an LVAD (Findings #7–16), the impact of an LVAD on the caregiver (Findings #17–21), recommendations for clinicians to promote QoL (Findings #22–24), and the role of advanced care planning (ACP) and palliative care (Findings #25–30).

Implantation of an LVAD decreases heart failure symptoms, improves QoL, and increases physical functioning (Findings #1 and #2); however, there are remaining functional limitations (Finding #5) and QoL is impacted by device-related complications and increased hospitalizations (Finding #6). The challenge of adapting to a new lifestyle and making adjustments (Finding #3), along with difficulty learning how to manage the device (Finding #4) were concerns expressed in multiple articles. LVAD patients experience role changes and changes in their interpersonal relationships (Finding #8), they report a lack of independence or control over their life (Finding #15), and psychological distress remained (i.e. anxiety,

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