In this month’s Magnet® Perspectives column, Colleen K. McIlvennan, DNP, ANP, lead nurse practitioner, Advanced Heart Failure and Transplantation at the University of Colorado, discusses her groundbreaking research encompassing patients’ and caregivers’ emotional, rational, and fundamental beliefs when considering a left ventricular assist device (LVAD). Results have led to the development of 2 innovative decision aids that are currently in use by LVAD programs across the United States and Canada. Dr McIlvennan’s efforts led to a $2 million grant from the Patient-Centered Outcomes Research Institute, as well as national recognition from the American Heart Association and the Heart Failure Society of America. Last year, she received the 2016 National Magnet Nurse of the Year Award in the Empirical Outcomes category. In addition to sharing her findings, Dr McIlvennan examines the value of performing research in a Magnet-recognized organization.

When I began caring for advanced heart failure patients at the University of Colorado Hospital (UCH) 7 years ago, it quickly became apparent that this population and their caregivers had few resources to help them make difficult care decisions. Patients considering a left ventricular assist device (LVAD), in particular, faced a complex choice. Once used only as a “bridge” to help patients survive until heart transplantation, LVADs are now a long-term, permanent treatment option for patients with end-stage heart failure who are not candidates for transplant. Known as destination therapy (DT), implantation carries both significant benefits and significant risks and burdens. Not surprisingly, patients are often unsure how to proceed.

My colleagues and I recognized the complexity of the decision for DT LVAD, often viewed as a “life or death” decision. Because of the lack of available resources for patients and their caregivers, our group proposed developing a decision aid to improve the decision-making process. Decision aids provide balanced, unbiased information about treatment options for patients and help to facilitate discussions with healthcare providers. Although decision aids have emerged as effective tools for a wide variety of conditions in recent years, only a small minority focuses on people with advanced illness, such as end-stage heart failure. Prior to our work, no decision aid existed for the DT LVAD population.

Through a small pilot grant provided by the University of Colorado Palliative Care Program

Author Affiliation: Section of Advanced Heart Failure and Transplantation, Division of Cardiology, and Adult and Child Consortium for Health Outcomes Research and Delivery Science, University of Colorado School of Medicine, Aurora.

The author declares no conflicts of interest.

Correspondence: Dr McIlvennan, University of Colorado, School of Medicine, 12631 E 17th Ave, B130 Aurora, CO 80045 (colleen.mcilvennan@ucdenver.edu).

DOI: 10.1097/NNA.0000000000000463
and the support of UCH nursing leadership, we assembled a research team to conduct qualitative interviews that would help us better understand the decision-making processes of patients who accepted or declined DT LVADs, their caregivers, and LVAD coordinators. We asked participants how decisions were made, what they felt was important to know during the decision-making process, and how to improve the process for future patients and their caregivers. Following the International Patient Decision Aids Standards,1 we used the results of the qualitative interviews to develop 2 decision aids: an 8-page pamphlet and a 26-minute video. Both present information about what an LVAD is; the benefits, risks, and burdens of either accepting or declining an LVAD; what life might look like with and without the device; and implications for caregivers.

The goal of the decision aids is to increase patients’ knowledge of their medical condition, fully explain the risks and benefits of available treatments, and empower patients to become more involved in the decision-making process. The decision aids provide concrete data and controlled testimonials so people can ground their decisions in their own beliefs, values, and goals. When we pilot-tested the decision aids, we found that people really appreciated the patient and caregiver testimonials because they presented an unbiased and balanced view of acceptors and decliners of an LVAD. Both the video and pamphlet are freely available online at patientdecisionaid.org.

The pilot work led to a $2 million Patient-Centered Outcomes Research Institute grant, led by Larry Allen, MD, to assess the dissemination and implementation of the decision aids in clinical practice. Currently, 6 hospitals across the United States are participating in this randomized controlled trial to explore how often the decision aid is used among eligible patients; how well it improves the quality of patient and caregiver decisions; and how well doctors, nurses, and hospitals adopt, implement, and continue to use the decision aid. Findings will contribute to the overall body of knowledge about decision aids for DT LVAD: the best way to use them, when they should be used, who should receive them, and what format is preferred.

All of the successes of this research were made possible by the collaborative work supported by UCH. The organization is strongly committed to Magnet principles and an environment of innovative nursing study and scholarly advancement. Not only were my leaders and mentors supportive, but also my nursing colleagues caring for these patients were instrumental in my success—helping to recruit patients and encouraging everyone to watch the video and read the pamphlet. I am privileged to work in a Magnet culture that embraces new initiatives and moves research forward while keeping patient education, improvements, and outcomes at the forefront.

Note: The DT LVAD decision aid pamphlet and video are available free of charge at Patientdecisionaid.org.

Reference