

EDITORIAL COMMENT

Living Unhappily on Left Ventricular Assist Device Support

The Impetus for Shared Decision Making*

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Morrie Schwartz, a sociology professor who developed amyotrophic lateral sclerosis and the subject of Mitch Albom's book *Tuesdays With Morrie*, may be quoted as having said, "Dying is only one thing to be sad over.... Living unhappily is something else."⁽¹⁾ Although the field of mechanical circulatory support (MCS) has improved survival and quality of life for thousands with advanced heart failure (HF), too many MCS patients fail to enjoy this success. Due to the complexity of MCS surgery, the comorbid state of most patients, the unique psychological and physical burdens from living on MCS, and the diffuse complication profile, predicting preoperatively who will fail to thrive on MCS is challenging. Thus, for MCS candidates and their loved ones, the process of shared decision making is integral to upholding the principles of medical ethics: patient autonomy (right of patients to make health care decisions); nonmaleficence (refrain from patient physical/psychological harm); justice (equality of health care); and beneficence (promote patient health and well-being)⁽²⁾. Shared decision making (SDM) not only is an encounter to share cognitive information about MCS (e.g., risks and benefits of MCS), but it also is a mechanism for soliciting patient treatment preferences as a means of aligning medical care, setting expectations for life on MCS, and reducing decision regret and unwanted

treatments⁽³⁾. The process of SDM in MCS was added to the 2013 Medicare National Coverage Determinations Manual and is part of the Clinical Practice Guidelines on Heart Failure^(4,5). In response, institutions have embraced SDM skills training of health professions and MCS programs have devised decision aids for MCS. In general, decision aids differ from usual health education materials (which help patients understand their diagnosis and what MCS is) because they are meant to provide detailed information on treatment options and associated outcomes so that patients can weigh the potential benefits and harms on their own intrapersonal scale.

In this issue of *JACC: Heart Failure*, McIlvannan et al.⁽⁶⁾ share important insight into the SDM process in MCS. In their original analysis, the authors assessed the impact of SDM support tools applied in a randomized, controlled manner to patients being considered for left ventricular assist device (LVAD) destination therapy (DT) implantation⁽⁷⁾. Small gains in patient knowledge (5.5% gain vs. controls) were achieved using the SDM intervention and concordance between patient treatment values and preferred treatment course improved after the intervention. However, the correlation between patient values and actual treatment received did not improve and decision conflict and decision regret did not decrease. Building on this prior study, the authors examined the impact of their SDM tools on the decision quality of 182 potential LVAD caregivers⁽⁶⁾. Decision quality was defined as the extent to which the medical decision enacted reflected the preferences of a well-informed caregiver. To arrive at decision quality, McIlvannan and colleagues tested caregiver knowledge before and after the control or intervention LVAD education encounters. In addition, they assessed the concordance between a caregiver's values ("Do everything for my

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loved one..." vs. "Have my loved one live with whatever time is left..." with medical management) and the ultimate patient treatment choice at 6 months (patient wanted vs. did not want LVAD).

For the caregivers, there was a nonsignificant trend toward improved knowledge (4.8% vs. control; $p = 0.08$) in the SDM intervention group and caregivers in the intervention group had higher concordance between values for their loved one and caregiver treatment choice than in the controls. However, caregivers in the control group exhibited a favorable decrease in decisional conflict (e.g., "I know the benefits of each option" and "I am clear about the best choice") after control education (decreasing ~9 points after control education) and this improvement was greater than that achieved after intervention group education (decreasing ~2 points, respectively; $p = 0.007$). Nonsignificant trends for less decisional regret ("I regret the choice that was made") were noted for control versus intervention groups ($p = 0.17$ and $p = 0.16$) and the intervention did not lead to better caregiver preparedness at 6 months.

The interpretation of the results from the study by McIlvennan et al. (6) are abstruse and unsettling. However, these adjectives highlight why this study is critically important for our field. The studies by McIlvennan et al. (6) and Allen et al. (7) raise many questions about the optimal tools for promoting SDM with LVAD patients and their caregivers, as well as the methods for comparing SDM interventions. For example, did the decision tools better characterize the potential risks and quality-of-life adjustments associated with LVAD therapy, leaving more decisional conflict and potentially more regret for caregivers? Alternatively, were the decision aids actually less beneficial to caregivers than information received during control education? Perhaps the decision aids led to more information presented in writing/video with less verbal discourse between patient, caregivers, and treatment team, leading to an incomplete SDM encounter? In refutation of the latter, studies examining decision aids in multiple facets of medical care suggest that they improve patient knowledge about care options and provide patients with a clearer expectation of harms and benefits (8). Studies, including that by McIlvennan et al. (6), have shown that the SDM process and use of decision aids also tend to reduce the number of surgical interventions patients undertake (6-8). Data is lacking, however, on whether they actually improve congruence between what a patient or caregiver truly values and the care choices made, nor is it clear the detail and best format for decision aid construction across different cultures, socioeconomic statuses, and disease processes (8).

In MCS, the SDM process is further complicated by unique MCS-related attributes. For many patients and caregivers, it may be hard to truly comprehend the emotional impact of batteries, driveline care, and requirements for frequent clinical follow-up until one lives on an LVAD. The medical urgency of the intervention also likely influences the effectiveness of the SDM process (8). In a study of patients with advanced HF by Blumenthal-Barby et al. (9), when faced with imminent death, many patients feel that they do not have much of choice in pursuing MCS. In the analyses by Allen et al. (7) and McIlvennan et al. (6), more intervention patients than controls were enrolled in the outpatient setting and 45% versus 18% of intervention versus control patients were INTERMACS 4-7. Although the aim of SDM is to get past the "anything but death" mind-set, it is possible that the urgency of decisions and emotional acuity of the largely inpatient control group led to greater acceptance of the LVAD plan with less attention to marrying of patient values on life and the dying process. Finally, 24% of the intervention group versus 8% of controls was deemed by the medical team not eligible for LVAD. Physician preferences, attitudes, and quality of the doctor-patient relationship (trust, confidence, and satisfaction with care) are known to influence patient SDM (10). For many in the intervention group, the decision to not receive a LVAD was made by the team and not necessarily the patient or caregiver, and this decision may have impacted decisional conflict and/or values-choice concordance.

Although the study by McIlvennan et al. (6) has raised more questions than it provided answers, it unveiled a critical need to establish a foundation of knowledge for SDM in MCS. The authors should be commended for being one of the first in the field to tackle this complicated process. Great quantities of research exist for helping clinicians elucidate who may die with MCS surgery. Although not to be trivialized, death for the DT LVAD patient is inevitable. For the many who survive surgery, the responsibilities and emotional burden of MCS extends beyond the patient's integument; they also permeate into the lives and psychology of caregivers. In the spirit of beneficence and nonmaleficence and the words of Morrie Schwartz, the field's focus should also be in better deciphering who will and will not "live unhappily" on DT-LVAD support.

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