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Being Unchosen for LVAD-DT

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Using a rigorous qualitative approach, Barg et al. illuminate several themes from patients who underwent LVAD-DT procedures and their family caregivers. In part, they argue that patients who adopt this life-saving technology do so under the influence of a salvation ethos, highlighting that this broader sociocultural process assumes technology is inherently beneficial. In this context, they suggest that this underlying drive towards salvation ethos may constrain choice for patients who undergo LVAD-DT procedures and their family caregivers. We focus on their discussion about how patients and their families draw on cultural tropes of “being saved”. While not the focus of the authors’ inquiry, we would like to consider how larger socio-medical processes that create salvation ethos erode choice – for both “chosen” and “unchosen”.

As with other costly medical technologies, there is unequal access to LVAD-DT across racial groups (Joyce et al., 2009). Whites are implanted at three times the rate of Blacks (Joyce et al., 2009, Lampropulos et al., 2016), despite higher rates of advanced heart failure in Blacks (Mensah et al., 2005). This disparity persists when rates are adjusted by geographical area and admission to academic medical center, suggesting it is in fact race that influences rates of LVAD therapy. It is unknown to what extent referral patterns, biomedical infrastructure, patient decision, other factors, or some combination of factors drive these disparities in LVAD use among White and Black patients, as this has not been well-studied. However, it is reasonable to imagine that the factors that go into deciding on LVAD implantation may vary between Blacks and Whites. Acknowledging that the voices heard in these interviews are primarily White (nearly 90%), we think it is valuable to consider whether salvation ethos might be more accurately described as White salvation ethos in this context. This question warrants more empirical work, which may help uncover cultural resistance to the salvation ethos and the impact of values and trust on healthcare decision-making. Better understanding these constructs may be important in empowering patients to make value-consistent healthcare choices about LVAD-DT, as they may highlight counter-narratives to the salvation ethos.

The authors focus on patients who received LVADs as “destination therapy” (LVAD-DT). They lay out an important distinction between LVAD-BTT (LVAD used as bridge-to-

transplant) and LVAD-DT. While perhaps obvious to some, we think that making this distinction is critical when interpreting the results of their study. By definition, patients who undergo LVAD-DT are ineligible for heart transplant – the preferred treatment for heart failure. As such, patients facing the choice of LVAD-DT are doing so from a narrow list of alternatives, in which the preferred treatment is no longer an option. Even assuming complete and full disclosure about the implications of LVAD therapy, it is imaginable that, at least for some, the choice of LVAD-DT may not be about the perceived benefit of the technology. While Barg et al. highlight the general need for patient-centered interventions related to pre-implantation communication, we think their work illustrates a more tangible education point: the meaning of destination therapy. This point itself may foster communication about the downstream effects of LVAD implantation and end-of-life goals.

The authors are careful to acknowledge that they did not include patients who declined LVAD-DT procedures nor patients who underwent the procedure and elected to turn off the machine. While we appreciate the feasibility challenges to capture these stories, the focus on those who chose LVAD-DT and do not elect to turn off the machine perpetuates the salvation ethos. We hear the story of being saved, as opposed to the stories about a broader decision-making process. While considering these patients' perspectives is important in improving pre-implantation communication and minimizing the potential for decisional regret, appreciating the viewpoint of those who do not elect to be "saved" by LVAD is vital in this endeavor and warrants further consideration.

Through this study, Barg and colleagues have contributed to our understanding of the values that drive the choice of LVAD-DT in advanced heart failure patients and how they can be used to improve these patients' experiences. As such, their approach and the themes elucidated focus on those who were chosen and chose to undergo life-saving LVAD-DT. This overlooks the larger process that arguably drives salvation ethos. Those unchosen, either by the medical system, by society, or through their own belief system, are left out. It is what these voices stand for that we contend needs further illumination, when counseling patients prior to LVAD implantation. What forces drive being unchosen and unsaved? What or who promotes these? Is it the patients' own biases and beliefs? Is it inadequate communication? The ability to assist patients in decision-making about LVAD implantation rests on understanding the factors through further explanation. At best, both the unchosen and chosen are making socially constrained choices with limited options to choose alternatives.

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