To DT or Not to DT, That Is the Question
Working Toward a Comprehensive, Patient-Centered Perspective on Left Ventricular Assist Device for Destination Therapy

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The machine does not isolate man from the great problems of nature but plunges him more deeply into them.
—Antoine de Saint-Exupery

Older patients with chronic progressive illness are increasingly facing difficult decisions around potentially life-prolonging technologies. A stark example is destination therapy left ventricular assist devices (DT LVADs), currently offered as a long-term permanent treatment option for patients with end-stage heart failure who are ineligible for heart transplantation. In carefully selected patients, DT LVAD produces marked gains in survival and quality of life measures compared with continued medical therapy.1 Yet, these striking benefits of DT LVAD come with a host of risks and burdens, which can spill over to caregivers. Meanwhile, the reasons that make patients transplant ineligible in the first place, including noncardiovascular morbidity and frailty, usually persist.2 Thus, although DT LVADs can be life saving for a period of time under some circumstances, a more holistic view of DT LVAD would characterize it as a complex set of potential trade-offs.

Although device technology has evolved at a rapid pace, there has been a much slower evolution in optimal ways to help patients grapple with the medical decisions created by life-prolonging machines. Up until now, there has been a complete absence of any type of evidence summary from which to anchor DT LVAD risk–benefit communication and shared decision making. Optimal informed consent includes not only a description of an operative procedure, but also an understanding of the full range of benefits and risks for the offered therapy and all reasonable treatment alternatives.3 A patient considering DT LVAD therapy should have a tried-and-true rating system and objective survey research from which to collect and transmit patient-centered information about the DT LVAD decision; yet, there is no equivalent Consumer Reports for the much more important and difficult decision to proceed with DT LVAD.

In this issue, Dr Boothroyd et al4 attempt to move us out of the DT LVAD decision-making darkness by summarizing the full range of expected outcomes for patients, their caregivers, and the clinicians who are charged with conveying such information. This project was initially designed to provide recommendations to the Quebec Ministry of Health, but the universal needs were so evident that the authors have worked to enhance and share their findings with the broader heart failure community. The authors set out to address 3 principle domains they felt were particularly relevant to DT LVAD decision making: (1) risks and benefits of implantation; (2) expectations for daily life with a permanent LVAD; and (3) end-of-life issues, including device deactivation. To achieve their primary objectives, the authors conducted 3 separate informal searches for finding evidence on relevant clinical considerations from implantation to death is particularly useful for clinicians to guide informed consent and shared decision making.

Perhaps more important than the provision of summary data is the simultaneous recognition of areas where evidence is most lacking. The included tables wisely describe the overall findings in the context of what we know and what we do not know. This format allows for the identification of strengths and limitations related to the available studies, as well as illustrating the gaps in our current knowledge. Furthermore, it directly acknowledges the uncertainty that will always be present in medical decision making and informed consent.

The authors should be commended for addressing this need; however, they ultimately do a better job of shining a light on the huge gaps in shared decision making for DT LVAD than illuminating an obvious way forward. Although the authors cannot be faulted for the small amount and low quality of existing data, they risk exacerbating these shortcomings. First, the authors have worked hard to condense large amounts of information on risks and benefits into easily digestible visual summaries; yet, their data tables on adverse events present point estimates of percentages of patients experiencing an event, without intrastudy confidence intervals or interstudy ranges. This is in contradiction to the argument that framing long-term LVAD must recognize inherent uncertainty.

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Ultimately, data summaries must find novel mechanisms for communicating not only the most relevant information, but also some quantification of the degree of uncertainty. Second, the search strategies used were narrowly defined, limiting studies on risks and benefits to only studies on HeartMate II devices restricted to the DT indication. Because the data on currently available therapies for DT LVAD are small, there may be lessons to be learned from other devices and bridge-to-transplant indications, which could assist in refining our understanding of expectations for DT LVAD, albeit with serious limitations. Finally, the authors summarize the significant overall limitations for data around the expectations for daily life and end-of-life issues; however, it would be useful for clinicians communicating these data to have a formal quality assessment for the 3 important data summaries.

Perhaps even more problematic is that the largest gaps in shared decision making for invasive technologies at the end-of-life have less to do with incomplete and inaccessible information on risks and benefits and more to do with the process itself. The traditional informed consent process is grounded in normative theories of decision making, such as Expected Utility Theory, based on the ideal that patients can approach decision making rationally, whereby they cognitively weigh the risks and benefits of their choices. Thus, information transfer is the primary objective of such an approach. However, as the authors state from the beginning, “the extent to which patients and their informal caregivers will be able to absorb this information … can be highly variable.” Our own research suggests that most patients experience the DT LVAD decision as a highly emotional process in which cognitive weighing of theoretical risks and benefits tends to play a secondary role to intuitive heuristics and automatic behavioral responses. Fear, sadness, and melancholy are pervasive in the DT LVAD decision process. We have found that the most reflective patients are able to use these emotions to guide exploration of values, thereby complementing the cognitive decision-making process. The result is that these reflective patients can then explore important trade-offs, such as potential modes of death and the balance between quantity and quality of life.

In the end, the rapid evolution of DT LVAD necessitates a rapid evolution in the way that we share decision making around technologies for end-of-life with patients and their loved ones. DT LVAD does not provide an excuse to put off difficult discussions; rather, it plunges us headlong into the deepest questions about what constitutes quality of life, the nature of our closest relationships, and what it means to have a good death. To do this, we need rigorous systematic reviews of the growing and changing data around the full range of outcomes for patients considering DT LVAD, and that can only be accomplished through collaborative high-quality research with standardized collection of outcomes meaningful to not only clinicians, but also patients and caregivers as well. Perhaps more important, we need to entirely reshape the way we think about this decision process, recognizing that people often make these decisions intuitively, drawing on past experiences, and often in the setting of tremendous fear and uncertainty. The rise of machines asks us to find ways to be even more human, not less.

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References


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