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. 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. 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.

**Article see p 179**

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. A patient considering DT LVAD therapy should have a tried-and-true 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. A patient considering DT LVAD therapy should have a tried-and-true informed consent and shared decision making.

The opinions expressed in this article are not necessarily those of the Editors or of the American Heart Association.

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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 this decision process 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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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
Colleen K. McIlvennan and Larry A. Allen

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