Family Caregiving
Benefits and Burdens

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Family caregiving (informal caregiving) has always been a valuable dimension of health care. Yet, in recent times, increasing numbers of individuals living for extended periods with chronic illness intensifies not just the complexity but the importance and value of family caregiving. A salient example of this trend is destination therapy (DT) left ventricular assist devices (LVAD) care.

Our dependence on family caregiving is further compounded by the shifting emphasis of health care from the hospital to the community and increasing fiscal constraints.

A recent RAND Corporation study estimated that informal caregiving of elderly people by friends and family in the United States cost $522 billion a year. This study further estimated that substituting that care with unskilled paid care at a minimum wage would cost $221 billion, whereas using skilled nursing care would cost $642 billion annually. These data underscore the substantial contribution of family caregiving to our society.

This metric, comprising the value of the time caregivers have given up to provide care, captures only the financial cost—the visible, tangible, and quantifiable aspects of care.

But the consequences of family caregiving are far reaching with physical, social, psychological, and financial implications. Commonly, caregivers are swept along by the consequences of decisions to which they have provided minimal input.

DT LVAD for those ineligible for heart transplantation is increasingly common, with over 1000 implanted in the United States in 2013 and an estimated 150,000 to 250,000 individuals who may potentially be eligible annually.

Although involving family members in caregiving is recommended in many clinical practice guidelines for heart failure, a family caregiver is essential for DT LVAD and the level of engagement intense.

Caregivers are required to not only assist in transportation to appointments, perform sterile driveline dressing changes, understand the technicalities of the LVAD equipment, but also provide assistance in activities of daily living and other aspects of medical management.

This is just the tip of the iceberg of living and caring for an individual with complex healthcare issues and who is often tittering on a life and death precipice. Commonly, family caregivers also have their own health issues, which are often ignored or dismissed. The burden of responsibility and yet the satisfaction of caregiving is commonly described as a roller coaster.

Individuals with a DT LVAD are often older with comorbidities that preclude heart transplantation. Therefore, the choice to undergo DT LVAD therapy is often a complex process of balancing the option of another chance for life with the complexity of treatment. This is a complex decision-making process.

McIlvennan et al in this issue of Circulation: Cardiovascular Quality and Outcomes conducted a qualitative, descriptive study using in-depth, semistructured interviews with caregivers of patients currently living with a DT LVAD, caregivers of patients who had died with a DT LVAD, and caregivers of patients who had refused DT LVAD. This study aimed to obtain information regarding caregivers’ experiences with decision-making surrounding DT LVAD.

In this study, caregivers emphasized the complexity of the decision-making process and their issues and concern the context, process, and outcome of the decision. Commonly, this decision was preceded by a time of disability and deterioration and in some cases, hopes for a transplant lost. Participants often felt the decision for DT LVAD implantation was rushed. This is a clear signal to healthcare professionals to anticipate deterioration and ensure families are aware of the likely prognosis.

Decisions were made amid the strain between feeling grateful for the patient being alive and the burdens associated with caregiving and the precarious nature of living with a DT LVAD. Study findings also underscore the range of knowledge and values among family caregivers and the need for an individualized approach in the caregiver dyad.

The findings of McIlvennan et al emphasize the importance of providing not just patients, but their caregivers, with a realistic expectation of what the future will look like and also assessing their capability and willingness to deal with this challenging situation. Family caregivers should be active and informed members of the decision-making process as they are integral members of the healthcare team, paid or unpaid.

Shared decision-making, enacting a collaborative process that meaningfully incorporates patients, providers, and caregivers, accounting for the best scientific evidence available, as well as the patient’s values and preferences, is critical.

In the context of DT LVAD, assessment of the caregiver capability and willingness is essential. Providing standardized mechanisms of assessment and monitoring of not only the patient, but caregiver is fundamental.
Three out of 5 caregivers also are actively engaged in the workforce. Working-age people under the age of 65 provide 22 billion of those 30 billion caregiving hours, and they often lose income because of reduced paid work hours. Moreover, the task of caregiving, although rewarding, can also have deleterious effects on an individual’s health.

The McIlvennan et al’s study adds to the increasing data on the complexity of family caregiving for individuals with heart failure. A recurrent theme across studies is the balancing of benefits and burdens, particularly in the context of DT LVAD.11,12

As healthcare providers, we have to be mindful and aware of the challenges commonly faced by families and provide interventions that not only assess appropriateness for this complex task but also provide both instrumental and social support.1 This will often require not only health, but also social service interventions. The complexity and demands on families is challenging, and these are likely accentuated in families with limited financial and emotional resources.

Informal caregiving is a significant economic burden in the United States, especially for working adults. Chari et al emphasize the need for workplace flexibility policies that provide paid time off for caregivers, as well as the potential value of Medicaid’s Cash and Counseling program, which gives elderly Americans compensation for their caregiving needs.2

As DT LVAD therapy becomes increasingly available and accessible, health professionals need to realistically assess the expectations of caregivers, and LVAD programs should recognize caregivers as part of the healthcare team. They need to be involved in decisions and provided ongoing support and skills training and information about financial and social support where available.

Anticipating the roller coaster of emotions and the benefits and burden of caregiving should be an essential part of DT LVAD care.6

Interventions to improve caregiver experiences should emphasize meaningful engagement and involvement in decision-making, not just at the point of implementation but throughout the healthcare trajectory. Family caregivers deserve the same respect and commitment we provide to our colleagues in our healthcare teams.

Families, particularly caregivers, require support, and we also need to monitor their capacity and resources over time. A diverse literature across many conditions presents family caregiving as a mix of benefits and burdens. Interventions to minimize burdens are urgently needed.

As our society and healthcare system becomes increasingly dependent on this valuable labor source, we need to develop systematic, scalable, and sustainable models of interventions that meaningfully engage informal caregivers in the healthcare team. The study by McIlvennan et al is a reminder that the multiple decisions we make have a profound and lasting effect on families. This is a powerful message to not only ensure we make the best decisions but that patients and their families are active partners in the process.

Disclosures

None.

References


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