

THE LIVED EXPERIENCE OF SPOUSES OF PATIENTS WITH A LEFT VENTRICULAR ASSIST DEVICE BEFORE HEART TRANSPLANTATION

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I think that the lived experience of spouses providing care to patients with a left ventricular assist device (LVAD), as described by Casida in this issue of *American Journal of Critical Care*,¹ is underappreciated by healthcare professionals, and the outcomes of this situation are not obvious. Although we, as professionals, provide education and support programs for patients and their families and caregivers, we are not living the lives of any of these groups. Nor are we intimately involved in the daily routine of any of them once patients are discharged, particularly those of use who work in a hospital setting as bedside providers.

Usually, we never see patients again once they leave the critical care unit, and therefore it is easy—too easy—to forget how inordinately difficult it is to live with a chronically ill loved one. Even more, we forget how terrifying it is to live with a critically ill loved one who is using sophisticated equipment. We can complete our shift and go home to our lives. Spouses who are caregivers for patients with an LVAD cannot, because the “shift” of a caregiver spouse encompasses his or her entire existence. Have we forgotten already how such complex equipment terrified us as novice critical care nurses? We had the entire support of preceptors, colleagues, perhaps even a critical care team, in a safe, learning environment. Regardless of the level of support provided by the LVAD coordinator, these families are living alone with the enormous responsibility of caring for the patient/loved one. And they are doing it without the constant, supportive presence of colleagues and team members. Further, the patient is someone they love. It is frightening to be a nurse, critical care or not, and to be faced at home with chronic illness, critical illness, or even severe signs or symptoms in someone you love. You are not then a critical care nurse, but a daughter, son, wife, husband, father, or

mother. That role as a family member must and should take precedence. Living with chronically ill family members without the benefit of the input of the critical care team, specialists, or even diagnostic equipment is overwhelming and draining even for trained professionals. For laypersons, it can only be a nightmare.

In addition, it is important to remember that not all family members are as formally educated as healthcare professionals are. Various levels of education will markedly affect caregivers’ ability to learn, their confidence regarding new situations, flexibility, ability to seek out further help or information, and coping strategies. Besides the formal knowledge that comes with formal education, all of these extra skills are learned as well.

Another underappreciated issue is the demand that the LVAD caregivers be available to their spouses 24 hours a day, while trying to incorporate shopping, cleaning, child care, working outside the home, and maintaining other relationships with family and friends, perhaps even aging parents. I wonder how many of us would be able to willingly accept being available to a spouse, ill or not, 24 hours a day, and without sacrificing all, or part of our own individuality, interests, and independence. I see this behavior on the part of these caregivers as truly heroic.

The Marriage Encounter model uses the term “married single lifestyle” to describe the current, prevalent marriage mode of thinking and acting in a marriage as if one were a single person.² The consequence of this mode is a downward spiral leading to disillusionment, wherein one mostly sees the other person’s faults. This outlook leads to eventual disintegration of the marriage bond. Although I am fully aware of the limitations of the sample size in Casida’s study, I found it exciting to read that one of the outcomes was the realization of a loving relationship. The lay literature is replete with articles describing anecdotal evidence of disruption of relationships due to coping with infertility, children’s illnesses, or the illness of one partner. Therefore, the evidence reported by Casida is indeed

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encouraging and does require further exploration with larger samples, other family structures, and other types of illnesses. Casida found that the process lived out by the patients and their caregiver spouses led to a renewal of relationship, a finding that somewhat parallels what is achieved by the Marriage Encounter process, in terms of restoration of satisfaction to the marriage. Rather than destroying their relationships, the couples coping with LVAD issues seem to have experienced a strengthening of their relationships.

Many of the current self-help, inspirational, and spiritual writers and speakers focus on changing our perception of situations that some would label as catastrophes so that we view the situations as opportunities to grow, changing our perception from one of disaster to one of challenge. These writers and speakers continually state that it is not what happens to us that matters, but what we do about what happens to us. Even more, they state that problems can be visualized as opportunities to move us to a higher level of spiritual and emotional functioning. Again, the article by Casida presents the excellent and inspiring point that the events experienced by the LVAD families transformed them and therefore prepared them for the next stage of living as transplant recipients. Thus, the caregivers and patients received the benefit of experiencing the transformational power of challenges.

We can only wonder how so many families coping with illness deal with simple issues that the rest of us take for granted, such as sexuality. Unless you have been obese, in chronic pain, experiencing the libido-depressing side effects of prescription drugs, or limited by structural problems (hips, knees, etc), you cannot imagine how difficult sexual activity can be, and certainly, no one wants to talk to you about it. Again, Casida's findings present a much-needed glimpse into another problem, that of sexuality, which also confronted these families. Lack of sexual intimacy puts an additional strain on couples already coping with enormous burdens.

In summary, rather than citing the obvious, some unexpected outcomes have been proposed by this research. Further, because the professional experiences of each of us in critical care differ in terms of exposure to home care, this kind of first-person testimony is necessary to keep us listening, hearing, interested, empathic, and supportive. In this way, we can begin the discharge planning early, in the critical care unit, armed with new insight into the nature of families' experiences at home.

REFERENCES

1. Casida J. The lived experience of spouses of patients with a left ventricular assist device before heart transplantation. *Am J Crit Care*. 2005;14:145-151.
2. *Worldwide Marriage Encounter Workbook*. San Bernardino, Calif: Worldwide Marriage Encounter; 1999.