

Spousal stress in acute illness

Ken Flegel MDCM MSc

■ Cite as: *CMAJ* 2017 January 23;189:E98. doi: 10.1503/cmaj.161449

The phone rings in the dead of the night. The 76-year-old woman picks it up. Her husband has been on a ventilator in the ICU for three days because of a stroke-induced coma. A voice on the line tells her, “The doctor needs to talk with you about your husband.” As she waits, hundreds of possibilities flood her mind. Finally, “Hi. Sorry to wake you. I need your consent to insert a nasogastric tube for your husband’s meds.” As she hangs up, she thinks it could have been worse. Her heart begins to thump; she breaks into a sweat. Her bladder signals urgently; nausea grips her. She will not get back to sleep. She is so anxious she thinks she might die. She might.

Her chance of dying in the next year has been estimated to be 3.7%,¹ a relative risk increase of more than 50%.² She also has a 67% chance of experiencing symptoms of depression in the first week and a 16% chance of them persisting after the first year, whether or not her husband survives.³ She may experience symptoms of post-traumatic stress and will likely neglect her own health. In addition, she will be much less free to engage in personal activities of life and socialization. These factors may prevent her from being a good caregiver and in fact may jeopardize her husband’s recovery.

The Canadian Critical Care Trials Group recently reported on the one-year outcomes among caregivers of family members discharged from an ICU.³ Depressive symptoms and worse mental health were associated with younger caregiver age, greater effect of patient care on other activities, less social support, less sense of control over life and less personal growth. Lower physical health scores in caregivers were associated with needing to provide more assistance, having less sense of control, being older and having a lower family income.³

We are familiar with the stress of acute illness in our patients, but all too often we simply assume the health of the caregiver. Intimate personal relationships usually entrain a sense that our own personal boundaries extend beyond ourselves to include those we love. It is not unusual to hear a caregiver remark, “It would be better if this had happened to me.” Our patients may get relief from medication or, sometimes, sleep. However, their caregivers are suddenly confronted with meeting the needs of their loved one as well as their own needs. Typically, the caregiver gives the patient’s needs priority, becoming the alternate to the patient’s memory, hope for future life and link to family and friends. In one study, high self-perceived strain in response to the question “How much of a mental or emotional strain is it to provide care?” was associated with higher one-year mortality than no or some strain in models adjusted for demographics, health status and caregiver involvement.²

We cannot prevent the visceral stress response and its aftermath

experienced by most caregivers, but we can minimize it. The first step is to acknowledge its presence. Identifying the main caregiver and simply asking how he or she is coping with everything can open the door. Making it clear to caregivers that keeping them well is part of the patient’s recovery gives the attention paid to them legitimacy. Just as joint meetings with the patient and caregiver are important to be sure they understand the same things, meetings with the caregiver alone are needed to ensure that his or her concerns are understood and that the caregiver is capable and trained to render the care. The need for both types of meetings should be made clear at the outset. The caregiver’s views should be given sincere consideration and never be dismissed or patronized. Clear information on diagnosis, prognosis and management decisions should be given early and only by health professionals directly involved in the patient’s care.

Patients do benefit from a strong emotional bond with family caregivers who show their commitment by being regularly present. Giving effective care engenders a sense of well-being in caregivers.⁴ We can help minimize caregivers’ stress by directing their energies toward more positive thoughts and productive activity. Also, caregivers can find a sense of purpose and fulfillment in their care responsibilities.

Many descriptions of caregiver stress related to specific diseases have been published, but little has been said about how to address the problem. When caregiver stress is present, practical help, counselling and referral may be offered. Formal care plans that have been proposed need to be studied so that effective elements can be expanded.⁵ Models developed in specific settings such as the ICU need to be extended and studied across the continuum of care.^{3,5}

References

1. Christakis NA, Allison PD. Mortality after the hospitalization of a spouse. *N Engl J Med* 2006;354:719-30.
2. Perkins M, Howard VJ, Wadley VG, et al. Caregiving strain and all-cause mortality: evidence from the REGARDS study. *J Gerontol B Psychol Sci Soc Sci* 2013;68:504-12.
3. Cameron JI, Chu LM, Matte A, et al.; RECOVER Program Investigators (Phase 1: towards RECOVER); Canadian Critical Care Trials Group. One-year outcomes in caregivers of critically ill patients. *N Engl J Med* 2016;374:1831-41.
4. Wittenberg E, Prosser LA. Health as a family affair. *N Engl J Med* 2016;374:1804-6.
5. Cameron JI, Naglie G, Green TL, et al. A feasibility and pilot randomized controlled trial of the “Timing it Right Stroke Family Support Program.” *Clin Rehabil* 2015;29:1129-40.

Competing interests: See www.cmaj.ca/site/misc/cmaj_staff.xhtml

Affiliation: Senior Editor, *CMAJ*

Correspondence to: *CMAJ* editor, pubs@cmaj.ca