
GUEST EDITORIAL

Isolated, invisible, and in-need: There should be no “I” in caregiver

A patient recently said to me, “Marriage is just as effective as chemotherapy.” And in so many ways, I agree. Informal caregivers — many of whom are spouses or partners — have become the backbone of our healthcare system, concurrently playing the role of partner/parent/child/friend, and physician, nurse, social worker, lawyer, and patient navigator. Without a doubt, the presence of a caregiver who is dressed in invisible armor, ready to advocate (fight) on behalf of patients, negotiate our complicated healthcare system, and attempt clear and productive communication with medical, administrative and legal professionals, is not only optimal, but essential to the well-being of patients today.

This armor, however, comes with a significant cost. This uncompensated care involves significant time and energy and requires the performance of tasks that are physically, emotionally, socially, existentially and financially demanding. In 2009, 65.7 million Americans served as caregivers, including 4.6 million to patients with cancer (AARP, 2009). This large number of caregivers is partly a result of cost shifting due to rising expenditures on health care; accordingly, the annual economic value of caregivers was recently estimated at \$375 billion (Gibson & Houser, 2007). The Institute of Medicine (2008) report “Retooling for an Aging America: Building the Health Care Workforce” highlighted the responsibility of palliative care professionals to prepare caregivers for their role and the need to establish programs to assist them with managing their own stress that results from providing care. Since the 2008 report, there has been growing recognition of the critical role played by caregivers and the responsibility of formal caregivers — health care professionals — to develop supportive structures to assist them with the demands of their role. However, the state of the science of empirically supported interventions for caregivers remains in its infancy and there exist significant gaps in our understanding of how and when to best support caregivers and protect them from deleterious psychosocial outcomes.

What is not unclear, however, is the magnitude of such potential negative psychosocial outcomes,

which have been robustly documented in the literature. For example, it is well established that the psychological burden associated with caring for a patient with cancer is often greater than that experienced by patients themselves, and that when left untreated, caregivers are at risk for severe and debilitating levels of anxiety and depression. These effects can increase risk for chronic illness including cardiovascular disease and cancer. As such, chronic, untreated burden experienced by caregivers increases their chances of becoming the next generation of patients and generally adding further burden to health care expenditures. Indeed, the increasing push in the United States for shortened hospital stays and outpatient care, coupled with the growing prevalence worldwide of adults with chronic and life-limiting illnesses, creates urgency for our field’s attention to the unique burden of caregivers, not only for their benefit, but for that of the patient whose care is highly impacted by caregivers’ well-being.

The articles in this Special Issue of *Palliative and Supportive Care* highlight critical research priorities and challenges we face in establishing effective and acceptable interventions for caregivers. Across studies, three common themes emerge: caregivers are often *isolated*, feel *invisible*, and *in-need*. First, the majority of caregivers are providing care on their own. Their support structures are often minimal and frail. Travel to and from treatment centers is frequently unrealistic due to the temporal and financial demands of caregiving, and impossible for caregivers in rural settings where access to care is limited. As such, care needs to find its way *to* caregivers, it needs to be easily accessible, and not perceived as an added burden. Increased use of telehealth interventions — such as psychosocial support provided over the Internet, Skype, or telephone, or multimedia educational and supportive resources — is one very logical yet relatively unexplored avenue of intervention. Additionally, hospice services offered in the home should incorporate supportive services for caregivers that target the anxiety and depression so often experienced but so infrequently addressed.

Second, Seal et al.'s meta-synthesis of qualitative studies of the experience of caregivers of patients with cancer highlighted the theme of *invisibility*: caregivers feel invisible, they feel left out of care planning, often without voices and abandoned by health care professionals. *This reality should be a grim one for professionals, since caregivers are our allies*: they are in the trenches daily, they have more knowledge and expertise about the day-to-day medical and psychiatric symptoms experienced by patients than any medical professional can (and how could they not? The extent of care provided by caregivers is significant, far exceeding the care provided by professional caregivers - averaging 8.8 hours/day over more than four years). And critically, caregivers have more comprehensive understandings of patients' wishes for end-of-life care than could ever be derived from a brief bedside interview with a (albeit well-trained) stranger. This isolation needs to be immediately addressed. Never again should a patient with advanced cancer be offered psychosocial support while their caregiver sits next to them, quiet, ignored, and distressed, nor should caregivers be offered support only in the context of already existing programs geared towards the needs of patients.

Which brings me to the third, and perhaps most critical theme, of unmet needs. The unmet needs of caregivers are great, particularly those of patients receiving palliative care and care at end-of-life. We must identify and provide services to caregivers at particular risk for poor psychosocial outcomes. Included in this group are caregivers of patients in the ICU, who are often responsible for making critical decisions about care, and hence, at risk for traumatic stress symptoms when such decision making results in either increased suffering or the death of the patient. Support for such caregivers should not only be offered during their experience in the ICU, but after. Caregivers are not responsible for the outcomes of end-of-life care, yet often feel as if they are. Helping caregivers of patients at end-of-life is a priority, particularly those who must take responsibility for patients who can no longer advocate for themselves. Moreover, identifying caregivers at high risk for distress and burden earlier in the caregiving trajectory can help to protect against poor psychosocial outcomes, both during the period of caregiving and into bereavement. In order to do this, however, our measurement technologies need to be addressed. Many measures of caregiver burden exist, and while some are widely used – such as the Caregiver Reaction Assessment (Given et al., 1992) — there is no gold standard. Research is needed to evaluate the use of these broad assessment measures across patients with a variety of illnesses and at various points in the caregiving

trajectory. More targeted assessments of the unique needs of caregivers of patients with particular illnesses or treatment regimens — such as caregivers of patients with brain tumors or those undergoing hematopoietic stem cell transplantations — are needed and will likely result in more productive and targeted referrals to care. I have yet to meet a caregiver who is not distressed, but I have certainly met many distressed caregivers who can manage their distress without the help of mental health professionals. Identifying distressed caregivers who are in great need for professional support and who will benefit from our therapeutic technologies is a critical priority for our field.

In addition to the three themes of caregivers being isolated, invisible, and in-need, three additional conclusions can be drawn from the contributions to this Special Issue. First, the value of qualitative data should not be underestimated. The real, lived experiences of caregivers will never be comprehensively captured by quantitative assessments alone, and therefore mixed-methodology research should be the norm for our field. Second, the reflections of bereaved caregivers — the EXPERTS — are our most valuable resource. Learning from these experts about when and how to provide support is the only way in which we will develop services that are effective and acceptable and integrated into usual care. And finally, despite the great potential for distress, burden, and psychopathology, the experience of providing care to a loved one at end-of-life has the potential to be a significant source of meaning and growth for caregivers. Helping caregivers to discover this meaning, identify their purpose, and realize their inner strengths through the process of caregiving, may indeed be the greatest gift we as professionals – and humans – can give them.

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