

The Caregiving Quandary

Deborah A. Boyle, MSN, RN, AOCNS®, FAAN

Long before I became a cancer caregiver, I worried about families. Providing care without a script, expanding their workload, solo decision making, incessant worrying, managing expectations, overseeing medications—that is the lay caregiver's all-consuming world. However, when cancer entered my residence, I started living what I had historically observed from a distance. The double-duty caregiving at work and home overwhelmed me. Years of experience did little to prepare me for the emotional tsunami and physical toll caregiving took on me. I questioned my ability to make decisions, I got my husband's medications mixed up, and I had trouble asking for and accepting help, despite how much I needed it.

A reality check for us is in order. Health professionals are not the main providers of patient care. The majority is rendered in the home by inexperienced lay family members (Wittenberg & Prosser, 2016). About 44 million adult caregivers, the majority of whom are women, engage in hard, relentless, and uncompensated caregiving; the economic value was estimated at \$470 billion in 2013 (National Alliance for Caregiving, 2015; Russo, 2016).

An ominous caregiving future is before us. By 2030, about 73 million Americans—or 1 in 5—will be aged 65 years or older (National Academies of Sciences, Engineering, and Medicine, 2016). Many of these older adults will have cancer and require some form of home-based care. However, despite an increasing demand, societal factors suggest that the supply of noncompensated adult care providers is shrinking. Reasons include the growing proportion of two adults working, negating the availability of “free” informal care (Wittenberg & Prosser, 2016); lower fertility rates; a growing unmarried,

divorced, or living alone status; and the mobile nature of society.

Caregiving in the United States is a major public health crisis with emergent implications. The National Academies of Sciences, Engineering, and Medicine (2016) recom-

“About 44 million adult caregivers engage in hard, relentless, and uncompensated caregiving.”

mended that the next presidential administration take immediate steps to address the health, economic, and social issues facing family caregivers of older Americans. Can this crisis be addressed quickly and comprehensively? I say, “yes,” and not just because I am an optimist, but also by virtue of key precedents that give me hope.

Case in point is the AIDS movement, when we identified the need to support an at-risk population—patients and caregivers alike. AIDS required us to expand our understanding of family and caregiving. Lovers/partners and friends were called on to provide the most intimate of personal care. AIDS prompted a mass movement and, ultimately, specialty nursing services were created and compensated in the home setting (Anne Hughes, PhD, FNP-BC, ACHPN®, FAAN, personal communication).

I can dream of the next presidential administration establishing an Office of Family Caregiving within the National Cancer Institute. I can envision a family caregivers' Walk on Washington. I can foresee a subsidized effort to support cancer caregivers similar to what is in place to address the burden of caregiving for families of patients with Alzheimer dis-

ease. However, different to these historical parallels is the potential for our nursing leadership.

There is no cancer care without nursing care. Patients and families repeatedly identify nurses as those who uniquely

walked them through their cancer experience. The oncology nurse-caregiver partnership can become our legacy of political activism. The time is now.

Deborah A. Boyle, MSN, RN, AOCNS®, FAAN, is an oncology clinical nurse specialist at Advanced Oncology Nursing Resources, Inc., in Huntington Beach, CA. Boyle can be reached at deboyle@cox.net.

The author takes full responsibility for the content of the article. No financial relationships relevant to the content of this article have been disclosed by the author or editorial staff, with copy to editor at CJONEditor@ons.org

REFERENCES

- National Academies of Sciences, Engineering, and Medicine. (2016). *Families caring for an aging America*. Washington, DC: National Academies Press.
- National Alliance for Caregiving. (2015). *Caregiving in the United States: 2015 report*. Retrieved from <http://bit.ly/1VsF9B6>
- Russo, F. (2016). The givers. *Scientific American Mind*, 27, 29–37.
- Wittenberg, E., & Prosser, L. (2016). Health as a family affair. *New England Journal of Medicine*, 374, 1804–1806.

KEYWORDS

caregiving; activism; leadership; advocacy

DIGITAL OBJECT IDENTIFIER

10.1188/17.CJON.139