Is the health care system supporting the needs of family caregivers?

Somewhat, say Kyler Godwin, Ph.D., M.P.H., and Mark Kunik, M.D., M.P.H. Caregivers are often family members who provide health-related care, including help with everyday tasks and physical and emotional support, to a loved one with illness or disability. In 2009, an estimated 48.9 million Americans spent, on average, 20.4 hours per week providing unpaid care for an adult family member. Fifteen percent of caregivers report a high degree of financial hardship due to caregiving. Twenty-four percent of those who have provided care for five years or more feel their health has declined because of caregiving. Godwin’s work with caregivers of stroke survivors found that, on average, the caregiver’s burden was at the same level after two or more years post-stroke as it was right after their spouse’s stroke. Kunik’s work with caregivers of persons with dementia has shown that many caregivers experience depression, isolation and unmet needs.

Because of the enormous role that caregivers play in supporting their sick or disabled loved ones and the huge toll that it takes on them, national efforts to better support caregivers are underway. One objective of Healthy People 2020, the nation’s 10-year agenda for improving the health of Americans, is to “reduce the proportion of unpaid caregivers of older adults who report an unmet need for caregiver support services.” The Affordable Care Act has specific provisions to provide low-cost or free training to family caregivers. Moreover, Congress has reviewed additional bills regarding the needs of family caregivers. The Strengthening Services for America’s Seniors Act proposes to fund programs to connect family caregivers with support services, such as respite care — a planned, short-term break from caregiving — and counseling. While promising, this bill was referred to a Senate committee.

However, progress has been made for caregivers of U.S. veterans. The 2010 Caregivers and Veterans Omnibus Health Services Act provides family caregivers of veterans with information and training as well as respite and counseling services. Caregivers of veterans injured as a result of their service after Sept. 11, 2001, are also eligible to receive health care coverage and a caregiver’s stipend. These services are being widely implemented across the Veterans Affairs system through a caregiver support line, local caregiver support coordinators and training classes.

Although these services are important first steps in supporting caregivers, often they alone are not enough to combat the depression, stress and burden most caregivers feel. Programs that offer a combination of psychosocial support, education and training tailored to caregivers’ unique needs offer the most promise. Several evidence-based programs exist (you can find a listing at www.rosalynncarter.org); however, the integration of these programs into the community remains a challenge because of the lack of funding and training in community-level organizations.

Caring for the nation’s caregivers is a complex task. The health care system does recognize that caregivers are critical to the health and well-being of patients, and that their care comes with an emotional, physical and financial cost. Although recent legislation provides some needed services for caregivers, much remains to be done to reduce the emotional and physical burden that many families endure while caring for a loved one.


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