



Challenges and Rewards of Caregiving

by Scott McNutt

In addition to her regular job, Joann, a 48-year-old Californian, figures she spends 20 hours a week helping her mother: running errands, making sure her mother takes her medications, helping her get around, cleaning up her place and other chores of daily life. She hasn't been keeping track of how much money she spends on her mother's needs, but she suspects it runs into the thousands of dollars. And while caring for her mother has given Joann a sense of satisfaction, being able to give back to the woman she owes so much to, she isn't sure how long she can keep up this pace. She suspects the cold she came down with last week may have been caused by stress as much as by a virus. Also, she'd like to go back to school to finish her degree in graphic design, so she could bring in more money, but between her job and her caregiving responsibilities, where is the time? Besides, finding reliable, affordable caregiving assistance isn't easy.



One in six caregivers reports that caregiving has had a negative impact on their health. Most have had some college education, but four in ten are from households earning under \$50,000 a year. Since 2004, more caregivers of adults are getting help from other unpaid caregivers and fewer are able to afford paid care.

“Joann” doesn’t exist, but she is a composite of the typical informal caregivers found in the report “Caregiving in the U.S.,” issued late last year. This survey, funded by MetLife Foundation and conducted for the National Alliance for Caregiving (NAC) in collaboration with AARP by Mathew Greenwald & Associates, was the result of interviews with 1,480 caregivers chosen at random, and is just one of several reports recently issued on caregiving nationally.

What facts emerge from “Caregiving in the U.S.”? Last year, about 66 million people in the US reported having acted as a family caregiver. By a ratio of almost two to one, these people are female. On average, the caregivers are 48 years old, and they care for a relative, most often a parent, usually over the age of 50. Their caregiving lasts an average of 4.5 years. The most common reasons people need care are old age (12 percent) and Alzheimer’s disease (10 percent), followed by mental/emotional illness, cancer, heart disease and stroke. One in six caregivers reports that caregiving has had a negative impact on their health. Most have had some college education, but four in ten are from households earning under \$50,000 a year. Since 2004, more caregivers of adults are getting help from other unpaid caregivers and fewer are able to afford paid care. Most would like to find more information from a reliable source on caregiving, and most would like some form of government assistance for their caregiving, possibly a tax credit or voucher program that the care receiver could use to pay the caregiver.

Reports on caregiving are not all negative. One study found that some caregivers report beneficial effects of caregiving, including feeling positive about helping a disabled spouse, feeling appreciated by the care recipient, and feeling that their relationship with the care recipient had improved. In addition, a recent survey of caregivers in New York found that the caregivers feel their work gives them a sense of:

- Helping the care receiver (99 percent)
- Satisfaction (92 percent)
- Helping family (90 percent)
- Accomplishment (90 percent)
- Being appreciated (87 percent)
- Having companionship (67 percent).



However, there can be little doubt that the burden of informal caregiving is growing more difficult. A 2008 study by AARP estimated that a caregiver spends an average of \$5,531

out-of-pocket on care annually and is at risk of being forced to quit his or her job or retire early and of suffering ill effects on physical and mental health. This study also estimated the total economic value of caregivers' unpaid work was approximately \$375 billion in 2007, up from an estimated \$350 billion in 2006. That figure is greater than the total 2007 Medicaid spending (\$311 billion).

"Now in addition to family and work, boomers have added caregiving, the equivalent of a part-time job, to their responsibilities," says Elinor Ginzler, AARP senior vice president for Livable Communities. "Their work, health and time with family and friends already bear some of the cost for this amped up juggling act."

"More and more people who are 65-plus are providing care to both children and adults," says Gail Hunt, president and CEO of the NAC. "The shift to an older population of caregivers points to a real need for assistance for these individuals from family, friends, employers and social service programs."

Efforts are underway in some quarters to address the problems caregivers face. For instance, after a 2009 survey showed that one of the major challenges faced by unpaid caregivers of people with diabetes was finding reliable information on the disease, the Endocrine Society's Hormone Foundation, which sponsored the study in collaboration with the NAC, announced that the foundation would develop a new tool to aid caregivers of people with diabetes.

"To address the needs identified through the survey, the foundation will be creating Diabetes Caregiver Central[®], an easy-to-use Web site containing the most up-to-date information relevant to diabetes caregivers," says Alvin M. Matsumoto, MD, chair of the Hormone Foundation committee that spearheaded the survey. "The new Web site will serve as a comprehensive one-stop shop including resources and information about diabetes; diet and exercise; optimizing blood sugar control; managing complications and coexisting illnesses; and handling patient and caregiver stress and mental health." Diabetes Caregiver Central[®] is expected to go live in the fall of 2010.

The White House also recently announced that its Middle Class Task Force would pursue a series of initiatives to help families with caregiving duties. These initiatives will include a proposed \$102.5 million investment to support more respite care, counseling, training, referrals and adult day care.

While these are notable endeavors, they only hint at the amount of assistance called for to address the needs of informal caregivers. As Terrell McSweeney, domestic policy advisor to Vice President Joe Biden, admits, "The caregiver initiative won't magically alleviate all the strain on caregivers and their families – but it is an important first step toward providing more support for families and caregivers and the vital services they are performing."

It is to be hoped that greater recognition of the extent of informal caregivers' work is forthcoming, as is additional aid for them – because, while "Joann" may not be real, tens of millions of Americans are just like her. And their numbers will only grow as our population ages. ■

