

Taking care of mom and dad

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Credit: AI-generated image ([disclaimer](#))

There are some 50 million informal caregivers in the United States providing unpaid care to older family members. Some help out a couple of hours a week while others are available around the clock. These informal caregivers, most of whom are spouses or children, save billions of dollars, but take on a financial and physical burden.

Not much was known about these caregivers—and there will be more of

them as the population ages—until the federally funded [National Health and Aging Trend Study](#) and its National Survey of Caregivers began collecting data in 2011.

Steven Cohen, MPH03, an adjunct assistant professor of public health and community medicine at Tufts School of Medicine, is analyzing survey data as part of his research about how family caregiving affects the health of the caregivers.

His interest is both professional and personal. He vividly remembers the six years his mother took care of his grandmother, who had dementia following a stroke. As a child he witnessed the stress the situation placed on his mother, who not only had her own family obligations, but also held a full-time job. He saw the strain it created in his mother's relationships with her siblings, who were not as involved in caring for their mother.

The number of Americans age 65 and older is expected to rise from more than 34 million to about 71 million by 2030, according to Cohen. During the same time, the population age 85 and above will grow from six million to nine million. Caring for a burgeoning elderly population, he says, may threaten the physical and [mental health](#) of caregivers.

Tufts Now asked Cohen, who is also an assistant professor of epidemiology and community health at Virginia Commonwealth University, what he has learned from his research so far.

Tufts Now: Who are the caregivers?

Steven Cohen: People in their 70s and 80s are more likely to have spousal caregivers, but when we're talking about the oldest of the old, those from mid-80s to 90s, usually it's a child. Nine times out of 10, it's a daughter, not a son. Sons tend not to do the intimate aspects of

caregiving, things like dressing and bathing, regardless of whether the parent is male or female. Sons tend to be involved with finances or transportation, not the really intensive caregiving that can be rough emotionally and physically.

What are some of the effects on the caregivers?

A large number of people leave their jobs or go to part-time work in order to do this. Some may be of retirement age, but the younger ones have issues maintaining their work: they are called for medical emergencies or to transport their relative to appointments and clinics. So they don't necessarily quit, but it affects their jobs. On average, working informal caregivers for older adults miss about seven days of work per year to fulfill caregiving duties.

What are some of the tasks they perform?

They tend to be intimate activities, such as bathing, dressing and toileting. If someone has severe dementia or Alzheimer's disease, they may need much more than that. People may need assistance with eating or walking. Then there are tasks such as helping with shopping or finances, things that are essential for living but are not as intimate or involved and are easier.

What does this cost?

Informal care, instead of paid home care, saved \$200 billion annually as of 1999 that would otherwise be spent on preventable hospitalizations, nursing homes and rehabilitation services. That represents about 50 million informal caregivers, ranging from one or two hours to full time around the clock. It's pretty startling. What's also interesting is that in 1999, the value of unpaid caregiving surpassed money paid to

institutions and home-health aides, and the figure is probably even higher now.

What are the costs to the caregivers?

We looked at three domains: physical health, mental health and preventive health behaviors. Caregivers were less likely to have dealt with their own medical care, such as annual physicals or cancer screenings. In terms of mental health, there is increased depression and anxiety and issues with marital relationships, especially for children who are caregivers for elderly parents. We found performing the same level of caregiving was slightly more detrimental for males than for females. We think that women may have better coping mechanisms to handle stress. Alternatively, women may feel less burdened because they see it as a duty.

It was surprising to find that caregivers exercise, though we don't know from the survey what their definition of exercise is. Perhaps it's the work they do in caregiving. If they are doing conventional exercise, my hypothesis is that it serves as a stress reliever. We also found they weren't eating well or making sure they were at a healthy weight.

Is there any kind of support for informal caregivers?

There are some support groups that are usually local or hospital-based and often tailored to a specific disease such as cancer or Alzheimer's. They're small, and don't reach most of the caregivers. There is no national caregiver support group. The irony is caregivers don't have the time and energy to go to support groups, even if there are some.

What impact will the baby boom have on informal caregiving?

Right after the baby boomers, there was a baby bust, with smaller families, so there will be a smaller number of people to take care of their parents than there were in prior generations. But as a cohort, the baby boomers tend to be more assertive than prior generations and are some of the biggest impetus of cultural changes. It remains to be seen what will happen with them.

What surprised you about the survey results?

I would have thought that rural caregivers would have a much harder time, because they are farther away from medical centers. But we found just the opposite. It turned out that rural caregiving was less challenging than suburban or urban caregiving. It could be a cultural thing; people in rural areas may live closer to their families or live in intergenerational households, so there are more people around to help. We're currently conducting a study with the National Cancer Institute to look at this.

What other surprises were there?

When you increase the number of children in the caregiver's family, it was detrimental to the caregiver and the impact was significantly worse. No one has quantified this before. I broke this down by race, and the effect of caregiving was much more severe on whites than on other groups. Caregiving is not that bad for whites without children. But as soon as one or more children are added to the picture, the problem increases by 20 percent. In the Hispanic community, there was no association at all; in the Asian community only a slight increase. Among blacks it was only significant when there were two or more children in the family.

What do you think accounts for this difference?

It could be cultural issues, or it could be the family structure. I think with whites, it's less culturally accepted to be caring for an older adult or have one living at home, and it's more perceived as a burden. In other races and ethnicities it may be more accepted: this is part of life, and I have a child I care for and an elderly relative I care for.

What coping strategies do people use to deal with elderly relatives amidst very busy lives?

Coping strategies are not addressed in these surveys, but I'm hoping they will be in the next data set to come out.

What will you do about caring for your parents as they age?

I fully intend to be as involved as one can be. The best thing would be for my parents to live long and healthy lives and pass away peacefully—to be healthy until they're 120. But that's wishful thinking.

Provided by Tufts University

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