



Stressed and strapped: Caregivers for friends, relatives suffer emotional and financial strain

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Family members or friends caring for aging or disabled individuals in California are under both financial and emotional strain and are likely to face even greater burdens, given recent cuts in state support for programs and services that support in-home care, write the authors of a new policy brief by the UCLA Center for Health Policy Research.

The study looked at California's estimated 6 million-plus informal caregivers of all ages and found higher levels of serious psychological distress and negative health behaviors, such as smoking, compared with the general population. Of particular concern are an estimated 2.6 million caregivers between the ages of 45 and 64 who may be setting themselves up for an unhealthy future due to higher rates of poor health behaviors, compared with both non-caregivers in the same age range and older caregivers. "This is the 'sandwich generation,' the group of people struggling to meet the needs of both growing children and aging parents, often alone and while holding down full-time jobs," said Geoffrey Hoffman, the brief's lead author. "Caregivers need help, especially as baby boomers age and place even greater strains on their and their families' abilities to cope."

Using data from the 2009 California Health Interview Survey (CHIS), the authors found that California caregivers provide an average of 20 hours of care per week for a friend or relative who can no longer do certain things for themselves, such as bathing, shopping, managing medications or paying bills.

Few caregivers are paid for their work or use state services that might help alleviate both financial and psychological burdens. And with the U.S. Census projecting that the population of those 65 and older will more than double in the next 30 years, the magnitude of largely uncompensated care by family and friends will rapidly increase.

"We may be seeing an association between caregiving and stress, where caregivers are both more likely to be seriously depressed and to exhibit certain health behaviors that put them at risk," Hoffman said. "These effects on caregivers' overall health merit attention from policymakers."

Among the findings:

Caregivers under stress/mental health: More than 1 million caregivers report moderate or serious distress levels, with almost one-third reporting that their emotions interfere a lot with their household chores (29.9 percent) or their social lives (32.9 percent).

Middle-aged caregivers struggling: Compared with both older caregivers and non-caregivers of the same age, middle-aged caregivers are more likely to binge drink (25.5 percent), smoke (15.9 percent) and/or be obese (30.1 percent).

Stress and smoking: Caregivers of all ages who reported serious psychological distress were 208 percent more likely to smoke than non-caregivers with serious psychological distress — an exceptional amount.

Middle-aged caregivers lack support: Nearly one-third (29.0 percent) of middle-aged caregivers are single, divorced or widowed, and more than two-thirds (67.1 percent) hold down full- or part-time jobs. Nearly one-quarter (22.5 percent) are low-income.

Caregiving is time-intensive: Approximately one-third of caregivers who live with care recipients spend an average of 36 hours on caregiving — almost as much as a full-time job. A majority (62.0 percent) of caregivers of all ages work full or part time.

Caregivers of all ages under financial strain: Only 7.4 percent of informal caregivers reported being paid for the help they provide. Moreover, nearly 20 percent spent \$250 or more of their own money on caregiving in the past month. The strains of caregiving may be alleviated by respite services (short-term temporary relief from duties), yet only 13.5 percent of caregivers report ever using any respite care.

The authors note that recent cuts to California's In-Home Supportive Services program and the scheduled Dec 1. elimination of the Adult Day Health Care program will likely place even greater burdens on informal caregivers.

"Family members and friends supporting loved ones in need provide the bulk of personal assistance services and often absorb the high costs of caregiving, both financially and emotionally," said Dr. Bruce Chernof, president and CEO of The SCAN Foundation, which provided funding for the analysis. "Programs that support family caregivers can help them create and sustain vulnerable elders in community settings, which promotes the values of dignity, choice and independence as loved ones grow older."

The authors urge support for the Community Living Assistance and Supports (CLASS) program, a voluntary, consumer-funded long-term care insurance program proposed under health reform, which would provide a cash benefit that could be used to compensate informal caregivers and to purchase needed respite or mental health services.

Other provisions in the health reform law also offer a range of initiatives to provide in-home care to seniors and people with disabilities and reduce dependence on high-cost Medicaid nursing homes, according to the authors. Programs like the Community First Choice Option, which provides community-based attendant supports and services to disabled individuals requiring an institutional level of care, as well as proposed new Medicaid funding for Aging and Disability Resource Centers, could significantly lift the burden off of family and other informal caregivers, the researchers say.

Read the policy brief, Stressed and Strapped: Caregivers in California, at www.healthpolicy.ucla.edu