

Today's Research on Aging

PROGRAM AND POLICY IMPLICATIONS

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Caregiver Health

In the coming decades, as the share of people ages 65 and older rises, the number of noninstitutionalized elderly with significant disabilities due to dementia and chronic diseases associated with aging will swell. The ranks of the elderly who need care will grow. And as a result, informal caregivers will play an increasingly vital role in the United States.

To promote healthy aging, the National Institute on Aging (NIA) supports research aimed at better understanding informal caregiving and its impact on those who care for the elderly. This newsletter highlights work by NIA-supported researchers and others that examines aspects of caregiver health, particularly negative health consequences and what can be done to ease caregiver burden.

The Costs of Long-Term Care

In the United States, family and friends supply most long-term care. Policies place primary responsibility on the contributions of family, with formal services playing a supporting role (Davey et al. 2005). An estimated 29 million informal caregivers deliver more than \$300 billion in services in the United States (Arno 2006). Still, among those who suffer from functional disabilities, fully 21 percent report receiving neither formal nor informal support (Davey et al. 2005).

Aging is directly associated with long-term care (LTC) spending. One study estimates that a one-percentage-point

increase in the share of the population age 65 or older is associated with a 28 percent increase in inpatient LTC and a 42 percent increase in home LTC expenditures (Byung-Kwang Yoo et al. 2004).

Informal caregivers save governments money. The availability of a spouse caregiver is associated with a \$28,840 annual reduction in formal LTC spending per additional elderly male in countries that are members of the Organization for Economic Cooperation and Development (OECD), according to a study by Yoo and colleagues. Adult child caregivers are associated with up to \$3,830 less in LTC spending per year. These effects on spending vary by country and across time.

The cost of informal care for patients with dementia—a common condition that affects up to 10 percent of Americans ages 65 and older—totals more than \$18 billion per year in the United States. Such informal care includes in-home assistance with any activity of daily living (eating, getting in or out of bed or a chair, using the bathroom, dressing, bathing, walking across a room) or any help with instrumental activities of daily living including preparing meals, grocery shopping, making phone calls, taking medications, and managing money. These usually involve help from a relative or an unpaid nonrelative with no organizational affiliation. The quantity and cost of informal caregiving for elderly persons with dementia rise sharply as cognitive impairment worsens, according to a 2001 study by Kenneth Langa and colleagues. Elderly with severe dementia received 41.5 more hours of care per week than their dementia-free peers. The yearly cost of informal care per case ranges from \$3,630 for mild dementia to \$17,700 for severe dementia.

How Caring for the Elderly Affects Caregiver Health

Caregiver burden is expressed in many ways. Much earlier research has focused on how a spouse's illness worsens the health of the caregiving spouse. The distress linked to caregiving has been associated with psychological and physical

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This review summarizes research related to the objectives of the National Institute on Aging, with emphasis on work conducted at the NIA demography centers. Our objective is to provide decisionmakers in government, business, and nongovernmental organizations with up-to-date scientific evidence relevant to policy debates and program design. These newsletters can be accessed at www.prb.org/TodaysResearch.aspx.

Caregiving as Unpaid Work

Most elders eligible to live in nursing homes continue to live at home, mostly due to the unpaid efforts of their caregivers. Such informal home-based caregiving often involves sacrifices on the part of the caregiver. A study of caregiver traits and reduced employment found that daughters, daughters-in-law, and caregivers who live with the patient are more likely to reduce work hours than other caregivers (Kenneth Covinsky et al. 2001). So too are caregivers of African American and Hispanic patients, which may partly explain lower rates of nursing home use among minority patients. Given the economic consequences of reduced employment, African American and Hispanic families assume a disproportionate share of the total societal cost of caregiving.

Patients who exhibit conditions associated with nursing home placement including dependence on others to help with activities of daily living such as meal preparation and household work, a history of stroke, or a history of dementia are also more likely to have caregivers who will cut their employment hours to care for them.

Paid Home Care: Effect on Family Caregivers

If family caregivers are overwhelmed by their elderly relative's needs, wouldn't paid home care help lighten the load and improve their well-being?

Findings are mixed. While some studies find that use of home care services effectively reduces feelings of burden among family caregivers of disabled elderly (Kumamoto, Arai, and Zarit 2006), paid home care may undermine rather than improve family caregivers' well-being.

One study showed that the onset of paid home care was associated with increases in family caregivers' feelings of worry and strain (Pot et al. 2005). In contrast, ending paid home care was associated with fewer depressive symptoms. It is possible that the increased feelings of worry and strain associated with the transition to paid help may be due to new stressors related to turning care of one's relative over to another person. One might worry about the reliability, quality, or dependability of care, or problems associated with overseeing and managing other caregivers. It is also likely that family caregivers who experience an increase in worry choose to bring paid care into the home. The link between a decrease in family caregivers' depressive symptoms and stopping paid home care may be explained by relief from the tension of trying to manage outside services. It is also possible that an improved mood preceded and contributed to the decision to stop using outside services.

illnesses. Caregivers are at greater risk for depressive symptoms, reduced well-being, poorer self-rated health, and even higher death rates than non-caregivers.

Stress is common among those who care for elderly patients, and some caregivers are more vulnerable than others. Those who care for patients with depression or hearing impairment tend to exhibit signs of stress (Desbiens et al. 2001). Among caregivers of the hospitalized oldest-old patients (ages 80 and older), women who are in poor health and spend eight or more hours a day caring for relatives are at high risk for caregiver stress. Caregivers who were stressed answered "a lot" or "a great deal" when asked whether caring for the patient added tension to their lives, reduced time for themselves, always made them feel tired, made them feel socially isolated, and made them feel they lost control over their own lives.

Caregiving has also been linked to physiological changes. For example, caring for an elderly spouse with Alzheimer's can put a caregiver at risk for cardiovascular disease. Research evidence from a 2006 study by Kirstin Aschbacher and colleagues suggests that among the elderly caring for their spouses, the tendency for the caregiving spouse to develop blood clots increases with the severity of the Alzheimer patient's dementia. This finding underscores the need to follow the cardiovascular health of caregivers of patients with late-stage Alzheimer's.

Preliminary findings also suggest that disturbed sleep might be linked with increased cardiovascular risk at a later date, especially in older caregivers under chronic stress of caring for an Alzheimer patient (von Kanel et al. 2006; Mausbach et al. 2006).

The strain of caregiving can also put people at higher risk of dying. A 1999 study by Richard Schulz and Scott Beach linked the mental or emotional strain associated with caregiving to a higher chance of dying for caregivers when compared to non-caregivers.

It may be roughly as bad for a caregiver spouse's health to have a partner hospitalized with a serious disease as it is for that partner to die. Diagnoses vary in their impact, but illness in one spouse can affect the health and risk of death for the other. While dementia is on the upper end of burdensomeness in terms of risk to a caregiving spouse's life, other diseases or conditions, such as hip fractures, congestive heart failure, and psychiatric conditions, appear to be nearly as detrimental. Illness or death in one spouse also deprives the remaining spouse of social support previously offered by the deceased (Christakis and Allison 2004, 2006).

Deterioration in caregiver health may be reversed. Changes can result in significant long-term improvement in both psychological and physical health. Brent Mausbach and his colleagues (2007) found that caregivers who place their spouses in extended care or whose spouse dies report significant reductions in psychological distress during the first six to 12 months following the transition.

Ethnicity and culture also play a significant role in stress and coping (Aranda and Knight 1997; Shurgot and Knight 2005). Not only do these factors influence the perception and use of family support, but they also affect the appraisal of stress. In addition, higher risk of chronic diseases and greater functional limitations at earlier ages in Latino and African American populations increase the caregiving challenge.

Interventions to Help Caregivers

Research has revealed some promising approaches to reducing caregiver burden and depression. The Resources for Enhancing Alzheimer's Caregiver Health (REACH) project is a multisite research program funded by the National Institute on Aging and the National Institute of Nursing Research. REACH involved two phases. In REACH I, researchers tested a combination of strategies including education, counseling, skill-building, and stress management at each site. Each intervention was offered in various settings such as homes or physician offices. Results from REACH I include findings that:

- Caregiver interventions can benefit caregivers during the grieving process (Schulz et al. 2006). Those caregivers who received any one of the six REACH I interventions showed less evidence than control groups of grief complicated by adjustment disorders such as depression.
- Caregivers with poor health benefit less from interventions, suggesting that interventions may also need to address caregiver health (Chee et al. 2007).

REACH II took elements of the REACH I interventions and developed a multipart home-based intervention that matched level of risk for home hazards, lack of education, caregiver stress, and need for skills to manage complex behaviors, with specific intervention strategies. When researchers tested these interventions, they found that proactive approaches that combine in-home counseling and skills-building sessions, stress management techniques, and telephone counseling and support groups help control conditions and reduce caregiver burden. One component of the project involved a simple computer-telephone technology

that gave caregivers access to local resources and online support groups. In addition, caregivers who actively engaged in skills training had significantly reduced levels of depression (Belle et al. 2006).

Even minimal support and attention can have positive effects on caregivers. Steven Belle and other researchers (2006) found that caregivers in REACH II reported that participating in the study improved their ability to care for the patient.

Some subgroups seem to experience more improvement than others. For women and those with a high school educa-

Measuring Caregiver Stress

With family caregivers at increased risk of depression, anxiety, and death, researchers agree that family caregiving is stressful. But just how much stress constitutes a real health risk?

One tool to assess caregiver mental health is the Zarit Burden Interview (ZBI). Unlike standard depression scales, ZBI enables caregivers to understand the relationship between their caregiving role and their feelings of stress (Schreiner et al. 2006; Parks and Novielli 2000). It also helps them gain insight into the magnitude of their stress. Questions include:

- Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?
- Do you feel strained when you are around your relative?
- Do you feel that you don't have as much privacy as you would like because of your relative?

The caregivers are asked how often they experience such feelings. In a comparison of depression scale scores and ZBI scores for a Japanese sample of caregivers, Andrea Schreiner and colleagues found that a cutoff score of 24 correctly identified 72 percent of caregivers with probable depression. Hébert, Bravo, and Préville (2000) have done similar work on reference values for assessing caregiver burden in a Canadian sample.

Using the ZBI with valid cutoff scores may enable health care professionals to identify family caregivers who need help to improve their coping skills, sense of self-efficacy, and ability to provide high quality care. Health care providers might also identify family caregivers at risk for depression and ultimately help improve their quality of life.

Zarit Burden Interview:
www.aafp.org/afp/20001215/2613.html

tion or less, active interventions reduced their burden to lower levels than that of participants in a control group (Gitlin et al. 2003). In REACH II, the interventions resulted in greater improvements in quality of life (as measured by indicators of depression, burden, social support, self-care, and patient problem behaviors) for Caucasian and Latino caregivers and for African Americans caring for their spouse, but not for nonspousal African American caregivers (Belle et al. 2006).

A short course of intensive counseling and readily available ongoing support can have long-lasting effects in reducing symptoms of depression in those caring for dementia patients, according to a 2004 study by Mary Mittelman and others. Spouse caregivers who received enhanced counseling and support showed fewer depressive symptoms than participants who received usual care after one year. Long-lasting improvements were detectable even more than three years after enrollment.

Future studies could add to the existing knowledge base by testing the effect of interventions over longer time periods and taking a look at effects among caregivers with more diverse backgrounds. Knowing which factors help reduce the emotional distress associated with caregiving over the long term will enhance caregiver quality of life and skills, and decrease factors related to depression. By helping informal caregivers perform more effectively, such research could affect the use of health care services and health care costs over the long run.

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The NIA Demography Centers

The National Institute on Aging supports 13 research centers on the demography and economics of aging, based at the University of California at Berkeley, the University of Chicago, Harvard University, the University of Michigan, the National Bureau of Economic Research, the University of North Carolina, the University of Pennsylvania, Pennsylvania State University, Princeton University, RAND Corporation, Stanford University, the University of Southern California/University of California at Los Angeles, and the University of Wisconsin.

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For More Information

Los Angeles Caregiver Resource Center
<http://geroweb.usc.edu/lacrc>

Rosalyn Carter Institute for Caregiving
www.rosalynncarter.org/natprog/

REACH
www.edc.gsph.pitt.edu/reach/

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