

Family caregiving stress filled and isolating

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Family members who provide care to relatives with dementia, but do not have formal training, frequently experience overwhelming stress that sometimes leads to breakdowns or depression, according to Penn State and Benjamin Rose Institute researchers. Interventions to alleviate this stress are not always effective, leaving caregivers isolated to deal with their stresses.

Steven Zarit, professor and head, human development and family studies, and his colleagues studied the 15 most common stressors for [caregivers](#) -- including financial strain, patient behaviors, frequency of help from family and friends, and caregiving time demands. The findings, published in a recent issue of *Aging & Mental Health*, showed that the 67 people in the study experienced radically different types and amounts of stress.

"Behavior issues are a common stressor, but caregivers don't always report that their family member has behavior issues," said Zarit. "Some people feel more strain from the sense that they've lost a relationship with their family member, or because of conflict with siblings or other [relatives](#). It's different for everyone."

About 4 million people in the country care for a family member with dementia, Zarit says. Most often care continues for five to seven years, but some caregivers take on this role for 15 to 20 years.

The most common approach for helping caregivers is teaching them specific coping skills for stressors, but many existing interventions target

only one set of stressors. For example, an intervention might focus on behaviors of dementia by explaining why certain behaviors occur and how caregivers can change those behaviors. This intervention is expected to improve stress levels after the dementia patient changes behaviors.

However, it will only help caregivers who are troubled by behaviors of dementia. As Zarit's study indicated, people experience a wide variety of stressors. A person coping with behavior problems may also have other difficulties not targeted by this single-stressor intervention. Some caregivers will not need to cope with behavior problems at all.

Intervention programs are expensive and many organizations are not able to offer comprehensive programs or can reach only a small subset of stressed caregivers.

"The majority of caregivers are living at home, with little or no help," said Zarit. "The family has to pay the physical, emotional, and financial cost of the caring, which can be staggering. When the caregiver gets overwhelmed, it raises the probability of a breakdown in the care situation." In a few cases, there are reports of neglect or abuse.

Most interventions operate as a preventive measure -- they reach people before the stress becomes overwhelming.

"Because stress profiles vary so widely, we just don't know how much of a given stressor will hit a threshold and when we should make an intervention," Zarit said.

According to Zarit, a promising approach is to use an adaptive intervention, one that can be customized to address the varying risk factors of each individual. Some of these interventions exist in the real world and are successful. However, most of these interventions are published and never become used widely, said Zarit.

Even if current interventions are not always effective, options exist to alleviate [stress](#) and maintain well-being in a caregiving relationship. Zarit's past research has found that family meetings—which enlist the support of extended family -- can improve well-being for both individuals in the relationship.

Another avenue that Zarit is now researching is adult day care services. He has seen positive feedback and recommends day care to those who can afford it, even if for only a couple of days every week. Adult [day care](#) not only gives the caregiver a break, but it provides structured activities for the person with [dementia](#).

Provided by Pennsylvania State University

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