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## Physical and Mental Health Effects of Family Caregiving

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### Abstract

*Adverse—and even positive—outcomes in a chronic stress experience.*

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The associations between physical and psychological health and being an informal caregiver are well established.<sup>1,7</sup> In this article, *caregiving* denotes care that is provided by a family member or friend rather than by a professional who is reimbursed for services.

Clinical observation and early empirical research showed that assuming a caregiving role can be stressful and burdensome.<sup>8,9</sup> Caregiving has all the features of a chronic stress experience: It creates physical and psychological strain over extended periods of time, is accompanied by high levels of unpredictability and uncontrollability, has the capacity to create secondary stress in multiple life domains such as work and family relationships, and frequently requires high levels of vigilance. Caregiving fits the formula for chronic stress so well that it is used as a model for studying the health effects of chronic stress.<sup>2</sup>

Caregivers are a critical national health care resource. Families often are a primary source of home care and support for older relatives, contributing services that would cost hundreds of billions of dollars annually if they had to be purchased.<sup>10,12</sup> Nurses' role in home health care has expanded from being primary caregivers to teaching and assisting family members to provide care. Similarly, social workers now play a critical role in providing advice and support to caregivers.

Evidence on the health effects of caregiving gathered over the last two decades has helped convince policymakers that caregiving is a major public health issue. Professional advocacy group, including nurses and social workers, have been instrumental in raising awareness about this issue.



## CONCEPTUAL FRAMEWORK

The dominant conceptual model for caregiving assumes that the onset and progression of chronic illness and physical disability are stressful for both the patient and the caregiver. Therefore, the framework of stress-coping models can be used to study caregiving.

Within this framework, objective stressors include the patient's physical disabilities, cognitive impairment, and problem behaviors, as well as the type and intensity of care provided. In caregivers, these objective stressors lead to psychological stress and impaired health behaviors, which stimulate physiologic responses resulting in illness and mortality.<sup>2</sup> The effects on the

caregiver's health and moderated by individual differences in resources and vulnerabilities, such as socioeconomic status, prior health status, and level of social support.

## RESEARCH FINDINGS

Tables 1 and 2 (online at <http://links.lww.com/A505> and <http://links.lww.com/A506>) summarize the physical and mental health effects, respectively, reported in the caregiving literature over the past three decades. A broad range of outcome measures has been examined, including cellular and organ-based physiologic measures, global physical and psychiatric health status indicators, and self-reports on health habits. These outcomes have been linked to primary stressors, such as the duration and type care provided and the functional and cognitive disabilities of the care recipient, as well as to secondary stressors, such as finances and family conflict. As a result of these stressors, the caregiver may experience effects such as psychological distress, impaired health habits, physiologic responses, psychiatric illness, physical illness, and even death.<sup>1,2,4,5,7,11–15</sup>

The detrimental physical effects of caregiving (Table 1) are generally less intensive than the psychological effects, regardless of whether they are assessed by global self-report instruments or physiologic measures such as stress hormone levels. Although relatively few studies have focused on the association between caregiving and health habits, researchers have found evidence of impaired health behaviors, such as neglecting their own health care appointments and eating a poor-quality diet, among caregivers who provide assistance with basic activities of daily living (ADLs) like toileting and eating.<sup>16</sup>

Measures of psychological well-being (Table 2) such as depression and stress, have been the most frequently studied consequences of caregiving. This research has consistently shown relatively large effects, which are moderated by age, socioeconomic status, and the availability of informal support. Older caregivers, people of low socioeconomic status, and those with limited support networks report poorer psychological and physical health than caregivers who are younger and have more economic and interpersonal resources.<sup>1–3</sup>

## PREDICTORS OF HEALTH EFFECTS

Given that caregiving can be detrimental to health, it is appropriate to investigate what aspects of the caregiving experience account for these effects.

### Physical health

Factors linked to caregiver's physical health include the care recipient's behavior problems, cognitive impairment, and functional disabilities; the duration and amount of care provided; vigilance demands (such as constantly having to watch a person with Alzheimer's disease to prevent self-harm); and caregiver and patient coresidence.<sup>1,2,4,7,13</sup> Feelings of distress and depression associated with caregiving also negatively affect the caregiver's physical health.

Caring for a patient with dementia is more challenging than caring for a patient with physical disabilities alone. People with dementia typically require more supervision, are less likely to express gratitude for the help they receive, and are more likely to be depressed. All of these factors have been linked to negative caregiver outcomes.<sup>7,17</sup>

### Mental health

Greater degrees of depression and stress and low ratings of subjective well-being in caregivers are consistently associated with the following factors<sup>1,2,4,5</sup>:

- the care recipient's behavior problems

- the care recipient's cognitive impairment
- the care recipient's functional disabilities
- the duration and amount of care provided
- the caregiver's age, with older caregivers being more affected
- the relationship between caregiver and care recipient, with a spousal relationship having a greater effect
- the caregiver's sex, with females being more affected

As is the case with physical health effects, caregiving for someone with dementia is associated with higher levels of distress and depression than caring for someone who doesn't have dementia.<sup>17</sup>

Recently researchers have focused not only on providing care as a cause of distress, but also on the caregiver's perception of how much the patient is suffering. Patient suffering is manifested in three related and measurable ways: overt physical signs, including verbal and nonverbal expressions of pain and physical discomfort, such as difficulty breathing; psychological symptoms of distress, such as depression and apathy; and existential or spiritual well-being, reflecting the extent to which religious or philosophical beliefs provide inner harmony, comfort, and strength or, alternatively, lead to despair.<sup>18,19</sup> Not all illnesses entail suffering, and some patients respond to illness or disability with calm and optimism while others respond with fear and hopelessness. We recently found that two types of patient suffering—emotional and existential distress—were significantly associated with caregiver depression and use of antidepressant medication.<sup>20</sup>

## POSITIVE EFFECTS OF CAREGIVING

In studies with large population-based samples, about one third of caregivers report neither strain nor negative health effects.<sup>21</sup> Particularly in the early stages of caregiving, negative effects may not occur.<sup>16,22</sup> Even when caregiving demands become more intense and result in high levels of distress and depression, caregivers often cite positive aspects of the experience. They report that caregiving makes them feel good about themselves and as if they are needed, gives meaning to their lives, enables them to learn new skills, and strengthens their relationships with others.<sup>21</sup>

Researchers have known for some time that individuals in supportive social relationships are happier and healthier and live longer than those who are socially isolated.<sup>24,25</sup> Recent findings suggest that supporting or helping others may be just as beneficial to health as receiving support. After controlling for baseline health status, Brown and colleagues found that individuals who provided instrumental support to friends, relatives, or neighbors and people who provided emotional support to their spouses had lower five-year mortality rates than individuals who didn't help others or didn't support their spouses.<sup>26</sup>

## LIMITATIONS OF EXISTING RESEARCH

Although the caregiving literature is vast, much of it is based on cross-sectional analyses of relatively small opportunity samples. Confounding effects such as the caregiver's level of education and health status have often not been controlled for in the study's design or statistical analysis.

Even large, longitudinal, or case-control studies are subject to biases. For example, differences in illness rates between caregivers and noncaregivers may not be the result of the caregiving experience, but may instead reflect differences that existed prior to assuming the caregiving

role. One example may be socioeconomic status; individuals of low socioeconomic status are more likely to take on the caregiving role, and low socioeconomic status is a risk factor for poor health. Higher rates of illness in spouse caregivers may be the result of assortative mating (people tend to choose spouses who are similar to themselves) or shared health habits (such as diet and exercise) and life circumstances (such as access to medical care). As a result of these factors, older spouses tend to develop illnesses and disabilities at about the same time; one partner may have health problems that require a caregiver, but chances are the other partner also has health problems, although they may be less severe.

### Transitions into and out of caregiving

Prospective studies that link declines in caregiver health to increasing care demands provide compelling evidence of the health effects of caregiving.<sup>14,27</sup> A few studies followed samples of noncaregivers until they became caregivers and then compared them with those who didn't take on this role.<sup>16,22,28,29</sup> Both Burton and colleagues and Hirst demonstrated that moving into a demanding caregiving role—providing assistance with basic ADLs for 20 hours or more per week—resulted in increased depression and psychological distress, impaired self-care, and poorer self-reported health.<sup>16,22</sup>

A few studies have examined the effects of making the transition out of the caregiving role because the patient improves, enters an institution, or dies. Improved patient functioning is associated with reductions in caregiver distress.<sup>30</sup> The death of the care recipient has been found to reduce caregiver depression, and caregivers are often able to return to normal levels of functioning within a year.<sup>31</sup> In the short term, the effects of transition to a nursing home are less positive, with caregivers continuing to exhibit the same level of psychiatric morbidity after placement.<sup>31</sup>

### Progression of negative effects

Conceptual models of caregiving and health suggest that health effects should unfold in a cascading fashion. Caregivers first experience distress and depression, which are followed by physiologic changes and impaired health habits that ultimately lead to illness and possibly to death. Although researchers have demonstrated the predicted effects for isolated components of this model, they have not shown how illness progresses sequentially or how one condition, such as depression, leads to changes in health habits or physiology.

Many studies show that caregiving causes psychological distress, but virtually none have demonstrated that stress results in physiologic dysregulation, such as increased cortisol secretion or changes in immune function, within individual caregivers over time. Similarly, researchers have not yet demonstrated that such physiologic responses are directly linked to illness outcomes in caregivers.

Demonstrating sequential causal relationships among variables considered critical in the path from caregiver stress to illness is certainly challenging. Nevertheless, these efforts should be of high priority.

### Moderating factors

The literature clearly shows that the intensity of caregiving, whether it is measured by the type or the quantity of assistance provided, is associated with the magnitude of health effects. Emerging evidence suggests that other factors, such as the level of patient suffering, may contribute just as much to a health decline in the caregiver. It is important to disentangle the effects of helping from those of other aspects of the caregiving context, such as patient suffering.

We also need a better understanding of the different types of caregiving experiences and their effects on health. Providing help that fails to enhance the quality of the patients life may lead to frustration, resignation, and negative health effects for the caregiver. But it is likely that providing help that significantly addresses the needs and desires of a patient is uplifting to the caregiver and contributes to positive health effects. Because research on the positive aspects of caregiving is relatively new, we know little about how these good experiences moderate the stress response and affect health.

The caregiver needs to be fully integrated into the planning and delivery of health care to the nation's older adults. Researchers in nursing and social work need to develop and test interventions designed to maintain and enhance the health of caregivers. (See "Behavioral and Psychosocial Interventions for Family Caregivers" on page 47 for cautions about study design.)

#### TAKE-HOME MESSAGE

- Caregiving often results in chronic stress, which comprises caregiver's physical psychological health.
- Depression is one of the common negative effects of caregiving.
- Caring for a person with dementia is particularly challenging, causing more severe negative health effects than other types of caregiving.
- Caregiving can also be beneficial, enabling caregivers to feel good about themselves, learn new skills, and strengthen family relationships.

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