PHYSICAL AND MENTAL HEALTH EFFECTS OF FAMILY CAREGIVING

Richard Schulz
University of Pittsburgh

Paula R. Sherwood
University of Pittsburgh

THE ASSOCIATIONS between physical and psychological health and being an informal caregiver are well established (Pinquart, 2001; Pinquart & Sorensen, 2003a, 2003b, 2006, 2007; Schulz et al., 1995; Vitaliano et al., 2003). 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 (Biegel et al., 1991; Haley et al., 1987). 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 (Vitaliano et al., 2003).

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 (Arno et al., 1999; Hayman et al., 2001; Langa et al., 2001). 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 groups, 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

***Journal of Social Work Education*, Vol. 44, No. 3 (Fall 2008); Supplement.**
Reprinted with permission from the *American Journal of Nursing 108*(9), 23–27 (2008).

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 (Vitaliano et al., 2003). The effects on the caregiver's health are 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 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 of 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 (Christakis & Allison, 2006; Pinquart & Sorensen, 2003a, 2003b, 2007; Schulz & Beach, 1999; Schulz et al., 1990, 1995; Vitaliano et al., 2003).

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 (Burton et al., 2003).

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 (Pinquart, 2001; Schulz et al., 1995; Vitaliano et al., 2003).

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 the caregiver's physical health include the care recipient's behavior problems, cognitive impairment, and functional

TABLE 1. Measures of Caregiving's Physical Health Effects

Type of Measure	Specific Indicators
Global health measures	Self-reported health
	•current health
	•health compared with that of others of same age and sex
	•changes in health status
	Chronic conditions (assessed by chronic illness checklists)
	Physical symptoms (assessed by Cornell Medical Index)
	Medications
	•how many
	•type
	Health service use
	•clinic visits
	•days in hospital
	•physician or NP visits
	Mortality
Physiologic measures	Antibodies and functional immune measures
	•immunoglobulin levels
	•Epstein–Barr virus presence
	•T-cell proliferation
	•responses to mitogens
	•response to cytokine stimulation
	•lymphocyte counts
	Stress hormone and neurotransmitter measures
	•adrenocorticotropic hormone (ACTH)
	•epinephrine
	•norepinephrine
	•cortisol
	•prolactin
	Cardiovascular measures
	•blood pressure
	•heart rate
	Metabolic measures
	•body mass and weight
	•cholesterol
	•insulin
	•glucose
	•transferrin
	Speed of wound healing
Health habit self-reports	Self-report on daily routines
	•sleep
	•diet
	•exercise
	Self-report on health care
	•self-care
	•medical compliance

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 (Pinquart & Sorensen, 2003b, 2007; Schulz et al., 1990, 1995; Vitaliano et al., 2003). 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 (Pinquart & Sorensen, 2007; Ory et al., 1999).

Mental Health

Greater degrees of depression and stress and low ratings of subjective well-being in caregivers are consistently associated with the following factors (Pinquart & Sorensen, 2003a, 2003b; Schulz et al., 1995; Vitaliano et al., 2003):

- 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 (Ory et al., 1999).

Recently researchers have focused not only on providing care as a cause of distress, but also on the caregiver's perception of how

TABLE 2. Measures of Caregiving's Psychological Health Effects

Measure	Specific Indicators
Depression	Clinical diagnosis Symptom checklists Antidepressant medication use
Anxiety	Clinical diagnosis Symptom checklists Anxiolytic medication use
Stress	Burden
Subjective well-being	Global self-ratings Global quality-of-life ratings
Positive aspects of caregiving	Self-ratings
Self-efficacy	Self-ratings

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 (McClain et al., 2003; Schulz et al., 2007). 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 (Schulz et al., 2008).

Positive Effects of Caregiving

In studies with large population-based samples, about one third of caregivers report neither strain nor negative health effects (Schulz et al., 1997). Particularly in the early stages of caregiving, negative effects may not occur (Burton et al., 2003; Hirst, 2005). 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 (Tarlow et al., 2004).

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 (Brown, 2007; House et al., 1988). 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 (Brown et al, 2003).

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 (Schulz & Beach, 1999; Shaw et al., 1997). A few studies followed samples of noncaregivers until they became caregivers and then compared them with those who didn't take on this role (Burton et al., 2003; Hirst, 2005; Lawton et al., 2000; Seltzer & Li, 2000). 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 (Burton et al., 2003; Hirst, 2005).

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 (Nieboer et al., 1998). 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 (Schulz et al., 2003). 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 (Schulz et al., 2004).

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 patient's 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 49 for cautions about study design.)

References

Arno, P. S., et al. (1999). The economic value of informal caregiving. *Health Affairs (Millwood)*, *18*(2), 182–188.

Biegel, D. E., et al. (1991). *Family caregiving in chronic illness: Alzheimer's disease, cancer, heart disease, mental illness, and stroke*. Newbury Park, CA: Sage.

Brown, S. L. (2007). Health effects of caregiving: Studies of helping behavior needed! *Alzheimer's Care Today*, *8*(3), 235–246.

Brown, S. L., et al. (2003). Providing social support may be more beneficial than receiving it: Results from a prospective study of mortality. *Psychological Science*, *14*(4), 320–327.

Burton, L. C., et al. (2003). Transitions in spousal caregiving. *Gerontologist*, *43*(2), 230–241.

Christakis, N. A., & Allison, P. D. (2006). Mortality after the hospitalization of a spouse. *New England Journal of Medicine*, *354*(7), 719–730.

Haley, W. E., et al. (1987). Stress, appraisal, coping, and social support as predictors of adaptational outcome among dementia caregivers. *Psychology and Aging*, *2*(4), 323–330.

Hayman, J. A., et al. (2001). Estimating the cost of informal caregiving for elderly patients with cancer. *Journal of Clinical Oncology*, *19*(13), 3219–3225.

Hirst, M. (2005). Carer distress: A prospective, population-based study. *Social Science and Medicine*, *61*(3), 697–708.

House, J. S., et al. (1988). Social relationships and health. *Science*, *241*(4865), 540–545.

Langa, K. M., et al. (2001). National estimates of the quantity and cost of informal caregiving for the elderly with dementia. *Journal of General Internal Medicine*, *16*(11), 770–778.

Lawton, M. P., et al. (2000). Two transitions in daughters' caregiving careers. *Gerontologist*, *40*(4), 437–448.

McClain, C. S., et al. (2003). Effect of spiritual well-being on end-of-life despair in terminally-ill cancer patients. *Lancet*, *361*(9369), 1603–1607.

Nieboer, A. P., et al. (1998). Spousal caregivers' activity restriction and depression: A model for changes over time. *Social Science and Medicine*, *47*(9), 1361–1371.

Ory, M. G., et al. (1999). Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. *Gerontologist*, *39*(2), 177–185.

Pinquart, M. (2001). Correlates of subjective health in older adults: A meta-analysis. *Psychology and Aging*, *16*(3), 414–426.

Pinquart, M., & Sorensen, S. (2003a). Associations of stressors and uplifts of caregiving with caregiver burden and depressive mood: A meta-analysis. *Journals of Gerontology, Series B, Psychological Sciences and Social Sciences*, *58*(2), P112–P128.

Pinquart, M., & Sorensen, S. (2003b). Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging*, *18*(2), 250–267.

Pinquart, M., & Sorensen, S. (2006). Gender differences in caregiver stressors, social resources, and health: An updated meta-analysis. *Journals of Gerontology, Series B, Psychological Sciences and Social Sciences*, *61*(1), P33–P45.

Pinquart, M., & Sorensen, S. (2007). Correlates of physical health of informal caregivers: A meta-analysis. *Journals of Gerontology, Series B, Psychological Sciences and Social Sciences*, *62*(2), P126–P137.

Schulz, R., & Beach, S. R. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *Journal of the American Medical Association*, *282*(23), 2215–2219.

Schulz, R., et al. (1990). Psychiatric and physical morbidity effects of caregiving. *Journals of Gerontology, Series B, Psychological Sciences and Social Sciences*, *45*(5), P181–P191.

Schulz, R., et al. (1995). Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *Gerontologist*, *35*(6), 771–791.

Schulz, R., et al. (1997). Health effects of caregiving: The Caregiver Health Effects Study: An ancillary study of the Cardiovascular Health Study. *Annals of Behavioral Medicine*, *19*(2), 110–116.

Schulz, R., et al. (2003). End-of-life care and the effects of bereavement on family caregivers of persons with dementia. *New England Journal of Medicine*, *349*(20), 1936–1942.

Schulz, R., et al. (2004). Long-term care placement of dementia patients and caregiver health and well-being. *Journal of the American Medical Association*, *292*(8), 961–967.

Schulz, R., et al. (2007). Patient suffering and caregiver compassion: New opportunities for research, practice, and policy. *Gerontologist*, *47*(1), 4–13.

Schulz, R., et al. (2008). Dementia patient suffering and caregiver depression. *Alzheimer Disease and Associated Disorders*, *22*(2), 170–176.

Seltzer, M. M., & Li, L. W. (2000). The dynamics of caregiving: Transitions during a three-year prospective study. *Gerontologist*, *40*(2), 165–178.

Shaw, W. S., et al. (1997). Longitudinal analysis of multiple indicators of health decline among spousal caregivers. *Annals of Behavioral Medicine*, *19*(2), 101–109.

Tarlow, B. J., et al. (2004). Positive aspects of caregiving: Contributions of the REACH project to the development of new measures for Alzheimer's caregiving. *Research on Aging*, *26*(4), 429–480.

Vitaliano, P. P., et al. (2003). Is caregiving hazardous to one's physical health? A meta-analysis. *Psychological Bulletin*, *129*(6), 946–972.

Richard Schulz is professor of psychiatry and director of the University Center for Social and Urban Research at the University of Pittsburgh. **Paula R. Sherwood** is assistant professor of nursing at the University of Pittsburgh.

Preparation of this article was supported in part by grants from the National Institute of Nursing Research (NR08272, NR009573) and the Alzheimer's Association.

Reprinted with permission from the *American Journal of Nursing*. This article was first published as a supplement to the September 2008 issue of the *American Journal of Nursing*. Continuing education contact hours are available to nurses at www.NursingCenter.com/ajnfamilycaregivers.

Address correspondence to Richard Schulz, annaca@pitt.edu.