

Family Caregiving at the End of Life

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A caregiver, defined as “a person who provides direct care (to children, elderly people or the chronically ill),” can be either formal (a trained health care worker) or informal (family or friend).¹ In any given year, an estimated 29% of the United States population, or 65 million people, are caregivers.² In Rhode Island, approximately 110,000 people were caregivers in 2004, 10% of the state’s population.^{2,3}

The health care system depends on informal caregivers: they supply the bulk of physical and emotional care for individuals with chronic or terminal illnesses. There are not enough formal services to substitute for the informal caregivers.⁴

Yet caregiving brings emotional, physical and financial stressors.² The clinician who understands these strains can better support both the caregiver and the patient.

There is a large evidence base examining the effect of caregiving, most based on caregiving of frail older adults, especially those with dementia. The evidence, as described in this volume by Tremont, demonstrates high levels of stress amongst caregivers, both physical and emotional (i.e., physical strains from assisting with activities of daily living, higher rates of anxiety and depression).^{2,5,6,7} These caregivers also suffer financial strain and a substantial impact on employment and career.^{5,6,7} Caregivers often reduce work hours, miss days or take leave, while tapping into savings.² These strains may well account for the higher mortality rate among stressed caregivers.⁷

Caregivers can experience the highest stress when caring for patients with a terminal illness at the end of life.^{4,6,8} These caregivers typically report the most strain, the highest number of hours of care, and assistance with the greatest number of activities of daily living.⁸ A study of caregivers of chronically disabled adults compared those whose patients died to those whose patients were still alive after a year: those involved in end-of-life care provided the most hours of care, a mean of 43 hours per week, 53.5% reported poor health themselves, and 28.9% reported emotional strain while 18.9% reported physical strain.⁹ Indeed, those caregivers had needs that often exceeded those

of the dying patient.¹⁰ However, more than 70% of caregivers reported feeling good about being a caregiver, and that the provision of care was a positive experience.⁹

To help family caregivers, a clinician should ask three questions:

First, what information and support will benefit family caregivers prior to bereavement? There are few longitudinal assessments of caregivers to dying adults but cross-sectional accounts provide useful information. A review by Docherty et al of 34 studies from eight nations found consistent evidence in support of caregivers’ need for greater education regarding pain management and improved communication between patient, caregiver and service provider.¹¹ In the United States, similar reports from Teno,¹² Wetle,¹³ Shield¹⁴ and others describe family concerns regarding patient pain, physician communication and insufficient staffing in institutional settings. Family members who receive longitudinal support from home care with hospice services¹² or a dementia caregiving program¹⁵ appeared to show more resilience and reported more acceptance of their experience with the dying process and bereavement.

Second, are there ways to identify caregivers at risk for complicated or prolonged bereavement, and may intervention be started prior to death? An estimated 10 – 20% of family caregivers are at risk for chronic depression or prolonged grief during bereavement.¹⁵ Increased burden and greater severity of the caregiver’s psychiatric symptoms prior to the care-recipient’s death are predictive factors for prolonged grief. Questions that may help a clinician identify a caregiver at risk for depression or prolonged grief are included in Table 1. Parental caregivers and dementia caregivers may also experience unique risks, as described below.

Third, during the period just prior to death, and during bereavement, what is helpful? To support caregivers, it is important to understand

who is the caregiver. The typical caregiver is a middle-aged woman who works either part or full-time, and has children at home.² The National Family Caregiver Association reports that more than 37% of caregivers have children at home, and that 66% of caregivers are women.² The typical person being cared for is an elderly parent. The average amount of time spent is 20 hours per week, though about 13% of caregivers dedicate over 40 hours per week.² Both gender and role (e.g. daughter, spouse) play a part in determining caregiver burden.¹⁶ Studies have found that men are more adversely affected by caregiving in areas of financial and social consequence; however, women experience more depression, lower life satisfaction and higher caregiver strain and distress.¹⁶ Children as caregivers report greater reward or satisfaction drawn from caregiving, compared to spouses.¹⁶

Dying, moreover, occurs in a context.¹⁰ The clinician should understand the ethnic, socioeconomic and familial context. For example, what may be seen as pathological grief to a clinician can be normal and expected from the perspective of family. Also, and of perhaps more concern, a caregiver who appears to be doing “well” to clinicians, may, in the minds of family, be coping poorly.

Ethnicity and socioeconomic status have been found to correlate with degree of caregiver burden and use of formal support services. Caucasians compared to African Americans report more difficulty adjusting to caregiving roles; however, African American caregivers use fewer formal support services and have worse health.¹⁶ Employed caregivers have higher stress levels and higher rates of depression than those who are retired or unemployed.¹⁶ However, lower socioeconomic status and lower educational

Table 1: Identifying At-Risk Family Caregivers

- Do you feel overwhelmed as a caregiver?
- Do you feel isolated?
- Do you have other family helping you?
- Do you feel prepared for your loved-one’s death?
- Have you felt intensely sad or anxious recently?

Adapted from Schulz, Hebert and Boerner¹⁵

Table 2: Local & National Resources for Caregivers & Providers

The Point: Rhode Island's Place for Seniors and Adults with Disabilities

http://adrc.ohhs.ri.gov/caregivers/caregiver_support.php

National Family Caregiver Association – Tips for Caregiver Health Protection

http://www.thefamilycaregiver.org/improving_caregiving/protect_your_health.cfm?gclid=CMLa59KvtKQCFd9n5QodxUWVGz

Caring Connections – A program of the National Hospice and Palliative Care Organization

<http://www.caringinfo.org/?gclid=CM2MnJiwtKQCFYs65Qod111NyA>

Today's Caregiver

<http://www.caregiver.com/>

The Compassionate Friends: Supporting Family After a Child Dies

<http://www.compassionatefriends.org/home.aspx>

level have been found to correlate with higher strain, more depression/anxiety, and poorer physical health.¹⁶

The “environment” or “culture” of the place where death occurs is also important. In institutional settings, where most people die,¹² families often feel that their dying loved one is not treated with respect.¹² Caregivers frequently feel compelled to advocate for increased attention to the dying person.¹⁷ As Shield reported, caregivers felt that hospice services took some of this advocacy burden, but that the services were offered too late, and sometimes the nursing home and hospice goals were not always aligned or the nursing home did not want to follow hospice recommendations.¹⁷ “Culture change” in nursing homes may be necessary to improve communication and support for family members during the end-of-life period.

Finally, parental caregivers and dementia caregivers merit specific attention. For parental caregivers who suffer the death of a child, end-of-life research is still developing. Surveys of bereaved parents have shown results consistent with caregivers of adults; parents are concerned about children's symptoms related to dying and value communication from clinicians.¹⁸ Identifying parents at risk for complicated bereavement and the development and study of interventions for parents are research priorities in pediatric oncology.¹⁹

Caregivers of dementia patients devote the greatest amount of time in caregiving, at least 46 hours per week.²⁰ As described in this volume by Tremont, dementia caregivers not only provide direct assistance to care-recipients but also struggle with the behavioral disturbances of dementia (i.e., wandering, sleep cycle reversal, agitation and aggression, and feeding

difficulties). The most difficult challenge is the cognitive decline: for those caregivers, the grief process begins before death. Indeed, for some dementia caregivers, the death can bring relief.²⁰ For most caregivers who experience pronounced grief, the reactions are considered normal and resolve gradually. Those who do not experience diminution of symptoms over time may instead struggle with major depression, post traumatic stress or a condition proposed as Prolonged Grief Disorder.²¹

In conclusion, by being aware of the strain on caregivers, clinicians can recommend services for family members who appear at risk. Families and patients can benefit from services, especially hospice, early in the disease trajectory. Table 2 lists community and on-line resources. Providers may want to watch for empirical reports of new technologies to assist dying patients and their families.²² Most importantly, at every visit clinicians should ask caregivers how they are doing, remembering that they are partners in the team of people who care for a dying, ill or disabled older adult.

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