



Care at the End of Life: Restoring a Balance

Caregiving for dying, frail elders places an enormous burden on family members and paid caregivers. Most people 65 and over live independently with minimal assistance. But as they approach death, a substantial number of people develop frailties that cause them to rely on the assistance of caregivers. The assistance required by frail elders who are dying is complex, often long term, and extremely taxing personally and financially.

Over half of people 65 and over die in nursing homes or at home, while about 48 percent of people in this age group die in hospitals (Alliance for Aging Research, 1997). For people 85 and older, the number of deaths that occur in nursing homes is 38 percent, and only 4.1 percent of deaths occur in hospitals (Alliance for Aging Research, 1997). Of those who die in a hospital, most have received many months to years of care at home from a family member prior to death. Similarly, whether they die in the nursing home or hospital, many nursing home residents have lived in a nursing home for many years, receiving daily care from personal care assistants who give most of the day to day care, and who often, because there are no living relatives, become the nursing home resident's surrogate family.

As older people approach death, they experience physical and functional deterioration frequently accompanied by debilitating cognitive impairments in memory and judgment. When the dying process occurs as a result of a chronic illness, such as congestive heart failure or Alzheimer's disease, it proceeds along a continuum over many months. The actual death often occurs as a result of a conscious decision by the patient or the family, supported by physicians, nurses, social workers, and others, to forgo resuscitation, intubation, and artificial nutrition and hydration.

Frail older people who remain at home or in other community settings (the rapidly proliferating board and care homes, adult foster homes, and assisted living facilities) during the dying process rely primarily on family and informal caregivers to provide care. This care is supplemented by intermittent paid caregiver services, sometimes (but all too rarely) including hospice care. Most hospice recipients have cancer; fewer than 2 percent of all hospice patients have a primary diagnosis of dementia (National Hospice Organization, 1999). The stress of caregiving on families, a focus of this paper, is expressed in increased physical and mental illness, increased stress and depression, less participation in social and recreational activities, and movement out of the workforce among caregivers (Brody, 1990, 1994.). At home and in nursing homes, while families typically continue to be involved (Mezey et al., 1996), the direct care of dying residents is either partly or primarily the responsibility of nursing staff, that is, formal caregivers. Nursing caregivers (licensed nursing staff and certified nursing assistants) also experience stress, which is revealed by caregivers distancing themselves from the dying patients and is also seen in job turnover, which, on average, is 100 percent annually.

The experiences of family and paid caregivers of frail elders at the end of life overlap but also differ in very significant ways. While many

family members and paid caregivers report satisfaction in caring for a dying elderly relative or patient, it is also true that caregiving of the frail and dying often exacts an enormous personal burden. Both family and paid caregivers are called on to care for a person who is often unable to provide the reciprocity that typically exists between care recipient and caregiver; the dying person is often unable to recognize the caregiver, to assist in the care, to acknowledge when care is appreciated or unwanted, and to show appreciation (Amella, Kennedy, and Kluger, 1998). Family members find it particularly wrenching to provide long-term, highly personal care to a loved spouse or parent who no longer resembles the person he or she once was and who, all too often, is no longer able to even acknowledge the family member (Shelkey et al., 1996). Paid caregivers, on the other hand, only know the person as he or she is now, and are not saddled with the life-long positive and negative context that characterizes family relationships.

Yet, paid caregivers too form strong attachments to older people both at home and in nursing homes (Wilson and Daley, 1998). Under such difficult circumstances, it is not unexpected that conflicts and disagreements should arise between family members and paid caregivers, especially as the end of life approaches. Family members may question whether the dying person is receiving sufficient or adequate care and may have strong opinions about how that care should be rendered. Paid caregivers, on the other hand, complain that family members sometimes "abandon" patients at the end of life and then attempt to compensate by seeking out opportunities to criticize the care that is provided. This lack of trust between family members and paid caregivers has consequences as to how care at the end of life is rendered, and may result in inadequate advance planning, inadequate and inaccurate communication, unclear or conflicted family decision making, and the inappropriate transfer of homecare and nursing home residents to the hospital in the few days prior to death.

The financial cost of this care is staggering, whether for out of pocket expenses to family members, for home health agencies, or for Medicaid and Medicare. For example, the aggregate cost of lost productivity for employed family caregivers is thought to be approximately \$11.4 billion, and the total costs of informal care for people with Alzheimer's disease is estimated to be \$38 billion (United Hospital Fund, 1998).

This paper reviews the process of caregiving at the end of life for family and paid caregivers, including common problems and solutions in the form of promising models that support family members and nursing staff in their caregiving roles.

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