



The Burden of Caregiving at the End-of-life

by David A. Fleming, MD

Physical, psychological and financial problems may develop in caregivers of dying patients. These problems should be addressed as well as acknowledging their important function and communicating with them.



David A. Fleming, MD, MSMA member, is Associate Professor of Medicine; Director, Center for Health Ethics, Department of Health Management and Informatics, University of Missouri - Columbia School of Medicine.

Abstract

Nonprofessional caregiving is crucial to effective end-of-life care for patients who wish to die at home. The burden of caregiving may lead to physical illness, emotional distress, financial hardship, and early mortality in the caregiver. Unmet caregiver needs have historically been poorly recognized and incompletely studied. Early recognition of caregiver distress, validation of the caregiver role, and effective communication by physicians may ease the burden of caregiving and help to secure a trusting partnership between the physician and the patient-caregiver unit at the end of life.

Introduction

Patients with terminal illness typically require the assistance of family members, 'significant others' and friends in order to avoid hospitalization and die at home. Nonprofessional caregivers are of central importance in end-of-life care. They provide essential day-to-day care and function as a liaison to physicians and other health professionals when patients need assistance with decision-

making and health care planning.

These services are not risk free for the caregiver. Assuming the responsibility of caring for loved ones at the end-of-life is frequently very distressing. Caregivers are at greater risk for depression, deteriorating physical health, financial difficulties, and premature death.¹ Caregivers are less likely to engage in preventive health behaviors, or otherwise attend to their own health needs, placing them at risk for deterioration of existing chronic health problems.²

Caregivers add a critical dimension to care that deserves recognition and validation. Physicians and others caring for patients with terminal illness often overlook the needs of caregivers and may fail to recognize their importance. The patient, family, and caregiver coalesce into a single "unit of care" that serves to reformulate and enhance the relationship grounded in trust that forms between patients and physicians. Mutual trust and understanding between patients and their physicians are critical elements for successful end-of-life care. The caregiver becomes an equal stakeholder in this trust relationship.

The goal of this paper is to

underscore the importance of caregiving as a valuable service in end-of-life care and to emphasize that physicians should be sensitive and responsive to caregiver needs. Recent research will be reviewed that has identified factors and physician behaviors most important to caregivers during the final months of their patients' lives and into bereavement. Early recognition of these factors may enable interventions that will be beneficial to the caregiver as well as their patient.

The Importance of Caregiving

In the United States cancer is the most frequent terminal illness requiring caregiving.³ Ten years ago it was estimated that six million people had a history of cancer; three million had the diagnosis for over five years.⁴ Over half a million people die of cancer each year. This number will rise because cancer rates increase with age.⁵ Many cancer patients are now being cared for at home. As the population ages and health care systems move toward earlier discharge from hospitals the care of more cancer patients is shifting to home and other outpatient settings. Family caregivers for terminally-ill patients are also necessary because of limited support and coverage by insurers for hospice and other home health care services.

The aging of our population is also creating a greater need for home caregivers. In the United States overall life expectancy has increased from 70.8

years in 1970 to 75.8 years in 1995.⁶ One implication of this phenomenon is that within 50 years the number of cancer diagnoses is expected to double.⁷ Other forms of terminal illness will also be increasingly prevalent due to the aging of our population. Approximately 360,000 new cases of Alzheimer's disease are being diagnosed annually and the prevalence doubles every five years beyond the age of 65.⁸

A study of Midwest caregivers of cancer patients revealed that most live with their patients, and in rural areas or smaller communities; only one-third live in urban populations of 50,000 or more.⁸ This data is important for rural Missouri areas where resources may be strained to support the increasing needs of terminal patients, caregivers, and the physicians who care for them.

The Risks of Caregiving

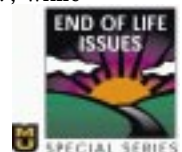
Most caregivers are older spouses or middle-aged adult children of severely disabled patients, and the majority of caregivers are women. Spouses have an increased mortality during the first year following the death of their mate.⁹ This risk is further enhanced when the spouse serves as the primary caregiver. The combination of dealing with the personal loss of a loved one, chronic emotional distress, the physical demands of caregiving, and the biological vulnerability of older adults combine to increase the risk for health problems and early death in caregivers, especially if they are elderly.^{1, 10, 11} Schultz and Beach found that mortality

risks were 63 percent higher in elderly caregivers who were experiencing distress compared to those who were providing care but did not feel stressed.¹ Caregivers who live with the care recipient tend to experience higher levels of strain and burden and are also at increased risk.

The Economic Impact of Caregiving

Very few dying patients receive paid caregiving in addition to family assistance; this suggests that there is a substantial financial burden on unpaid caregivers. It is estimated by the National Center for Health Statistics that over 54 million Americans serve as caregivers for chronically ill or disabled family members.¹² Most caregivers are women family members. Of caregivers, 43 percent have a household income of less than \$30,000 and 54 percent are between the ages of 35 and 64 years. These are the primary wage earning years. Household income, often from two-wage earners, is frequently jeopardized as family members sacrifice employment to stay home and care for totally dependent loved ones.

The importance of caregiver services has historically been under recognized and under-valued economically. Non-professional caregiving was estimated to be worth \$196 billion in 1997, while expenditures for commercial home health and nursing home care totaled



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\$32 and \$83 billion respectively.¹³ As the number of caregivers increases the impact of caregiving will become increasingly evident with important social and economic implications.

The Unmet Needs of Caregivers

Caregivers living with their patients have more personal needs than caregivers who do not live with their patients.⁴ The majority of patients with terminal illness report a need for assistance but relatively few receive assistance from paid caregivers.³ Most rely on family members and friends for help with transportation, housework, nursing, and personal care. A recent study of caregivers of patients with metastatic cancer provides insight and understanding about the caregiving experience and details of the burdens and unmet needs of caregivers.¹⁴ Findings indicate that physicians need to be attentive to patient quality of life issues and attempt to provide assistance. Caregivers may need assistance in balancing caregiving with other family, financial, and work responsibilities. It is also important for physicians to communicate effectively with the patient and caregiver and acknowledge the importance of caregiving.

Caregivers desire that physicians pay close attention to the medical care of the patient, both on an interpersonal and at the institutional level. A caring nature and

good physician bedside manner are consistently rated high as an important caregiver need. Feeling secure that there is effective communication about test results, diagnosis, and the course of treatment, especially when more than one physician is involved is also important. Effective communication within health care systems and between providers to streamline the use and transfer of medical information, billing, and scheduling is also emphasized.

Effective and compassionate communication is perhaps the most important need stressed by caregivers. This includes disclosure of medical information, prognosis, treatment, discussion of health care directives and the dying patient's wishes regarding future intervention. Earlier involvement of palliative care services and timelier referral to hospice care was also identified as important.

Caregivers, at the time of diagnosis and throughout the course of illness, desire information to assist them in understanding and deciding about next steps in the patient's illness. Disclosure of medical mistakes and charting errors is important to secure trust in both the physician and the health systems in which they practice. At the organizational level reducing errors and inconvenience through better handling of charts, x-rays, lab data, scheduling, transportation and eliminating the need for burdensome administrative requirements (such as having to repeatedly fill out health forms and re-registering each visit) will

reduce patient and caregiver stress.

Counseling and other forms of psychological and emotional support during the illness may provide caregivers with realistic expectations of their patient's illness. These interventions also provide an opportunity to screen for depression and anxiety in caregivers. From the initial diagnosis and repeatedly during the course of illness the physician should emphasize the importance of caregivers seeking and accepting additional practical and emotional support. Involving other members of the health care team, such as social workers, counselors, and chaplains, can be invaluable in this process.

Caregiver Trust

Trust in the physician is a primary mediator of emotional distress because it is a major predictor of patient and caregiver satisfaction.¹⁵ Trust may be damaged when there is poor communication and inadequate disclosure of the patient's health status. The quality of the doctor-patient relationship and the mutual trust the relationship embodies are influenced by the physician's effectiveness in communication, interpersonal treatment, and the patient's or caregiver's perception of clinical skill, especially in the relief of pain and suffering.^{16 17} Other important traits are compassion, honesty, empathy, respect and a genuine sense of caring.¹⁸

Responses from caregivers about their unmet needs suggest that loss of trust can be very distressing.¹¹ Trust is



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damaged when communication fails. Truth telling is of particular concern in relation to full disclosure about medical mistakes as well as the patient's medical condition. Actual or perceived poor communication or inattentiveness to the caregivers can undermine trust in the doctor's skill and reputation.

The Council on Scientific Affairs of the American Medical Association espouses a model of care that considers both the caregiver and patient as a single unit of care. The caregiver becomes a partner with the physician and patient.¹⁹ During end-of-life care the patient's caregiver becomes naturally intertwined within the physician-patient relationship, and as a valid stakeholder often becomes the ultimate surrogate decision-maker for the patient. Failure to win caregiver trust or involve caregivers in end-of-life health decisions can compromise quality of care and prevent adequate symptom relief.

Caregiver Relief

The United States is the only developed nation that does not financially support caregivers. Medicare does not cover expenses of long-term care. In January of 2000 President Clinton proposed a \$3000 annual tax credit for the two million families that provide long term care for a seriously ill member.²⁰ This proposal fell victim to budget constraints and other policy issues.

This past summer, The Living Well with Fatal Chronic Illness Act of

2002 was introduced in the United States House of Representatives (H.R. 5139). This bill would allow a Medicare buy-in option for caregivers over 55 years of age and a \$3,000 tax credit for the primary caregiver of a low-income individual who has long-term care needs.²¹ A similar Medicare waiver provision for caregivers already exists in Missouri. While the tax credit is not enough to completely pay for the financial costs incurred by many caregivers, it would demonstrate support for the significant commitment and contributions made by those who help loved ones at the end-of-life. The bill would also authorize the Department of Health and Human Services to establish research, demonstration, and education programs to improve the quality of end-of-life care across multiple federal agencies. Finally, the bill would authorize the Department of Veterans Affairs to develop and implement similar programs for thousands of disabled veterans.

This bill is estimated to cost over \$1.5 billion a year. There is some doubt that the present political environment will accept a bill with such broad implications for social relief. The fact that such a bill has been introduced is evidence that the needs of caregivers are being recognized and relief measures may be on the horizon in our society.

Conclusion

The unmet needs of caregivers of terminally-ill and chronically-disabled

patients are a burgeoning problem. Caregivers will benefit from early recognition of their important role and enhanced, direct communication by their patient's physician. Physicians should be equipped to identify caregivers at risk in the months preceding death and in the early months of bereavement.

Specialists who treat patients with terminal illness are positioned to recognize and implement the steps necessary to alleviate caregiver distress. Primary care physicians play a particularly important role in addressing these issues. Caregivers at risk for physical and emotional illness may seek assistance from their personal physician for physical and emotional health problems while they are still in the caregiving role or during bereavement.

The World Health Organization confirms that the caregiver and patient should be considered a single unit in the relationship they form with the physician.²² This means that caregivers have an equal stake in discussions about treatment, prognosis, and health care planning. Physicians should therefore be simultaneously sensitive to the needs of patients and their caregivers. Open and honest communication, including listening to caregivers' opinions, is very important. Recognition and validation of the caregiving role, compassionate bedside manner, and attention to caregiver quality of life issues also contribute to caregiver



satisfaction and trust in the physician. Ongoing emotional support and early referral to appropriate services may be very beneficial to this important group of people.

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