Caregiver Stress: The Physician's Role

Abisola Famakinwa, MD, Instructor in Medicine, Harvard Medical School; Staff Physician, Edith Nourse Rogers Memorial Hospital, Bedford, MA, USA.

Increases in life expectancy and the aging of the baby boomer generation has resulted in unprecedented high numbers of older adults in the U.S. and Canada and, thus, a rising number of frail older adults with chronic medical conditions. Informal caregivers, primarily family members, have traditionally provided a large proportion of care at home, and their contribution is expected to be of even greater significance. Informal caregivers provide care at great expense to themselves, because caregiving can result in emotional, physical, and financial stresses. This article discusses the role physicians play in identifying and alleviating caregiver stress.

Key words: *family caregivers, informal caregivers, caregiver stress, physician, older adults*

Introduction

Informal caregivers are the adult relatives and friends who provide essential, but unpaid, care to frail older adults as well as those who are ill or disabled.[1] It is estimated that there are 44 million U.S. and 933,000 Canadian caregivers.[2,3] While the majority of caregivers are female, a substantial proportion of caregivers are men, and male caregivers are more likely to be employed outside the home.[2,3] The responsibilities of the caregiver include everyday activities relating to managing a household and performing personal care activities such as bathing and dressing. In addition, they carry out medical procedures ranging from giving medications to tube feedings and complex wound care, and interact with the formal health care and social service systems on behalf of the care recipient. They may be also required to play an active role in legal and financial planning and participate in making advance directive decisions. Most care recipients indicate that they are satisfied with the care provided.[4] While caregiving can be very rewarding and emotionally satisfying, vigilant caregiving has been associated with physical, emotional, and financial stress for the caregivers.

Caregiver Stress

It has been well documented that the population of older adults in North America is rapidly increasing. In the U.S. alone, it is projected that the number of older people will almost double by the year 2030.[5] This will result in a large proportion of older adults with chronic medical conditions and disabilities, and the role of the informal caregiver will become even more important. In 2006, unpaid caregivers' contributions to the U.S. health care system had an estimated economic value of about US$350 billion.[6] Annual costs of informal caregiving for specific diseases have been estimated at over US$1 billion for cancer,[7] US$6.1 billion for stroke,[8] and US$18 billion for dementia.[9] Hence, it is essential that health care professionals acknowledge and support family caregivers.

Informal caregivers have to deal with the emotional burden of watching a loved one decline physically and mentally, and even die. Caregivers are more likely to have psychiatric morbidity, physical illnesses, and exposure to chronic stress.[10,11] These effects may manifest as high blood pressure,[12] altered lipid profiles,[13] an increased risk of coronary artery disease,[14] and even increased mortality among caregivers.[15,16] Other consequences of caregiver stress are immune system impairment[17,18] and slower wound healing.[19] Caregiver stress is considerably increased in situations where care is provided to an individual who is terminally ill or has dementia. Such caregivers have to provide help with greater frequency and intensity.[20–23]

Caregivers often have to take time off work to perform their caregiving responsibilities. This can result in financial stress as income is lost from reduced work hours, time out of the workforce, family

Table 1: Assessment Questions

Who is the person who provides the most care to the patient and makes the medical, financial and legal decisions (the primary caregiver)?
Who else is available to assist with the care of the patient (the secondary caregivers)?
What are the capacities and current responsibilities of each caregiver? For example; Do they feel they are adequately trained to administer medications? Do they know when they should call the doctor? Can they describe exactly how they help the patient?
What does the caregiver need to reduce their stress? For example, if transporting the patient to medical appointments is causing significant time out of work, the physician can refer the caregiver to programs that provide transportation for the elderly and disabled.

leave, or early retirement.[24] At times, the caregiver must pay for services for the care recipient that may not be covered by government or private insurers.[25]

The Physician's Role

Primary care physicians have a critical role in identifying stressed family members and taking steps to support them as caregivers. Primary care physicians have an in-depth understanding of their care recipients' medical history and social and psychological needs, usually developed over a long period of time. Thus, they are more likely to fully understand the caregiving situation and adequately assess and manage the needs of the caregivers.

Table 2: Physician Interventions

Explore social supports and resources: For example, enquire about the possibility of adult children, other family members, neighbours and friends helping out.

Make appropriate referrals: For example, if the patient has difficulty with bathing or dressing, refer them to a social worker or agency that can arrange the services of a home health aide.

Provide information and training: For example, if a caregiver has to dress a wound, arrange for a homecare nurse to visit the caregiver at home and demonstrate how this is done.

Table 3: Websites

U.S. National Alliance for Caregiving:	www.caregiving.org
U.S. National Family Caregivers Association:	www.nfcacares.org
Alzheimer Society (Canadian):	www.alzheimer.ca/english/index.php
U.S. Alzheimer's Association:	www.alz.org
Caregiving Online:	www.caregiving.com
Family Caregivers' Network Society (Victoria, British Columbia):	www.fcns-caregiving.org
The Family Caregiver Newsmagazine, Canada's National Home Care Publication:	www.thefamilycaregiver.com
Canadian Caregiver Coalition:	www.ccc-ccan.ca
Family Caregiver Centre:	www.familycaregivers.ab.ca
Long Term Care Planning Network:	www.caregiver.on.ca

Table 4: Books

Carol Levine, *Always on Call: When Illness Turns Families into Caregivers*. New York: United Hospital Fund of New York; 2000.

Nancy L. Mace and Peter V. Rabins, *The 36-Hour Day: A Family Guide to Caring for Persons with Alzheimer's Disease, Related Dementing Illnesses, and Memory Loss Later in Life*, 3rd edition. Baltimore (MD): The John Hopkins University Press; 1999.

Maria M. Meyer and Paula R. Derr, *The Comfort of Home: An Illustrated Step-by-Step Guide for Caregivers*. Portland (OR): Caretrust Publications, LLC; 1998.

James A. Wilkinson, *A Family Caregiver's Guide to Planning and Decision Making for the Elderly*. Minneapolis (MN); Fairview Press; 1999.

The Council on Scientific Affairs of the American Medical Association[26] suggests a model that considers the caregiver and the care recipient as a single unit of care, and also considers the caregiver as a partner with the physician in the care of the care recipient. This approach should be an essential part of primary care as it promotes the health and well-being of both care recipients and caregivers.

Caregiver and Care Recipient as a Single Unit of Care

Although a physician's legal obligation is to his or her patient, it is important to note that supporting the patient's caregiver leads to better care for the patient, prevents re-admissions, and postpones institutionalization.[27–31] Caregivers have been referred to as "hidden patients"[32]; often, because of the time constraints associated with caregiving, the care recipient's physician may be the only physician the caregiver sees on a regular basis.

The first step to ensuring adequate support for family caregivers is identification and recognition. The clinician should be able to identify the primary and secondary caregivers, understand their responsibilities, and acknowledge their work wherever possible (see Table 1).

The next step is to determine the caregivers' emotional and ongoing support needs. This could be determined by asking simple questions such as: "How are you coping?" "When was the last time you saw a doctor?" "How is your health?" and "How many hours do you spend caregiving?" In addition, there are several formal caregiver stress assessment tools such as the Zarit Burden Scale[33] and the American Medical Association's caregiver self-assessment questionnaire.[34] Most caregiver stress assessment tools can be administered by nonclinical staff or completed by the caregivers themselves. These tools can be made available in waiting rooms or mailed out to the caregivers. A physician

Table 5: What to Tell Patients and Their Caregivers

Describe to family members what they might expect during the course of the care recipient's illness. For example, in patients with dementia this illness will not get better, but is expected to worsen with significant problems with feeding, continence and ambulation as the disease progresses.
Discuss what might constitute a crisis for which families should seek medical assistance. For example, if the patient becomes more confused than usual, there might a medical problem responsible and the doctor should be called.
Give written or audiovisual educational materials and instructions. For example, a lot of medical journals have patient pages that can be printed up, and several caregiver web sites have links to order instructional videos for different diseases.
Provide family members with a professional to contact if they need to change the plan of care or require additional information. All caregivers should know who the care recipient's doctor is, their office number and a number to call the physician's coverage after office hours.

Clinical Pearls

At every encounter with a caregiver, ask how they are doing and wait for a response. This can help to determine if there is any caregiver stress.

who is familiar with these tools can quickly review the completed questionnaires and make recommendations.

Following the assessment, the physician has to ensure that caregivers receive the specific help that they need (see Table 2). When the physician initiates the process, it is more likely to be implemented by the caregivers, who can then work with a social worker or other clinic support staff.

The physician's intervention could be as simple as counselling the caregivers while in the office and teaching coping skills. When counselling caregivers, it is very helpful to provide written lists of available resources such as telephone numbers, books, and websites (see Tables 3 and 4). The National Alliance for Caregiving is an excellent resource, and the Alzheimer's Association is particularly helpful for caregivers of patients with dementia. It may be necessary to refer caregivers to specific programs that have been shown to reduce caregiver burden. These include interdisciplinary team care in geriatric clinics,[35] home-based primary care,[36] and specialized programs that provide psychosocial support and family counselling.[37,38] Adult day care and respite care for the care recipients are also beneficial.[39] There are federally and provincially funded programs implemented through area agencies on aging that provide education, support groups, and financial assistance to the caregiver.

Caregiver as a Partner with the Physician

The partnership approach encourages the physician to consider family caregivers as members of the health care team and partner with them in the management of the care recipient. To be an effective team member, the caregivers need to be educated about the care recipient's medical condition. The physician can provide this information by direct communication as well as through written and audiovisual materials (see Table 5).

Training caregivers to perform their specific tasks is also important. As described previously, caregivers perform several tasks ranging from assisting with activities of daily living, which may involve lifting and turning the patient, to complex medical tasks, which may involve assisting with home-based technologies. The physician should ensure that caregivers are adequately trained to perform both the basic tasks and medically oriented treatments. They should also assist caregivers in obtaining assistive devices and other technologies to improve the quality of the care they provide. This improves patient care and reduces caregiver burden.

Conclusion

Family caregivers play an important role in ensuring that adequate care is given to care recipients. This service is associated with many stresses. Failure to recognize and support caregivers leads to increasing caregiver stress and burnout. This, in turn, results in a larger number of institutionalized or homebound older adults receiving multiple services, often at government expense. Primary care physicians play an important role in acknowledging and supporting these caregivers while partnering with them to provide high-quality care to frail and disabled older adults.

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Key Points

Family caregivers provide unpaid, but essential care to older adults with disabilities.
Caregiving can result in physical, emotional, and financial stresses for caregivers.
Studies have shown that there are effective ways to support caregivers and reduce caregiver stress.
The physician's role is to identify and intervene to reduce caregiver stress, while partnering with caregivers to provide high-quality care to the care recipients.

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