Caring for the caregivers

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Although direct care of the patient with Alzheimer's disease remains the focus of the physician's concern, the importance of evaluating and responding to the needs of that patient's caregivers cannot be ignored. Osteopathic physicians provide a truly holistic approach to treatment of the patient with Alzheimer's disease when that treatment includes the care of the entire family. This article provides a brief overview of the major issues affecting caregiving for the patient with Alzheimer's disease. It describes the warning signs of caregiver burnout; and it provides guidelines for accessing resources available to assist the caregivers.

(Key words: Alzheimer's disease, dementia, memory loss, caregivers)

Few diseases affect an individual's caregivers more profoundly than Alzheimer's disease (AD). Family members deliver much of the care for the patient with AD during the inexorable course of progressive loss of memory and physical function. Caregivers are frequently confronted with a loved one who has become not only unpredictable but also, in many cases, completely unrecognizable. Because AD affects not only cognition, but also physical, affective, and behavioral function, both formal and informal caregivers must respond to myriad manifestations of the disease. Ultimately, caregivers bear responsibility for end-of-life decision making for their loved one. Caregiving for patients with AD is demanding, physically exhausting, and emotionally stressful. Thus, it is not surprising that the gerontologic medical and nursing literature support a causal relationship between burden of care and the development of physical and psychological illness in the caregiver.

Caregiving for a patient with AD can be a full-time job. Caregivers are forced to

curtail or limit their social interactions because of the level of care and surveillance demanded by the patient. They may become isolated and withdrawn. Estimates vary based on age, gender, and relationship of the caregiver to the individual afflicted with AD; but it is well recognized that caregiving frequently leads to depression. Thirty percent of caregivers of patients with AD rate their own health as fair or poor, as opposed to an overwhelming trend of the elderly to rate their health, despite multiple conditions, as good to excellent. In addition, caregivers may fail to pay attention to their own medical needs, compounding the stresses of caregiving and resulting in serious illness.

Physicians, traditionally trained to focus on improving the health and quality of life of patients, may overlook the importance of the caregiver's physical health and emotional well-being. Many healthcare providers are unskilled at recognizing caregiver strain so that by the time caregiver burnout is recognized, interventions are instituted too late to have maximum effectiveness.

The importance of physical and psychological health status of a caregiver cannot be underestimated. Loss of a primary caregiver produces a ripple effect that has an impact on the patient, the family, and the medical community. A patient with AD who loses a caregiver typically requires placement in a nursing home. Although nursing home care is inevitable and accept-

able for many patients with AD, those who are emergently institutionalized because of the death or burnout of a caregiver lose not only that well-known person but also the "least restrictive environment" of their own familiar surroundings. This type of crisis can precipitate a catastrophic reaction in the patient. The perils of catastrophic reactions in demented elders include falls (which can result in a range of injuries from fractures or lacerations to subdural hematoma, acute psychoses, and delirium).

Clearly, physicians who care for the elderly must be aware of crucial caregiving arrangements. They must be sensitive and responsive not only to the patient, but also to the family, encouraging them to continue the caregiving role with as much support and ease as is possible.

Caregiver issues

There are important reasons why AD is more of a burden to family members than other chronic diseases. The patient's memory impairment gives way over time to behavioral and psychiatric problems, and the need for assistance with activities of daily living (dressing, bathing, grooming, feeding, toileting) is both ongoing and progressively more demanding. Not to be minimized, either, are the safety issues; for example, is the patient safe to be left alone, can he or she continue to drive, use the stove, pay bills, make decisions? As the disease progresses, all such activities will be impaired, and family caregivers must anticipate the need for closer surveillance.

A particular difficulty not encountered with other chronic diseases (with the exception of chronic progressive neurologic disorders such as multiple sclerosis) is the unpredictable course and rate of progression of the disease. Patients may exhibit periods of lucidity that are interpreted by family caregivers as a return of the loved one's "old self." This interpretation can lead to lack of acceptance of the diagnosis and ultimately results in delayed treatment and planning.

Compounding the difficulty in obtaining the diagnosis of AD, there is no completely effective medical treatment available, and virtually no equipment or technology helpful for use with the cognitively impaired. Finding adequate, comprehensive primary care for patients with AD can be difficult. At the point at which the patient becomes homebound because of gait apraxia or behavioral concerns, it may

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become even more difficult to obtain medical care at home. Coupled with the scarcity of reliable, trained care providers, the high incidental costs of caregiving, and the emotional strain of watching a loved one slowly deteriorate, it is clear why caregivers of patients with AD have been called "the hidden victims."

Demographics of caregiving

Family caregiving has been referred to as a "neglected and hidden part of health care delivery."¹ As the population ages, the importance of family as a healthcare resource will increase. Between 2010 and 2030, the US population older than 65 years is expected to increase 78%, whereas those younger than 65 will increase only 6.5%.² With this increased longevity comes the challenge of caring for elders with chronic diseases such as AD. This population change has been termed the "parent support ratio," defined as the number of persons aged 85 years and older per 100 persons aged 50 to 64 years. According to the US Bureau of the Census, in 1990, this ratio was 9:100; by 2050, the projection is 28:100.³

Caregivers are primarily females (greater than 50% are wives and more than 25%, daughters) who spend an average of 56 hours per week in direct care. The median length of in-home caregiving prior to placement in a nursing home is 6.5 years. One third are employed outside the home in addition to caregiving and maintaining household(s).^{4,5} The term "sandwich generation" describes the stressors having an impact on persons in their middle years who must juggle the demands of raising a family while also providing care for aging parents. The worth of this unpaid care, based on what it would cost to pay trained home care providers, is estimated to be \$34,000 annually. For those who curtail employment to care for a loved one, the costs of caregiving include lost income.

Although much research has focused on spouses and daughters as caregivers, other relatives, such as siblings, sons, and in-laws are often pressed into service (Figure 1). Although a particular constellation of factors, such as gender, level of education, or social position may affect one's coping ability and subsequent perception of stress and burden, it is also true that each individual's response to the experience of caregiving differs. Physicians must not assume that caregivers who are

male in generally good health are at lower risk for depression or burnout. The following discussion will target some of the factors affecting caregiver strain.

Caregiver strain

Several studies evaluating caregiver burden and stress effects have looked at gender differences as well as whether the caregivers are spouses or offspring. A cross-ethnic study of depressive symptomatology in primary caregivers of patients with AD demonstrated that female gender was the most "robust risk factor" for caregiver depression, being strongly predictive in all groups except Caucasian children.⁶ In this study, greater than 50% of wives, regardless of ethnicity, reported clinically significant depression.

It is generally accepted that male caregivers fare somewhat better with respect to their reported physical and psychological health. An ongoing, prospective study at the Karolinska Institute in Stockholm, Sweden, examines differences between and within genders of individuals who are caregivers for demented persons and those who are noncaregivers for nondemented persons (such as son or daughter of an elderly, cognitively intact parent). This group has attempted to "tease out" the differences in caregiver strain between and among these groups, asking a series of questions, such as "do caregivers for demented elderly people and noncaregivers for nondemented elderly people differ in strain experiences?" and "Do females and males differ in strain experiences?" The answers, based on statistical analysis, show that strain is not necessarily exhibited uniformly among caregivers and noncaregivers, but does vary with gender. They noted that female caregivers and noncaregivers exhibited higher levels of caregiving strain than their male counterparts, with females having a specific role as caregiver for a demented elderly person being the most affected in their relations with family and others. This finding may relate to the fact that female caregivers, especially daughters, may be more stressed than others due to pressure from several simultaneous situations. In addition to being a primary helper for a frail, demented older individual and having concurrent roles of wife and mother, caregivers often work outside the home, as well (in this study, 80% of the caregiving daughters were employed outside the home).⁷

The literature on caregiving indicates that 30% to 60% of caregivers report clinically significant depression, with 15% to 20% fulfilling the *Diagnostic and Statistical Manual of Mental Disorders*, 3rd edition, revised,⁸ criteria for major depression. Many studies also note the strong association between caregiver burden and family conflict, as well as the increased risk for substance and alcohol abuse among caregivers.^{7,9}

A particularly negative result of caregiver burden is elder abuse and neglect. In 1993, an anonymous questionnaire to 342 caregivers resulted in 11.9% of respondents admitting to having been physically abusive (for example, pinching, shoving, biting, kicking, striking) toward the demented individual under their care.¹⁰ The factors that were linked to the abuse included longer period of time caring for the elder, lower level of function of the elder, high caregiver burden, and caregiver depression. The abuse occurred twice as frequently if the patient had been aggressive before or after the onset of the dementia. This study demonstrated that the relatively high psychological and physical demands placed on family members caring for relatives with dementia can have physically abusive repercussions.¹⁰

The effects of caregiving on physical health have also been examined and have rendered conflicting results. That is, although many caregivers report perceived reductions in their health status, the actual health risk may be more closely related to the age and baseline health status of the individual. However, a recent study monitored blood pressure of caregivers every 2 to 6 months for 6 years and found an association between hypertension and the chronic stress of caring for a spouse with AD.¹¹ The analysis showed a 67% increase in the risk for borderline hypertension compared with control subjects after 3 years of cumulative 2- to 6-month assessments. The difference retained statistical significance after controlling for age, gender, education, socioeconomic status, body mass index and use of antihypertensive medications.¹¹

Assessing caregiver strain

It should be clear from the preceding discussion that family caregivers of patients with AD are at an increased risk for physical and psychological problems. As such, it might follow that physicians are acute-

Cover. The 92-year-old caregiver (right) of her 96-year-old sister (center) with Alzheimer's disease is assisted by home helper (left).

(Photograph by Bruce Fairfield, Philadelphia College of Osteopathic Medicine Creative Services Department)

ly aware of the needs of these caregivers. However, a physician caring for a demented elder may be confronted by family members who are unable to articulate their own needs, and instead they focus the medical interaction on issues concerning the patient. Such caregivers may feel awkward or guilty requesting help for themselves when the patient is the one so obviously in need of care; voiced concerns for the patient may mask cries for help from the caregiver.

How can physicians recognize cries for assistance before it is too late to fully help?

Consider the following case presentation:

Rose is a 78-year-old white woman with AD diagnosed 6 years ago who lives in a Northeast Philadelphia row-home with her two unmarried middle children. The eldest child, who holds power of attorney for his mother, is a son living in Reading, Pa, with his wife and family. The youngest child, a daughter, lives two doors down with her husband. Rose is brought to your office by this daughter, Frances, who relates that during the past few months, Rose has been sleeping during the day and is awake and increasingly agitated at night. Rose has started wandering and has successfully eloped from the house on two occasions, despite the family's attempts at securing locks on the doors. Frances tells you that neither of her siblings seems to be able to "keep tabs on Rose" and that she has taken it as her own responsibility to watch over their mother. Therefore, she has been sleeping at her mother's home.

In addition to these problems, Frances calls your attention to several "rashes" on her mother, which are noted to be actinic keratoses. She then alerts you to the fact that Rose's bowel habits are not regular and that she fears that Rose may have "colitis." After a physical examination of the patient followed by lengthy discussion about these issues, you prepare to wrap up the visit.

As you are leaving the room, Frances remembers to tell you that two nights ago,

Rose awakened her from her sleep to say that she was itching all over and wanted something from the drugstore. Frances appears very distressed about this mysterious nocturnal itching that her mother is experiencing, and she urges you to do whatever testing is appropriate to pinpoint the cause of the problem.

What is really going on here?

Several "red flags" should alert you to the possibility of caregiver burnout. First, Rose lives in her own home with two of her adult children, yet neither of them have power of attorney; she is currently being cared for by her youngest daughter, who maintains another home with her husband. Second, the youngest daughter's statement that "nobody can keep tabs" on her mother alludes to the possibility of family conflict. Third, Frances is married with her own home, yet she has indicated to you that she has moved in to her mother's home. The final litany of patient complaints, voiced by this daughter, masks the hidden agenda of her need to disclose feelings of care burden, stress, and family conflict.

It is possible to assess stress levels using formal psychological testing, such as the Zarit Burden Scale.¹² However, recognition of caregiver burden can and should be based on the clinician's intuition. Recognition of caregiver burden is only the first step in addressing the problem.

Resources

It is important for physicians not only to recognize and acknowledge caregiver burden, but also to facilitate the family's access to support resources. Resources such as respite care for caregivers, ranging from helper(s) in the home for several hours (Figure 1) to stays in nursing facilities for more extended periods, afford caregivers some time away from the day-to-day routine of caregiving. Adult day care has shown benefit not only for patients, but also for caregivers. A recent study¹³ demonstrated that use of adult day care by caregivers of patients with dementia resulted in lower levels of caregiving-related stress and better psychological well-being compared with a control group.

Physicians should be aware of the presence of a local Area Agency on Aging (AAA) in most states. The AAA can be contacted for information regarding the resource network in each community available to caregiving families. This network of services encompasses Meals on Wheels, adult day care programs, respite care, and adult protective services. The local AAA can identify social workers to assist the family in obtaining needed services. They can also make referrals to volunteer or guardianship programs, hospice care, dementia special care centers, and give direction for initiating placement in retirement communities or assisted-living or

Checklist

- **Agency for Health Care Policy and Research (AHCPR) of the US Department of Health and Human Services**
 - *Clinical Practice Guidelines for Early Alzheimer's Disease* (AHCPR Publication No. 97-0703)
 - *Patient and Family Guide*, which can be useful for caregivers (AHCPR Publication No. 96-0704)

Agency for Health Care Policy and Research
Publications Clearinghouse
PO Box 8547
Silver Spring, MD 20907
Phone: (800) 358-9295

- **Alzheimer's Association**
919 N Michigan Ave, Suite 1100
Chicago, IL 60611-1676
Phone: (800) 272-3900
Web site address: www.alz.org

- **Alzheimer's Disease Education and Referral Center (ADEAR)**
PO Box 8250
Silver Spring, MD 20907-8250
Phone: (800) 438-4380
Web site: adear@alzheimers.org

- **TriAD**
Support hotline: (888) TriADHELP [(888) 874-2343].

Figure 2. Resources for family caregivers.

nursing facilities as needed.

Another excellent community resource for caregiving families is home care/visiting nurse associations. These agencies can provide nursing and social services as well as in-home physical and occupational therapy, speech therapy, psychological evaluation and treatment, and homemaker services. In many communities, churches have organized parish nursing groups or other forms of congregational support such as respite care for family caregivers.

Families should be counselled to seek financial advice regarding government assistance and how to conserve family assets. Legal consultation is recommended early in the course of the disease, so that the patient can participate in anticipatory planning. It is becoming easier in many states to locate lawyers with special expertise in geriatric law (Elder Law services) for advice and assistance with decision-making challenges.

An excellent "old-standby" book for caregivers of loved ones with AD is *The 36-Hour Day*.¹⁴ Encourage family members to

participate in community support groups for AD. These caregiver groups provide information, support, and friendship as well as an opportunity to share trials and successes with others experiencing similar caregiving challenges.

The Agency for Health Care Policy and Research (AHCPR) of the US Department of Health and Human Services has developed *Clinical Practice Guidelines for early Alzheimer's Disease* as well as a consumer version *Patient and Family Guide*, which can be useful for caregivers. These publications include practical advice and lists of further resource options. Figure 2 provides a detailed listing for these and other important resources for family caregivers, including TriAD, a caregiver and patient support program endorsed by the Alzheimer's Association and the National Council on the Aging. This free-of-charge program provides educational materials for physicians as well as families.

Comment

By the year 2040, it is estimated that between 7 and 12 million patients with dementia will receive personal, custodial care from their spouses or adult children.⁹ Although direct patient care remains the focus of the physician's concern, we cannot ignore the importance of evaluating and responding to the needs of the patients' caregivers. A truly holistic approach to treatment of AD includes the care of the entire family.

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