The family caregiver’s role in Alzheimer’s disease

William E. Haley, PhD

Article abstract—Family caregivers play an essential role in caring for patients with Alzheimer’s disease (AD), but caregiving stress often leads to problems in caregivers’ mental and physical health. Certain factors predict caregiver distress, such as the presence of patient behavioral problems and the nature of the caregivers’ social supports and coping responses. Several tools are available to assess the level of caregiver distress: The results are useful in research as well as in the clinical setting, in which they can provide insight into patient problems. Caregivers value written information about AD. They also value support groups and respite services, although the effects of these interventions are commonly less dramatic than the effects achieved by more intensive psychosocial interventions. Physicians and other health care professionals are obliged to address the concerns of AD family caregivers because they play a crucial role in the optimal care of these patients.

Health care professionals and the lay public both understand that family caregivers of patients with Alzheimer’s disease (AD) face extreme difficulty and stress. What is not commonly acknowledged is that caregivers represent a major and hidden part of our health care system and that unpaid care by family members is a critically important but fragile part of long-term care in the United States. Research on family caregiving has produced important information that can guide clinicians and policy makers beyond merely having sympathy for the plight of these families and toward constructive efforts at intervention.

This article reviews what is known about the caregiving role and its importance; evidence that caregiving can have negative physical and mental health effects; patient and caregiver factors that contribute to difficulties; clinically relevant assessments of caregiving issues; and effective interventions for caregivers. The role of physicians and other health care providers in identifying and responding to caregiving issues effectively is also discussed.

The caregiving role and its importance. Approximately 80% of the care of AD patients is provided in the community by family members. One recent large-scale longitudinal project focusing on dementia patients and their family caregivers reported that median length of in-home caregiving before nursing home placement is 6.5 years. The value of informal (unpaid) care for community-dwelling AD patients by family members averages more than $34,000 per patient each year, based on the cost of such care if it were provided by paid health care/home care providers.

In the case of AD, primary family caregivers whose relatives live in the community report spending an average of 60 hours per week on caregiving responsibilities. These caregiving duties change predictably as AD progresses. In early stages, family members take over higher-level functions, such as managing finances and medications. As dementia progresses, caregivers become increasingly involved with self-care tasks such as bathing, dressing, and feeding. Patient safety becomes an increasing concern, and problems such as incontinence often develop. Behavioral problems, such as patient depression, agitation, and wandering, are rated as most stressful by caregivers, as they can occur unpredictably and often require continuous monitoring.

In addition, caregivers face the progressive deterioration of the personality of a loved one, or the “loss of self” that occurs when spouses or parents who appear physically healthy lose their core personality. Witnessing the decline, suffering, and death of a relative from dementia is among the most traumatic aspects of caregiving. A recent book conceives of caregiving as an “unexpected career”; what often begins as part-time assistance can become an all-encompassing role. Families commonly continue caregiving duties even after nursing home placement, averaging 9 hours per week of continued caregiving.

In addition to stresses directly related to caregiving, families often experience secondary stresses that proliferate as a result of the caregiving career. Competing demands may produce family conflict, strains on finances and employment, and changes in self-concept as caregiving spills over into all aspects of life. In some cases, however, positive spillover oc-
Mental Disorders, Third edition, revised. Washing-
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rates, and smaller family size could hinder families' 
ability to continue the caregiver role at the current
level. This is a concern, particularly in the face of
projected vast increases in the numbers of Ameri-
cans with AD over the next 50 years.16,17 Some re-
search suggests that women born in recent cohorts,
particularly college-educated women who have been
employed outside of the home, may be more likely 
than their elders were to assume the caregiving role,16 
despite pressures to maintain employment.

Family caregivers also play a key role in the pro-
vision of professional health care for patients with 
AD. Health care providers depend on the family
member's reports regarding the history and nature 
of symptoms, and family caregivers are largely re-
ponsible for implementing any medical or psychoso-
cial treatment plan for the patient. Concern is in-
creasing that primary care physicians lack 
important knowledge about AD and fail to provide 
families with necessary referrals and support. Many 
patients do not receive a proper diagnosis of AD until 
the disease has progressed for several years, and 
their caregivers do not receive important information 
about supportive services, legal issues, and other 
caregiving tasks and the caregiving role in
self-report instruments: These rates are two to 
three times higher than those reported in population 
norms and demographically comparable control 
groups.4,24 Caregivers also have much higher rates of 
diagnosable mental disorders, particularly depres-
sion, than noncaregivers, when assessed through 
structured diagnostic interviews.24 One study26 found 
that although few caregivers had a history of depres-
sion before caregiving, 23% of spousal caregivers met 
DSM-III-R (Diagnostic and Statistical Manual of 
Mental Disorders, Third edition, revised. Washing-
ton, DC: American Psychiatric Association, 1987) cri-
teria for a depressive disorder, far in excess of con-
trol groups. Another study of caregivers of AD 
patients with coexisting depression found that more 
than 70% of these caregivers had depressive disor-
ders.26 Mental health effects of caregiving have been 
found to persist even after nursing home placement 
or the death of the patient.27,28

Findings regarding the physical health effects of 
caregiving have been less consistent,29 although sev-
eral studies that used sensitive and sophisticated 
measures of health status have found evidence of 
negative effects (table). Kiecolt-Glaser et al.29 found 
that spousal caregivers of AD patients exhibit im-
paired immune system functioning compared with 
noncaregivers: These ill effects persist even on longi-
tudinal follow-ups up to 4 years after the death of 
the AD patient. Such immune system alterations 
have been linked to increased rates of respiratory 
illness,29 decreased response to influenza vaccina-
tions,30 and slower wound healing.31 Another project 
documented elevations in blood pressure during 
caregiving episodes among caregiving women who 
were tracked with ambulatory blood pressure moni-
toring equipment.30 Plasma lipids are also signifi-
cantly altered in caregivers who use avoidance cop-
ing or who have problems with anger control, 
potentially increasing caregivers' risk for cardiovas-
cular disease.33 Caregivers have been found to be at 
risk for poor self-care, including lack of exercise and 
sleep.34 Other studies have suggested that caregivers 
use more psychotropic medications and that their 
self-rated health is poorer than that of comparison 
groups.24

Factors predicting caregiver distress. Re-
searchers who study caregiving have generally used 
stress process models that identify such factors as 
stress appraisals, coping responses, social supports, 
and activities of the caregiver as variables that likely 
mediate between the stresses of caregiving and sub-
sequent ill effects, such as depression.12,35,36 Although 
the nature of caregiving stressors changes as the 
dementia progresses, the available evidence suggests 
that severity of patient impairment in cognitive and 
self-care skills rarely predicts caregiver depres-
sion.24,36 Patient behavioral problems are most 
closely associated with caregiver depression.24,36,37

Caregivers differ substantially in their percep-
tions of caregiving tasks and the caregiving role 
in general. Those who view their tasks as satisfying

Table Effects of caregiving on physical health

<table>
<thead>
<tr>
<th>Condition</th>
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<tr>
<td>Impaired immune system function</td>
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<td>Elevated blood pressure</td>
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<td>Altered plasma lipid levels</td>
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<tr>
<td>Poor self-care (lack of exercise, sleep)</td>
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<td>Relatively high use of psychotropic drugs</td>
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Mental and physical health effects of care-
giving. Although clinicians generally understand 
that caregiving is stressful, it is not well appreciated 
that caregivers often experience clinically significant 
alterations in physical and mental health. A large 
body of evidence suggests that family caregivers for 
patients with AD experience substantial risk for depres-
sion. Recent reports suggest that 30 to 55% of AD 
caregivers report clinically significant depression 
on self-report instruments: These rates are two to 
three times higher than those reported in population 
norms and demographically comparable control 
groups.4,24 Caregivers also have much higher rates of 
diagnosable mental disorders, particularly depres-
sion, than noncaregivers, when assessed through 
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and not subjectively upsetting, and themselves as effective caregivers, have low levels of distress.\textsuperscript{30-41} Coping responses characterized by solving problems, seeking information, and directly confronting caregiving problems, as well as traits such as optimism, have also been associated with low caregiver depression.\textsuperscript{42,43}

Caregivers who have greater emotional and social support usually report low levels of depression and high levels of life satisfaction.\textsuperscript{24,44} In addition, caregivers who are actively engaged in social and recreational activities, such as church attendance or visiting with family members and friends, also adapt to caregiving with less depression than those who are more socially isolated.\textsuperscript{36}

Gender and age have inconsistent relationships with caregiver depression, although spouses are generally more depressed than other family caregivers.\textsuperscript{24} Several recent studies suggest that ethnicity has substantial impact on the caregiving experience. Comparisons of Caucasian and African–American caregivers of dementia patients have found that African–American caregivers experience lower rates of depression and subjective burden than Caucasian caregivers.\textsuperscript{45,46} African–American caregivers appear to appraise caregiving tasks as less subjectively stressful and themselves as having higher effectiveness than Caucasian caregivers.\textsuperscript{39} These differences may be due to cultural differences in such factors as expectations about caregiving and previous experiences with adversity.

Assessment of caregivers. Assessment of caregiving issues can provide important information for clinical or research purposes. The assessment should consider the caregivers’ daily tasks or stresses and their subjective reaction to these stressors. Several instruments are available to provide structured assessments of caregiving stresses and related caregiver reactions, including measures of Activities of Daily Living,\textsuperscript{45} Instrumental Activities of Daily Living,\textsuperscript{46} the Revised Memory and Behavior Problems Checklist,\textsuperscript{7} and the Neuropsychiatric Inventory.\textsuperscript{47} With each of these instruments (or revisions used in research), caregivers are asked to report the occurrence of various self-care and behavioral problems and to rate their subjective reactions to these problems.\textsuperscript{7,36,47} A related measure, the Caregiver Activity Time Survey, can assess the amount of time caregivers spend in various caregiving duties. The results of this instrument have been shown to change in response to the patient’s drug therapy.\textsuperscript{48} Other measures, such as a behavioral log, have also been used in research to quantify the types and amount of caregiving duties.\textsuperscript{49} Such instruments can also provide clinicians with valuable insights concerning patient problems that might be addressed through medication or behavioral management strategies.

Depression can be assessed reliably and economically through several available self-report measures, such as the Center for Epidemiological Studies–Depression Scale\textsuperscript{50}; brief measures of caregiver burden are also available.\textsuperscript{11,41} Caregiver assessment can also be adapted to clinical settings using less formal assessment questions,\textsuperscript{19} and can be readily incorporated into a geriatric assessment protocol.\textsuperscript{52}

Interventions for caregivers. Psychosocial interventions aimed at improving caregiver adjustment have been developed, and some have been carefully evaluated. Early efforts emphasized education and information, support groups, and respite services as sources of support and relief for caregivers. Information about AD is now widely available from a variety of sources, including the Alzheimer’s Association (1-800-621-0379), the Alzheimer’s Disease Education and Referral Center (ADEAR; 1-800-438-4380), and Parke–Davis’ Family Care Program (1-800-600-1600). These organizations provide brochures and referrals for caregiver support services. Family caregivers particularly value brochures about AD, and in one survey identified availability of brochures as one of the most important resources for physicians’ offices.\textsuperscript{40} Caregivers also value books that provide practical information about AD.\textsuperscript{5}

Support groups, widely available under the auspices of the Alzheimer’s Association and other agencies, are generally well received. Caregivers cite the value of sharing with other families, learning about community resources, and accumulating tips on behavior management.\textsuperscript{5,53} Although support groups are valued by participants, they may be less effective than highly structured group interventions or individual and family treatments that can individualize the intervention to the caregiver’s needs.\textsuperscript{36,54,55} Such interventions often focus on teaching caregivers specific skills, such as anger management, increasing pleasurable activities, and managing disruptive patient behaviors. A recent meta-analysis of caregiver intervention programs found that individual and family interventions are highly effective in reducing caregiver distress compared with control groups.\textsuperscript{56}

An ongoing large-scale study has documented that intensive psychosocial intervention reduces the rate of depression among caregivers\textsuperscript{55,56} and dramatically lowers the level of nursing home placement\textsuperscript{57} of AD patients. These differences are retained at long-term follow-up. In many settings, however, individualized intervention programs are generally less available than support groups.

Respite care, such as adult day care and sitter services, are also highly valued by caregivers who use them.\textsuperscript{58} Such services may be vital to enable the caregiver to continue employment or to have time away from the patient. Evaluations of the effect of respite services has generally been disappointing, however. Respite care has little positive impact on caregiver mental health and does not substantially delay nursing home placement.\textsuperscript{58,59} One problem is that many caregivers resist using these services, even when their cost is underwritten by research projects; clinical suggestions on overcoming such re-
sistance have been offered. For example, caregivers may be advised to begin with very brief periods of respite, or to remain in the home during initial visits, to overcome negative beliefs about how the AD patient may respond to a stranger in the home. Given that respite care is a valued and essential service for families who use it and that these families may be less likely to place their relatives in nursing homes, referral for respite services should be encouraged.

Finally, little attention has been paid to the continuing problems experienced by caregivers even after nursing home placement or death of the patient. Interventions are needed to help families adjust to nursing home placement and bereavement.

Issues for health care delivery. Recognition that caregivers are an essential component of health care and long-term care calls for more attention to their problems and concerns. This unpaid, informal assistance is a dam against the flood of AD cases that could overwhelm the United States in the years ahead. Caregiving remains a largely hidden problem with potentially serious consequences. Given the morbidity associated with depression, it is alarming that up to 50% of caregivers experience significant depression. Because institutionalization of patients with AD is often related to an interplay between patient decline and caregiver vulnerability, interventions for caregivers can potentially relieve distress and save money.

Health care professionals should be prepared to address the concerns of caregivers across all stages of dementia. Caregivers look to physicians for much more than medical evaluations; they also view the physician as a key source of information and referrals. Because many caregivers initially present AD patients for evaluation in primary care settings, there is a need for primary care physicians to improve detection of AD and their referral and education of caregiving families during early stages of dementia. Failure of proper diagnosis or referral may lead to years of delays in receiving necessary legal, psychological, and social services. As specialists, neurologists are often viewed by families and primary care providers as the final authority on AD diagnosis and treatment, and should therefore also be aware of referral sources and community services.

Consideration of caregiving issues has important implications for medical care. Open communication about the diagnosis of AD and appropriate caregiver education may help the caregiver to understand that patient behavior problems are unintentional, may give families a socially acceptable way to explain the patient’s behavior to others, and may enable families to plan ahead.

As dementia progresses, families require guidance concerning the timing of nursing home placement and the possible withholding of life-sustaining treatments. Appropriate information to guide such choices is essential, and the physician can elicit preferences from families in advance of crisis situations.

In summary, caregiving issues are a critically important aspect of AD. In our efforts to provide state-of-the-art diagnostic and treatment services for AD patients, we must not forget the family members who provide much of the daily care for these very difficult patients under extremely trying circumstances.

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References


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