

Caregivers for Persons With Alzheimer's Disease

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Families have always cared for relatives with dementia, but scientific advances in diagnosis, management, and treatment will make caring more challenging as more people are diagnosed in early stages and more live longer in severe stages with better health care. This paper discusses the increasing prevalence, the economic value and cost of caregiving, the impact of caregiving in families with and without dementia, the subjective experience of dementia and quality of life, the ethical challenges of clinician-family partnerships, the complexity of family systems and processes that impact care patterns, homicide-suicide in caregiving, long-term care staff training, and theoretic models.

Introduction

Over the past 25 years of research in caregiving for persons with Alzheimer's disease (AD) and related disorders, a number of significant findings have emerged with profound health and social policy implications. The prevalence of AD and other dementias has created an urgent public health challenge because the number of affected individuals is growing with the aging of the population, and people are living longer with the disease because of better health care. Family members have always provided the majority of care over the course of dementia, and today they are providing more care for longer periods of time than ever before. This trend is projected to continue well into the next millennium as life expectancy continues to increase, and more persons live into the higher risk age categories for dementia [1••].

Family caregiving can be a satisfying experience, but caregiving creates a range of physical, emotional, and financial demands that place family members at risk for negative outcomes, eg, physical and mental health problems, disruptions in the work and family environment, as well as immunologic changes that affect vulnerability to infections [2]. Staff caregivers in long term care

facilities, eg, nursing homes and assisted living facilities, are also at risk for health problems, work stress, and poor morale, because most are not trained to handle the challenges of residents with dementia who make up about 60% of the long term care population.

This is an opportune time to write a review of the latest advances in the area of dementia caregiving for at least two reasons. Dr. Carl Eisdorfer and I have been asked to update our 1986 book *The Loss of Self: A Family Resource for Alzheimer's Disease* [3••] for publication in winter 2000. Both of us also co-chaired, with Marsha Ory and Sara Czaja, a meeting of leading researchers in caregiving for a 2 day meeting in Las Vegas, NV, in June 1999 (The Next Generation of Caregiving Research, June 24-25, 1999). The purpose was to review what is known about caregiving, identify research gaps, set research priorities for the next generation of caregiver research, and create an agenda for a national research conference in 2000 sponsored by the National Institute on Aging (NIA). Common themes across the presentations were the complexity of the dynamics of the caregiving process, the heterogeneity of caregivers and caregiving families, the need for defined outcome measures, the importance of studying family process, the lack of knowledge about minority caregiving, and the need to identify family interventions that are most effective for risk reduction and prevention, as well as treatment and management [4-15].

This paper focuses on research advances in the 1999 literature on caregivers for persons with AD and related disorders. The areas discussed are consistent with priorities identified in the Las Vegas meeting (Las Vegas, NV, June 1999): the increasing prevalence, the economic value and cost of caregiving, the impact of caregiving in families with and without dementia, the subjective experience of dementia and quality of life, the importance of clinician-family partnerships, the complexity of family systems and processes that impact care patterns, homicide-suicide in dementia caregivers, long-term care staff training, and theoretic models.

The Public Health Challenge of Dementia Caregiving

The results of the most recent national survey in the United States by the National Alliance for Caregiving (NAC) and American Association of Retired Persons (AARP) showed that 22.4 million households, or 25% of American households,

were caring for a relative or friend 50 years or older in 1996 [16], a growth of 15 million households since 1987 [17]. About 22%, or 5 million of these caregiving households reported caring for someone with AD or another dementia. The NAC/AARP study, which was the first national survey to oversample minority populations, showed that 28% of black American caregivers reported a care recipient with dementia compared with 20% of Hispanic Americans, 10% of Asian Americans, and 43% of white Americans.

The economic costs of this prevalence of dementia family caregiving at home coupled with nursing home care are high. Using national data sets [1,16,18], the national value of informal dementia caregiving in 1997 was calculated to be \$45 billion. Furthermore, employee costs for working dementia caregivers, eg, absenteeism, workday interruptions, retraining costs, health care coverage, in 1997 were estimated to be \$33 billion. Finally, about 60% of the \$83 billion (\$50 billion) spent on nursing home care in 1997, was spent on residents with dementia. The aggregate economic value of this level of caregiving underscores the urgency of research in family caregiving as well as health and social systems to support the family [1,18].

Prevalence and Impact of Caregiving Between Dementia and Nondementia Caregivers

Although studies in the past have examined differences in dementia and nondementia caregivers, the results have been inconsistent. None of the study samples were nationally representative, and although these studies examined differences in caregiver mental health, they did not give detailed descriptions of the caregiver samples and did not control for many other factors known to mediate mental health outcome.

A paper by Ory *et al.* [19••] analyzing data for over 1500 family caregivers from the NAC/AARP National Caregiver Survey clearly documented that dementia caregiving is more demanding than nondementia caregiving. Dementia caregivers spent significantly more hours per week in care activities than nondementia caregivers (17.1±17.4 h vs 12.4±14.5 h). A higher percentage of the former provided 40 or more hours of care of constant care than the latter (28.1% vs 17.0%).

The negative impact of caregiving in terms of work disruptions, mental and physical health problems, family conflict, caregiver strain, and other life roles were significantly greater in the dementia caregivers than nondementia caregivers. Twice as many dementia caregivers took early retirement, gave up working, lost job benefits, and turned down promotions than nondementia caregivers. Although all caregivers reported distress and burden, dementia caregivers reported significantly more negative consequences and strains. Seventy-five percent of dementia caregivers reported conflict with family members who were not seen as doing their share of caregiving compared to 59% of nondementia caregivers. More dementia

caregivers reported mental and physical health problems (22% vs 73%). Dementia caregivers also reported significantly higher levels of physical strain, emotional distress, and financial hardship than nondementia caregivers.

Several findings were consistent with previous studies: women reported higher levels of strain than men; caregivers with lower incomes reported greater physical strain and greater economic hardship; caregiver age predicted physical strain; and caregivers with higher education reported greater emotional strain. None of the race comparisons showed significant differences in reported strain when income and education were controlled.

The race findings were consistent with those reported by Patterson *et al.* [20] who compared dementia caregivers and noncaregivers in Shanghai, China, and San Diego, CA. Caregiver groups in both cultures were comparable in level of mental health problems, physical health problems, and role overload, but they were more distressed in all areas relative to noncaregiver controls. Coping styles differed across the two cultures, but neither caregiver groups' coping efforts differed from their controls.

Although caring for a sick or frail relative exacts a personal and family toll, there are unique circumstances and pressures affecting dementia caregivers. Watching the progressive, unrelenting loss of self and the painful death of the mind, managing difficult behavioral problems, the lack of certainty about an unpredictable and uncontrollable future, and the constant vigilance to ensure safety and well-being affect even the most resourceful families and family caregivers. Intervention research will be a critical priority for the future. Several recent papers have addressed the treatment of depression in caregivers [21,22], as well as the value of family education [23], and spirituality [24] to help family caregivers cope more effectively.

The Subjective Experience of Alzheimer's Disease and Quality of Life

Every year there are compelling books written by caregivers that can be therapeutic bibliotherapy for other caregivers as well as instructive for health care professionals. In 1999 John Hauge published an illustrated book, *Heavy Snow: My Father's Disappearance Into Alzheimer's* [25], the moving story of a son caring for his father. It is also a story that shows how understanding and reconciliation of an estranged father and son are possible because of the disease. The intimate transactions are revealed in story and illustrated cartoons. The introduction sets the stage for an evolving growth of understanding and personal sharing between father and son:

One winter morning I was walking with my father outside his nursing home. It was snowing heavily. I glanced back at our trail and noticed that his tracks had almost vanished, while mine were still defined. I joked with him about this and asked what he thought it meant. He replied, "I'm not surprised. I often feel like I'm disappearing." [25]

Understanding the subjective experience of the person-turned-patient is a powerful tool to support individuals as they try to make sense of the illness and to advise family members about the best ways to interact with patients [3]. Harris and Sterin [26] conducted in-depth interviews with persons in early stages of AD to clarify their concept of self and perceived identity. Three core themes emerged to define perceived identity: 1) reasonable autonomy, 2) meaningful activities and productivity, and 3) a need for comfort and security. Afflicted individuals understood that the disease would eventually rob them of independence, but they wanted respect for their need to participate in decisions about themselves and others. Living a productive life within the limits of their abilities and skills, even if they failed at times, was a powerful value system.

In an excellent special journal issue on quality of life in AD, guest editors Steven Albert and Rebecca Logsdon [27••] assembled 10 papers authored by leading researchers that provide a valuable foundation for future research. Although most of the papers reviewed conceptual and practical issues in the measurement of quality of life, clinical applications of the concept to caring for patients and family caregivers are described. One paper by Jennings [28], analyzing the philosophical and ethical issues, clarified how to structure the environment and caregiver behaviors to maximize personal meaning, communication, comfort, pleasure and meaningful activities. The treatment objectives for persons with dementia are to maximize their functional effectiveness, comfort, freedom, and dignity. Within the limits of their cognitive and emotional skills individuals have the right to participate in their care and chose how they will live. The roles of health professionals are to monitor the changing capacities and needs of the patient and to help the patient and family redefine expectations and goals.

Clinical and Family Partnerships

Family members usually look to physicians and other health professionals for information and support, but it is a challenge for clinicians to deal with the needs of family caregivers. Reimbursement is limited, and clinicians vary in their interest, motivation, experience, and resources to work with family. However, not to integrate the needs of family members and patients in a careplan is to violate the fundamental clinical ethical principle of nonmaleficence—to do no harm.

A basic tenet of clinical care for persons with dementia is the necessity of managing and supporting the family in the care of the patient. Families are not only primary care providers and managers of care, they are companions, surrogate decision-makers, and advocates for quality care. Although some clinicians are sensitive to the important roles family members play, many are not. Levine and Zukerman [29••] have written a thoughtful, compelling paper describing the general tendency to regard family caregivers

as problems in health care practice rather than as partners. A significant source of tension between medical professionals and families is differing beliefs about the roles family members should play and how and when they should play them. Other sources of conflict are disagreements among family members, disagreements among clinicians, differing religious, ethnic, and cultural traditions, challenges to physician authority, and fear of litigation by clinicians.

As the responsibilities and burden of health care continue to be shifted to family and other caregivers, there is an urgent need for family-sensitive policies, practices, and interventions. The problems families face over the course of dementia encompass every aspect of life, and many of the choices, decisions, and actions required in caring are ambiguous, painful, and ethically challenging. Most families need a framework to identify and deal with the multiple problems associated with caregiving. The needs of cognitively impaired relatives require identifying and weighing the values, needs, and desires of one person against others. Over time the choices become more complicated, and an organized approach is needed to turn caring into a manageable set of choices with outcomes acceptable to most of those involved.

Working with families requires the development of an ethical framework for negotiation and accommodation as the basis for patient/family/clinician relationships [29••]. A clinical ethical theory that recognizes and articulates the different roles, values, and interests involved in a caring partnership and that guides negotiations where interests are conflicting would be an important contribution to clinical practice. A partnership is not a friendship, and the division of responsibility is not always equal. A partnership is a dynamic relationship based upon the acceptance of certain ground rules as well as exercising the knowledge, respect, and communication to meet the challenge.

Important areas for professional education include family dynamics and illness, the vulnerability and loneliness of caregivers, the complexities and diversity of relationships, *eg*, homosexual couples, unmarried couples, mixed-race marriages, as well as ethnic and cultural traditions that affect health care behaviors and family roles. Communication skills are probably the most critical component of working with patients and families. These involve active listening and talking with families to deal with the diagnosis, family concerns and conflicts about health care treatment, management of difficult behavioral or family problems, long-term care decisions, and end-of-life care decisions.

There are no easy prescriptions, but a great deal can be done if the clinician acts as a coach, focusing family members on a process of problem-solving to segment the complexities of caregiving into manageable parts. Not all problems of caregiving can be solved, but goal-setting and shared decision-making create a sense of limited mastery in the face of the unrelenting losses of dementia.

The Complexities of Family Caregiving

Most caregiving research has focused on a primary caregiver, examining how and why people care, the vulnerabilities of gender and kinship groups, the negative sequelae of caring, as well as commonalities in the caregiving process. Caregiving in the context of the aging family system with multiple informants and measures of family structures and processes has rarely been studied [1••]. AD creates transitions affecting disease-related roles as well as nondisease-related family roles and functions.

Several studies in 1999 advanced our knowledge of family systems. Lieberman and Fisher [30••] reported initial findings from a longitudinal study of the impact of AD and vascular dementia on the health and well-being of multigenerational families. Caregiving affected many non-caregiving family roles in second-generation family members. A striking finding was that male in-laws reported more marital strain than female in-laws independent of caregiving strain. However, marital and caregiver strain was also mediated by family variables. In-laws in close and well-organized families reported lower marital strain than in-laws in less cohesive families.

Some family influences exerted protective effects on caregiving strain, and others increased the caregiving distress. Families who valued high life engagement, *ie*, active in many activities, and who were emotionally distant, showed increased caregiving strain in many domains of family life. Families in which adult children and affected parents were emotionally separated and where general conflict was a common occurrence were at high risk for strain. In contrast, families who were close and cohesive and who managed conflict well, reported less caregiver strain. In another study, Lieberman and Fisher [31] reported that families who were characterized by a focused problem-solving style and who managed conflict well provided more help than families who did not have these characteristics. Understanding family world views, problem-solving styles, and emotional management styles clearly mediates the effectiveness of care allocation.

Caregiver Burden, Depression, and Homicide-Suicide

Dementia caregiver burden is a construct that has been used to refer to both the physical, emotional, and financial distress of caregiving as well as appraisal of caregiving as stressful. Despite advances in definition and measurement, caregiver studies over the years have shown considerable variability in the experience and impact of burden on caregiver adaptation. Furthermore, there are controversies about whether burden is an antecedent of depression, whether depression is an antecedent of burden, whether burden and depression are two co-existing domains, and whether caregiver gain and satisfaction are the absence of perceived burden.

Our research team analyzed the predictors of burden and depressive symptoms in a sample of 311 caregivers

enrolled in a national Alzheimer's registry who were living at home caring for a relative with dementia (Cohen D, *et al.*, Unpublished data). Depression and burden were significantly correlated with each other, but analyses suggested they are separate albeit overlapping psychological domains. Stepwise regression analyses showed that two caregiver variables, reduced time for leisure activities and not having help when sick, as well as two patient variables, the presence of agitation and impaired instrumental activities of daily living, were the most significant predictors of caregiver depression. These variables consistently predicted caregiver depression for all kinship groupings except for adult son caregivers, where financial security substituted for leisure. One-caregiver variable, no help when sick, and two-patient variables, presence of agitation and impaired activities of daily living, were the most significant predictors of caregiver burden.

Depression is the most commonly documented negative health consequence of caregiving, with women and spouses at the highest risk [4]. When severely depressed male spouse caregivers begin to feel hopeless, they begin to think of taking their own life and even the life of the person for whom they are caring. The increasing numbers of homicide-suicides involving older couples highlight the lethal consequences of overwhelming depression and hopelessness in older married men [32••,33]. A husband is almost always the perpetrator, usually using a gun to kill his wife who has serious health problems. In 20% of cases the wives have AD or a related disorder [34].

A recent study compared the characteristics of older married men who committed a homicide-suicide with an age-matched group of older married men who committed suicide [35]. Half of the homicide-suicide perpetrators were caregivers compared with 13% of the suicides. The men who committed suicide had significantly more medical problems at autopsy compared with the homicide-suicide perpetrators, but twice as many of the latter had a significant decline in health before committing the homicide-suicide. Depression was prominent in both groups, but none of the perpetrators in either group were positive for antidepressants at autopsy.

These results confirm the important role of undetected and untreated depression in both groups, but differences emerged. Suicides by older men appeared to be associated with depression coexisting with poor physical health and feelings of hopelessness about their own future. A significant group of homicide-suicides appeared to be associated with depression resulting from the demands of caregiving. The nature of the marital relationship and perceived responsibility of the husband for the wife are probably important factors in the events leading to a homicide-suicide.

Older couples who have been together a long time in which one is suffering from dementia or other chronic illnesses have real reasons to be upset and depressed. It is common for spouses to wish a wife or husband who is very sick with dementia, cancer, or other chronic illness to be

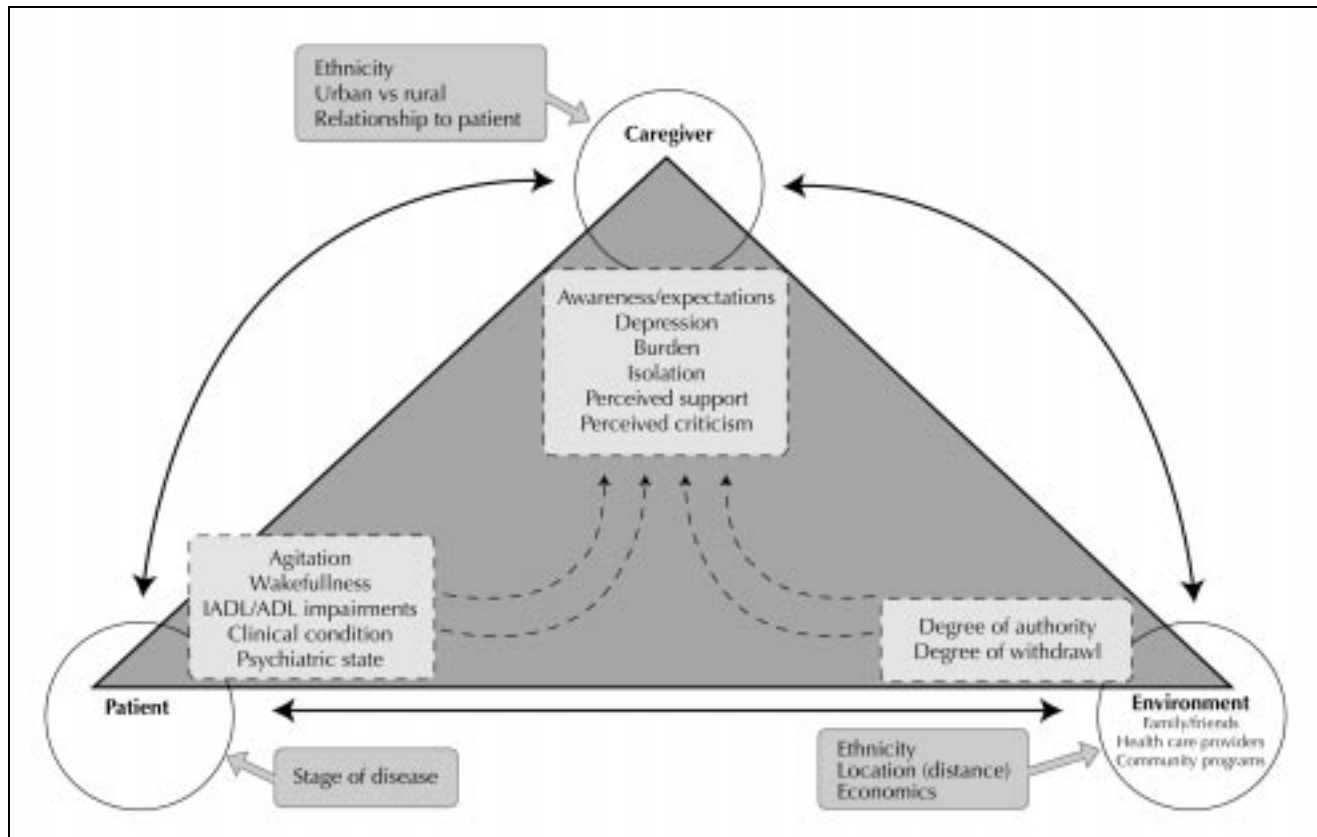


Figure 1. A descriptive interactive model of the dementia caregiving system: Diagram of the caregiver-patient-environment triangle. ADL—activities of daily living; IADL—instrumental activities of daily living. (Adapted from Eisdorfer [11].)

dead, but most are afraid or unwilling to talk about these wishes. Most caregivers do not know these feelings are normal and that talking can relieve the pain, distress, and sense of being alone. The following circumstances are risk factors for homicide-suicide where an older couple have been married a long time and the wife has dementia: depression or alcohol abuse in the husband, isolation, a real or perceived deterioration in the caregiver's health or the husband's health, pending institutionalization, complaints of burn-out, hopelessness, pain, and isolation by the husband.

Behavioral Problems and Nursing Home Care

A consistent finding in the literature is that family members caring for persons with high levels of behavioral problems, *ie*, agitation, wandering, combative and violent behaviors, are at the greatest risk for placing relatives in nursing homes. Caregiver depression and utilization of home care and respite care services are also predictive factors, indicating that families are doing everything possible to keep relatives out of nursing homes [36••].

Unfortunately, long-term care staff are not prepared or trained to deal with behavioral problems in this population. Schonfeld *et al.* [37••] described the development, implementation, and efficacy of an innovative university-based long-term care training program to train nursing

home and assisted living staff to manage residents with memory impairment. A 16-hour curriculum addressed eight areas: philosophy of dementia care, individualized goals and activities, causes of dementia, detecting behavioral problems, behavioral techniques, communication strategies, environmental modification, and staff stress management. A total of 135 staff were recruited from 26 facilities and assigned to one of three training conditions: university classroom instruction, facility-based instruction, and train-the-trainer instruction. All three strategies resulted in improved knowledge and skills which were maintained at a 3-month follow-up.

Theoretic Models for Caregiver Research

Caregiving is a complex process in which changes in the components of the caregiving system, *ie*, the identified patient, the primary caregiver, the family, and the environment, interact with each other to mediate negative and positive outcomes for the patient, caregivers, and the family. Eisdorfer [11] presented a model of the dementia caregiving system at the Las Vegas meeting (Las Vegas, NV, June 1999) which represented a synthesis of the discussions of a group of researchers working on an NIA-funded cooperative agreement collaboration known as REACH (Resources for Enhancing Alzheimer's Caregiver Health). The caregiving

Table 1. A stress-diathesis model for understanding negative health outcomes in dementia caregivers

Stress	Diatheses
Patient characteristics	Caregiver characteristics
Agitation	Expectations
Sleep/wake disruptions	Attributions
Psychiatric state	Personality
Clinical condition	Depression
Awareness of self	Clinical condition
Family system characteristics	Isolation
Cohesiveness	Perceived support
Resonance	Caregiver health behaviors
Conflict resolution	
Developmental stage	
Marital strain	
Sibling strain	
Parent/child strain	
Characteristics of health care partners	
Primary care physician	
Knowledge, involvement, communication	
Geriatric specialists	
Involvement and communication	
Other providers	
Other resources	

system seen in Figure 1 consists of a caregiver-patient-environment triangle in which factors associated with each component affect one another. This is a comprehensive and descriptive model which identifies the multiple component characteristics known to affect caregiver health.

One criticism of the REACH system model is the location of family in the environmental component rather than specifying family process as a fourth component. Family structures, relationship systems, decision-making processes, organization, and conflict resolution processes shape caregiver responses. The relationship between patient and caregiver variables need to be studied in the context of the stressors and life changes families face. A stress-diathesis model of caregiver health is an alternative theoretical framework to describe the caregiving system and make predictions about caregiver health. This model proposes that caregiver outcomes are the result of additive or multiplicative effects of diathesis or vulnerabilities and stressors. In Table 1 the stressors include patient characteristics identifies in the REACH model. Family system or process properties and the availability and responsibilities of health care partners are also listed as stressors. A series of caregiver characteristics also identifies in the REACH model are potential vulnerabilities of the caregiver. The diathesis-stress framework is also a descriptive model, but it conceptualizes many interactive factors that mediate caregiver vulnerability to poor physical and mental health.

The Future

Even if we are successful in treating and preventing AD and related dementias through applications of research discoveries in genetics and the genomic sciences sometime in the next millennium, we will still likely be caring for millions of patients and family caregivers [38]. Scientific advances in the detection, diagnosis, management, and treatment of AD will make caring for affected relatives more challenging for families as well as society in the future. With the anticipated ability to detect AD in very early stages and to possibly prevent dementia with neuroprotective drugs, there will likely be greater numbers of patients who are mildly impaired [39••]. Likewise, with decreasing mortality from physical diseases there will also be increasing numbers of dementia patients with severe dementia and medical comorbidities living longer. Caring for a growing population of mildly as well as severely impaired persons will present social, clinical, and ethical challenges. We have no choice but to do our best!

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- Of importance
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