Caregiving: Research · Practice · Policy
Series Editor: Ronda C. Talley
An Official Publication of The Rosalynn Carter Institute for Caregiving

Steven H. Zarit
Ronda C. Talley *Editors*

Caregiving for Alzheimer's Disease and Related Disorders

Research • Practice • Policy

Series Foreword by
Former First Lady Rosalynn Carter

Springer

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Series Foreword

From its inception in 1987, the Rosalynn Carter Institute for Caregiving (RCI) has sought to bring attention to the extraordinary contributions made by caregivers to their loved ones. I grew up in a home that was regularly transformed into a caregiving household when members of my family became seriously ill, disabled or frail with age, so my interest in the issue is personal. In my hometown of Plains, Georgia, as in most communities across our country, it was expected that family members and neighbors would take on the responsibility of providing care whenever illness struck close to home. Delivering such care with the love, respect, and attention it deserves is both labor intensive and personally demanding. Those who do so represent one of this nation's most significant yet underappreciated assets in our health delivery system.

When the RCI began, "caregiving" was found nowhere in the nation's health lexicon. Its existence was not a secret but rather simply accepted as a fact of life. In deciding on the direction and priorities of the new institute, we convened groups of family and professional caregivers from around the region to tell their personal stories. As I listened to neighbors describe caring for aged and/or chronically ill or disabled family members, I recognized that their experiences reflected mine. They testified that, while caregiving for them was full of personal meaning and significance and could be extremely rewarding, it could also be fraught with anxiety, stress, and feelings of isolation. Many felt unprepared and most were overwhelmed at times. A critical issue in the "field" of caregiving, I realized, was the need to better understand the kinds of policies and programs necessary to support those who quietly and consistently care for loved ones.

With the aging of America's Baby Boomers expecting to double the elderly population in the next 20 years, deinstitutionalization of individuals with chronic mental illnesses and developmental disabilities, a rising percentage of women in the workforce, smaller and more dispersed families, changes in the role of hospitals, and a range of other factors, caregiving has become one of the most significant issues of our time. Caregiving as an area of research, as a focus and concern of policy making, and as an area of professional training and practice has reached a new and unparalleled level of importance in our society and indeed globally.

As we survey the field of caregiving today, we now recognize that it is an essential component of long-term care in the community, yet also a potential health risk for those who provide care. The basic features of a public health approach have emerged: a focus on populations of caregivers and recipients, tracking and surveillance of health risks, understanding the factors associated with risk status, and the development and testing of the effectiveness of various interventions to maximize benefits for both the recipients of care and their providers.

The accumulated wisdom from this work is represented in the volumes that make up the Springer Caregiving Series. This series presents a broad portrait of the nature of caregiving in the United States in the twenty-first century. Most Americans have been, are now, or will be caregivers. With our society's increasing demands for care, we cannot expect a high quality of life for our seniors and others living with limitations due to illness or disability unless we understand and support the work of caregivers. Without thoughtful planning, intelligent policies, and sensitive interventions, there is the risk that the work of family, paraprofessional, and professional caregivers will become intolerably difficult and burdensome. We cannot let this happen.

This volume focuses attention on a most important topic for those caring for loved ones in their later years. Specifically, the volume examines the complex and highly challenging issues related to the onset, emergence, and progression of symptoms of Alzheimer's disease. The growing prevalence of individuals experiencing progressive cognitive disorders leading to increasingly serious problems with dementia requires that every avenue for their prevention and treatment be pursued. But, as explained across the volume's chapters, we must simultaneously make known and take advantage of every possible avenue to serve the needs of those caring for individuals with Alzheimer's disease across its multiple admittedly unpredictable stages. The volume's chapters provide important information on how each stage of Alzheimer's impacts caregivers. Readers will gain an appreciation of how the caregiving demands evolve across the disease's progression and acquire valuable insights into how to maximize their capacity to serve those they love and care for themselves as well. Readers will once again understand that caregiving is provided by the young and the old; those involved represent all races, genders, and economic groups. Alzheimer's exacts a toll on those with the disease and those who care for them. This volume serves both groups extremely well.

Readers of this series will find hope and evidence that improved support for family and professional caregivers lies within our reach. The field of caregiving has matured and, as evidenced in these volumes, has generated rigorous and practical research findings to guide effective and enlightened policy and program options. My hope is that these volumes will play an important role in documenting the research base, guiding practice, and moving our nation toward effective polices to support all of America's caregivers.

Rosalynn Carter

Preface

Alzheimer's Disease Caregiving: The Needs of Family Caregivers

Over the past 30 years, family caregiving has captured the public's attention and that of the research community as well. The media frequently portrays the challenges and heartbreak of ordinary people and celebrities alike who are struggling with the care of a parent or spouse. Scholarly studies validate these dramatic portrayals, providing compelling evidence that caregiving takes an ongoing toll on the health and well-being of the caregiver.

Every care situation presents its own set of hardships, but assisting someone with Alzheimer's disease or other illnesses that cause dementia is perhaps the most consistently demanding and stressful for the family. Like many disabling conditions, Alzheimer's disease leads to difficulty or inability to carry out common activities of daily life, and so family members take over a variety of tasks ranging from managing the person's finances to helping with intimate activities such as bathing and dressing. Added on top of these disabilities, however, are a set of distinctive problems that make the care of people with Alzheimer's disease and other dementias consistently more challenging than other care situations.

First among these problems is that the underlying brain disease erodes aspects of personality, and makes the person less and less like himself/herself and less connected to the people in his/her life. Former first lady Nancy Reagan poignantly captured the feelings of loss associated with Alzheimer's disease when she characterized President Reagan's illness as "the long goodbye." Each day the person with dementia has less awareness and recall, and less connection with the important people in his/her life. Slipping away gradually produces a sense of despair and even mourning among many family caregivers that goes on over the course of the illness.

Another feature that makes caring for someone with dementia so difficult is that the primary symptoms of memory loss and other cognitive difficulty are frequently accompanied by behavioral and emotional disturbances. People with dementia may be restless, agitated, impulsive, and unreasonable. They may insist on trying to do things that they cannot do safely, such as drive, or may wander off from home and get lost. Their mood may be unpredictable and they may shift from depressed to anxious to angry without clear indications of what triggered their reactions. Many of these behavioral and emotional eruptions are directed at the people who are closest to the patient, namely, the caregivers. It is difficult for caregivers not to take these problems personally, yet their effectiveness, and perhaps even their survival as a caregiver, depends on somehow remaining objective.

A third characteristic that contributes to the difficulties families experience is that people with dementia reach a point where they need constant supervision. The longstanding best seller among popular books on Alzheimer's Disease, *The Thirty Six Hour Day* (Mace & Rabins, 2011), captures this feature of the disease in its title. Caregivers frequently lack the support needed to take regular breaks. They may also become so enmeshed with the patient's needs that they do not feel they can get away. This feeling of being trapped or a captive of the caregiving role may deplete the caregiver's remaining emotional reserves and lead him/her to institutionalize the patient (Aneshensel, Pearlin, Mullen, Zarit, & Whitlatch, 1995).

In the face of these overwhelming challenges, caregivers wage a heroic struggle to preserve dignity and the quality of life of the person with dementia. Though some caregivers wear down from the pressures, others manage to maintain their sense of commitment and purpose and to find ways of diminishing the toll that caregiving takes. There is much that can be learned from these caregivers, but the continuing challenge is to find ways of getting information into the hands of new caregivers in a timely and understandable way. Many caregivers lament that they wish they had learned more earlier on about their relative's illness and the many coping strategies that can help in managing it.

As the number of older people in the population has increased, so have those people who are involved in caregiving in one way or another. It has been estimated that 44 million Americans who are 18 and older provide care to another adult on a regular basis. Almost one quarter of those individuals state they are assisting a person with Alzheimer's disease or related symptoms (National Alliance for Caregiving & AARP, 2003). Some of these caregivers may be helping on an occasional basis, for example, when a daughter gives her mother a break from the care of her father. Others provide full-time care, or are on call all the time. Most of the care to elders, including those with dementia, is provided in the home. One study of a large, representative sample of people with dementia found that the median duration of caregiving from the onset of the illness to the patient's death was 11 years (Aneshensel et al., 1995). On average, caregivers in that study provided assistance at home for 7 years, and most continued to help their relative even after placement into an institutional setting. Of course, there is considerable variability in how long people are able to manage as primary caregivers, with some helping out for a relatively brief period of time, and others steadfastly giving care at home for 20 years or more.

Definitions of Alzheimer's Disease, Dementia, and Caregiving

This book focuses of caregivers of people with Alzheimer's Disease and other degenerative neurological disorders that lead to dementia. Dementia refers to a syndrome characterized by decline of memory and other cognitive functions and the gradual loss of ability to perform most work, household, leisure, and personal care activities. The rate and extent of decline is much greater than found with normal aging. Alzheimer's disease is the best known and most common of the disorders that can lead to dementia. Other common types of dementia include vascular dementia, frontotemporal dementia, and Lewy body dementia. These disorders have different types of brain pathologies. The location and extent of brain changes in these disorders also differ from Alzheimer's disease. Vascular dementia and frontotemporal dementia represent syndromes causes by any of several diseases that lead to similar patterns of brain changes. Alzheimer's and Lewy body dementia may also include subtypes with varying etiologies. It is not surprising, then, that symptoms vary not only by diagnosis but also within diagnostic groups (see Zarit & Zarit, 2007, for a review).

Although we typically refer in this book to Alzheimer's disease, and sometimes to "Alzheimer's disease and related disorders," our focus is on all dementia. To a large extent, the issues faced by family caregivers on a daily basis do not vary much depending on diagnosis. Although the specific symptoms vary somewhat by type of dementia, families face a similar set of challenges in all these disorders—assisting with activities of daily living, monitoring behavior to keep the person safe, having to manage behavioral and mood problems, and interfacing with formal service providers. These are the types of challenges that are addressed throughout the book.

One feature of dementia that has significant implications for caregiving is the age of onset. Typically considered a disorder of aging, Alzheimer's disease and the other dementias can affect some people as early as the fourth decade of life. Frontotemporal dementia tends to have an earlier average onset than the other disorders, but cases of Alzheimer's and vascular dementia can have their onset during the 40s and 50s. Age of onset undoubtedly affects how families respond, and the resources available for caregiving. A woman in her 40s with two adolescent children who must suddenly cope with her husband's dementia and all the changes associated with that faces very different challenges than a 75-year-old woman with health problems of her own who is caring for her husband.

Like dementia, the term "caregiving" can have many different meanings. To define caregiving, we have turned to several well-known researchers and advocacy groups. In a landmark national survey, the National Alliance on Caregiving (NAC) and the American Association of Retired Persons (AARP) (2004) define caregiving as "assisting another person age 18 or older with at least one of thirteen tasks" of daily life. The National Association of Family Caregivers (2006) offers another definition that caregiving involves providing the necessary physical and mental health support needed by a family member. In relation to its National Family Caregiver Support Program, the Administration on Aging (2012) defines a caregiver as assisting anyone providing unpaid help to an older person who lives in the community and has at least one limitation of activities of daily living. The National Family Caregivers Association (NFCA) (2006) advocates for the term *family caregiver* to be defined broadly to include friends and neighbors who assist with care by providing respite, running errands, or a whole host of other tasks that support the caregiver and care recipient. The Administration on Aging (2012) mentions spouses, adult children, other relatives, and friends. Similarly, in this volume, we will use the terms *informal caregiver* and *family caregiver* interchangeably and employ the comprehensive definition of *family caregiver* to refer to caring relatives, friends, and neighbors.

Among the various descriptions of informal or family caregiving, one originally proposed by Horowitz (1985) has been widely accepted. Horowitz proposed that informal care involves four dimensions: *direct care* (helping to dress, managing medications); *emotional care* (providing social support and encouragement); *mediation care* (negotiating with others on behalf of the care receiver); and *financial care* (through managing fiscal resources, including gifts and service purchases). Caregivers would be those family members or other informal (i.e., nonpaid) persons assisting in one or more of those areas.

These definitions all strive to cast as wide a net as possible, but more precise definitions are useful for research, as well as determining eligibility for programs or other benefits. A starting point is to consider what the boundary is between caregiving and normal patterns of exchange within a family. Spouses help each other under ordinary circumstances. Likewise, aging parents and their middle age children exchange many types of assistance with each other on a regular basis (Fingerman et al., 2010). Should these situations be viewed as caregiving, or should that role be limited to circumstances where one person has a disability, and cannot perform some activities without help? The specialization of tasks associated with traditional sex roles can also complicate the definition of caregiving. A woman may have always deferred to her husband for managing the household finances. If her husband dies, she might turn to one of her children to help with her finances, although she might not have cognitive limitations that would prevent her from doing those tasks herself. Is that situation caregiving, or would it fall under a different category of normal family exchanges? As these observations suggest, giving and receiving care is an ongoing part of family relationships, beginning with birth and continuing through the life course until its end. The help that we see in response to dementia and other disabling conditions reflect at least to some degree these earlier patterns of family relationships and exchanges.

Another definitional issue has to do with the distinction between primary and secondary caregivers. In many cases, one person in the family provides most of the assistance. Other people will be involved in helping, sometimes giving a considerable amount of help, and sometimes only contributing criticism and advice. The primary caregiver will usually be a spouse, if there is one. When the care receiver is widowed and lives with a child or other relative, that person then usually assumes the major responsibility. When a person with dementia lives alone, determining who has the responsibility may be a contentious issue in some families.

These distinctions in the type and amount of caregiving responsibility have important program and policy implications. Service programs usually want to target primary caregivers for services, because those will be the people under the greatest stress. Primary caregivers are also most likely to have legal responsibility for the person with dementia. As we will see in subsequent chapters, reaching out to other family members and friends can be very helpful in reducing stress on the primary caregivers. Policy-makers, in turn, will be concerned with setting a definition of caregiving that is not so broad that virtually anyone might qualify for new programs or benefits. The downside is that efforts to limit eligibility often have led to cumbersome or confusing rules about who might receive a benefit. A web of obfuscation has accompanied many publically supported programs in this country and can be an additional source of burden to caregivers, as we will see in later chapters.

Throughout the book, we use the term *professional caregivers* to refer to paid care providers such as physicians, nurses, social workers, psychologists, case managers, hospice workers, and home health aides. The designation as professional caregiver excludes those family caregivers who may receive funds to provide care from new and emerging sources, such and the Medicaid Cash and Counseling Demonstration Program.

Genesis of the Rosalynn Carter Institute Caregiving Book Series

The efforts to develop this book began in 2000, when Johnson & Johnson, an international health care business leader, and Dr. Ronda Talley, who was then Executive Director of the Rosalynn Carter Institute for Caregiving, began discussions that led to the creation of the Johnson & Johnson/Rosalynn Care Institute Caregivers Program. In the program, a Science to Practice component was established that allowed the Rosalynn Carter Institute to convene a series of 10 expert panels over a period of several years to address a wide variety of caregiving issues. The topics included disability; Alzheimer's disease; cancer; mental health; life span caregiving; rural caregiving; intergenerational caregiving; education, training, and support programs for caregivers; interdisciplinary caregiving; and building community caregiving capacity. This volume is the product of the Alzheimer's disease panel.

Overview of This Volume

We begin the volume with three chapters that define the issues facing caregivers and individuals with dementia. In their chapter, Early Diagnosis of Alzheimer's Disease, Caregiving, and Family Dynamics, Glenn Smith and Angela Lunde describe the trend toward early diagnosis of Alzheimer's disease and the potential benefits as well as challenges for families of early diagnosis. Early detection is rapidly becoming commonplace and the boundary between Alzheimer's disease and mild cognitive impairment is becoming increasingly blurred. Smith and Lunde describe the complexities of early diagnosis as well as how genetic information can be useful for diagnosis. The chapter concludes with a discussion of how families react to and are affected by the diagnosis, as well as strategies that may help families in the critical period following a diagnosis.

In the chapter, "Psychosocial Interventions to Address the Emotional Needs of Caregivers of Individuals with Alzheimer's Disease," Mary Mittelman examines the central issue in dementia care—the emotional and physical toll it takes on the family, and how psychosocial interventions can be used for treatment and prevention. She begins by describing the progression of the disease. Typically, not only caregivers provide assistance over several years but the demands they face are also continually changing. Just as they adjust to a problem, something new may emerge that throws them off balance. The buildup of stress leads frequently to depression and may also have an adverse effect on health. Mittelman observes that one of the most difficult aspects of dementia is how it undermines the relationship between the person with dementia and those family members who are closest to his or her. Contrary to expectations, placement is not the end of stress on caregivers, but rather a time when the family places a set of new challenges and worries. In spite of the many challenges that caregivers face, a number of interventions have been shown to be effective in lowering stress on caregivers. Mittelman describes some of the most promising approaches, including an in-depth look at the highly successful New York University program that she heads.

In their chapter, "Education, Training, and Support for Alzheimer Family Care," Connie Siskowski and Lisa Gwyther highlight the central role that education plays at every point in the caregiving career. From the initial transition to providing care to assisting a relative now living in an institutional setting, caregivers will benefit from timely and pertinent information. As Siskowski and Gwyther note, caregivers who face the biggest challenges, including those with low income and education, or who spend the most time with their relative, need information the most, but may be the least able to access the usual sources. Siskowski and Gwyther provide a sweeping review of the ways in which education currently is delivered. They look at explicitly educational approaches, such as Web sites and videos, as well as how education has been incorporated into a variety of other types of interventions. They also examine the mixed results of evaluations of the effectiveness of educational strategies in reducing caregiver strain or burden, and call for more careful targeting and evaluation of these types of approaches, as well as policies that will enhance education, training, and support of family caregivers.

The second section of the book addresses issues in providing quality of care. In the chapter "Developmentally Appropriate Long-Term Care for People with Alzheimer's Disease," Steven Zarit and Allison Reamy examine principles of care and strategies for helping patients and their families at each stage of the disease. The concept of "developmentally appropriate long-term care" integrates a person-centered perspective with an understanding of the evolving awareness and capability of individuals with dementia. The core of any successful program needs to be person centered, that is, built around an understanding of the values, preferences, and personhood of the individual with dementia. A person-centered program consistently puts the needs of the person first, ahead of the convenience of the staff or administration. Early stage programs build on the opportunity created by trends toward early diagnosis of Alzheimer's disease, and engage people with this disease at a time when they are still able to express their preferences, and to do some planning for their own care. Zarit and Reamy emphasize the potential of respite programs to assist caregivers and people with dementia in the middle stages of the illness. They then describe the challenges faced with institutional care in later stages of the illness. Despite the ongoing mediocrity in most institutional settings, new models show considerable promise for supporting people with dementia in ways that maintain their dignity and autonomy. A key feature of these therapeutic models is inclusion of the family in thoughtful ways.

In their chapter, "The Economics of Caring for Individuals with Alzheimer's Disease," Mary Sano, Karen Dahlman, Margaret Sewell, and Carolyn Zhu provide a comprehensive overview of the staggering economic costs associated with Alzheimer's disease. They make a compelling case that the monetary and nonmonetary costs of Alzheimer's disease and other dementia make it a top national priority for research and policy initiatives. They examine the components of the costs of caregiving, including direct costs, such as medical expenses, unpaid costs of the assistance provided by family caregivers and other individuals, indirect costs such as increases in health problems, morbidity, and premature morality among caregivers, and other factors such as lost earnings. They provide a critical review of approaches that have been used for estimating the monetary value of care provided by family and other informal caregivers. They then consider costs specifically associated with Alzheimer's disease, including estimates of the total amount, who pays for these costs, and the human costs involved. The chapter concludes with consideration of the economic implications of early diagnosis and treatment.

Karen Meier Robinson's chapter, "Faith and Spirituality: Supporting Caregivers of Individuals with Dementia," takes us to the frequently overlooked dimension of how spiritual and religious beliefs may contribute caregivers' adaptation, health, and well-being. The chapter begins with a review of contemporary perspectives on the definition of spirituality and the importance of finding meaning in adverse circumstances. Robinson describes studies of spirituality as a coping mechanism, and the integral role it has in influencing positive experiences in caregiving. She then explores implications for practice, particularly the role that clergy can play in supporting family caregivers, as well as spiritual care for individuals with dementia. To increase support for people with dementia and their families, Robinson proposes educational initiatives for clergy and church groups that increase awareness and knowledge. She concludes with a discussion of racial, cultural, and ethnic differences in the role of spirituality and religion in people's lives, underscoring that support for caregivers needs to build on their traditional beliefs and practices.

In his chapter, "Family Caregivers as Members of the Alzheimer's Treatment Team," Jeffrey Nichols describes the critical role that family members have in the medical care of people with dementia. Good medical care depends on all those qualities that pose difficulty for patients with dementia—awareness, understanding, ability to follow up on a treatment plan, yet there is often little thought to involving caregivers to help implement and sustain treatment. Nichols provides powerful case examples that illustrate the potential of a team approach that respects the knowledge of the caregiver and incorporates it into treatment plans. He describes in detail an innovative acute care unit for dementia patients that was designed to reduce the unnecessary complications that can arise when patients are sent to ordinary hospital wards. He also cites the growing anecdotal evidence that these approaches produce good outcomes for both patients and caregivers, and challenges the field to conduct systematic studies that consider patient, caregiver, and economic outcomes.

After Alzheimer's disease has run most of its unyielding course, many families hope that death will come peacefully, but end-of-life issues can sometimes be handled by our medical system in puzzling and clumsy ways that seem only to extend suffering of the person with dementia and the pain experienced by relatives. In the chapter "End-of-Life Issues for Caregivers of Individuals with Alzheimer's Disease," Donna Cohen describes the unique circumstances and challenges as individuals with dementia near death. Family members are placed in the position of making decisions about medical care that affect the timing and death. As Cohen describes, families faced with these decisions can experience considerable conflict. They may want the ordeal to end for the person with dementia but feel guilty or embarrassed for having those thoughts, or they may want to hold onto the person as long as possible out of fear of somehow letting him/her down. Cohen examines current standards of care at the end of life for individuals with dementia. She notes that very little caregiver education is directed at end-of-life issues. She then provides an in-depth review of research on end-of-life decisions and care and policy issues affecting these decisions. She ends with a discussion of resources for dealing with these issues for clinicians and caregivers, and proposes new directions for research and policy.

The third section of the book considers cross-cutting issues. Peter Whitehouse begins this section with the chapter "Ethical Issues: Perspective 1: Providing Care for Individuals with Alzheimer's Disease: Practice, Education, and Research." Whitehouse challenges conventional definitions of Alzheimer's disease, and the pathologizing process associated with diagnosis. He explores bioethical approaches to values and the overriding issue of whose perspective is used in philosophical deliberations, the individual with dementia, the caregiver, or the wider society. He then examines a series of issues from an ethical perspective, including diagnosis and labeling, genetic testing, disclosure of diagnosis, and research ethics. He concludes with a discussion of future directions in care of people with dementia from several perspectives—policy and advocacy, practice, education and training, and research.

Stephen Post's chapter, "Ethical Issues: Perspective 2: Supporting Caregivers of Persons with Dementia," provides a complementary perspective to Whitehouse. Post begins by examining cultural and ethical views of people with dementia and the need to expand our concept of "personhood" to include people with impaired cognitive abilities. He suggests that a basic principle of care would be to enhance the quality of life of individuals with dementia through supporting their view of reality, rather than imposing our own. He then considers ethical issues that impact on clinical care, discussing in detail cognitive enhancing drugs, research risks, and end-of-life care.

The legal issues surrounding the care of people with Alzheimer's disease are an essential component of education and services for caregivers. When families take appropriate legal steps, and have in place the mechanisms for caring for an individual who becomes incapable of doing so for himself/herself, there will be fewer problems. Families, however, who stumble ahead blindly, can face complex and vexing problems that may cost them considerable financial cost and emotional pain. In their chapter, "Legal Issues for Caregivers of Individuals with Alzheimer's Disease," Jack Schwartz and Leslie Fried provide a clear and concise overview of the legal framework surrounding care of a person with dementia. They discuss advance planning, including assigning power of attorney, as the optimal strategy, but also point out the barriers to its greater use. They also describe how the regulatory procedures, which govern care in nursing homes and other settings, lack the flexibility to deal with complex clinical situations. They show how these processes can end up making worse the very situations that they are trying to ameliorate. These processes also require vigilance, as they show in their discussion of Medicare. The chapter concludes with a discussion of an overlooked topic, the involvement of the person with Alzheimer's disease in the criminal justice system.

Jiska Cohen-Mansfield's chapter, "Advances in Alzheimer's Disease Research: Implications for Family Caregiving," explores three areas of research: on the person with dementia, on the process of caregiving, and on the impact of caregiving. The section on research on the person emphasizes procedures for assessing deficits at different stages of the illness, which is a critical step for planning intervention. Cohen-Mansfield also suggests the importance of assessing remaining abilities, rather than just focusing on deficits. Building on these remaining abilities is an overlooked, but promising, strategy for helping patients and their families. She concludes this section by suggesting that outcomes for people with Alzheimer's be evaluated in light of the concept of "successful dementia," using indicators of quality of life that are appropriate to the level of severity of the disease. Turning to the caregiving process, Cohen-Mansfield summarizes assessment of the activities and functions performed by caregivers. She also shows how these assessments can be used for planning intervention. In the last section of the chapter, she examines correlates of impact of care-related stressors on caregivers, and links these outcomes to the need for caregiver interventions.

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Part III Cross-Cutting Issues Impacting Caregivers and Caregiving

About the Editors

Steven H. Zarit, PhD, is Professor and Head of the Department of Human Development and Family Studies at Pennsylvania State University, and is also Adjunct Professor at the Institute of Gerontology, Jönköping University, Jönköping, Sweden. He has conducted research on late-life issues, particularly family caregiving and adaptation for older adults. Dr. Zarit is a recipient of the Distinguished Career Contribution Award from the Gerontological Society of America.

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Part I
Issues Affecting the Care Triad

Chapter 1
Early Diagnosis of Alzheimer's Disease, Caregiving, and Family Dynamics

Glenn E. Smith and Angela Lunde

With the aging of society, Alzheimer's disease (AD) poses a potential public health crisis. This potential crisis has spurred research on making an early diagnosis of AD. Progress has been made in identifying AD risk factors, including those involving genetics. This progress has led to hope that prevention models might work in AD as they have in cancer and heart disease. These trends offer exciting new directions in AD research. However, the potential impact of these trends on AD caregivers has received little consideration. The goal of this chapter is to explore the potential impact of early diagnosis, advances in genetics, and prevention models on AD caregivers. An examination of what is currently known in these areas will be followed by discussion of the research, education, practice, and policy needs these trends have created. Finally, we will speculate about future directions in AD caregiving that may result from early diagnosis and prevention efforts.

Throughout this chapter, the term *families* will be used for convenience. It is recognized that caregiver systems often include people other than family, such as friends and neighbors. In most contexts of this chapter, the term *families* is meant to include these other caregivers as well. Also, throughout this chapter we will move between the terms early diagnosis and prevention. These concepts are related but not identical. Early detection involves identifying people who show the earliest detectable signs of the disease. Prevention involves intervening with people at risk of AD but showing no signs of the disease. As technology improves, this boundary can become less distinct. For example, some might view the intervention on behalf of people who have Mild Cognitive Impairment (MCI) as prevention if these people do not go on to display dementia. However, in this chapter we ascribe this activity to early detection since persons with MCI have a detectable sign of disease.

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What Is Known?

Trends Towards Early Diagnosis

Prevention as a viable model in Alzheimer's disease. In its strategic plan for years 2001–2005, the National Institute on Aging has emphasized an Alzheimer's Disease Prevention Initiative (National Institute on Aging, 2001). This initiative grew, in part, out of analyses that showed that if the average onset age of AD could be delayed just 5 years, the number of cases in 2050 would be reduced by 50% (Brookmeyer, Gray, & Kawas, 1998). This reduction in cases is predicated on the fact that AD occurs in people who live beyond the median expected survival. Any delay in age of onset will significantly reduce the morbidity of AD because at-risk persons will likely die of other causes. The hope of preventing the manifestation of AD by delaying onset has been reinforced by the development of medications that seem to slow the progression of memory impairment in people affected by AD. The first medication, tacrine, became available in the mid-1990s. Subsequently, four other medications, donepezil, rivistigamine, galantamine, and memantine, have been approved for use in AD by the Food and Drug Administration. None of these medications are reported to cure AD or lead to persistent improvement in functioning. Rather, all are reported to delay the course of progression. Thus, many clinicians and researchers believe early intervention with these medications is critical. These professionals equate delaying progression in high-risk individuals who do not yet have dementia to preventing AD. Several studies are now underway, seeking to combine early detection and early intervention with currently available medications in the hopes of significantly reducing the number of people who develop AD. Figure 1.1 represents the possible outcomes of early intervention. It remains to be seen what type of impact early intervention will have on people at risk for AD.

The boundary between normal aging and Alzheimer's disease: Mild cognitive impairment defined. Dementia is a term that applies whenever someone shows a decline in two or more cognitive abilities (e.g., memory and language) to the point that they can no longer maintain their usual routine. By current convention, a person must have dementia to receive the diagnosis of AD. Numerous factors contribute to confidence that significant risk for AD can be identified before dementia is present. Among the research initiatives leading to this confidence are studies involving neuropsychological testing. These studies have identified the presence of certain focal cognitive changes in people well before the diagnosis of dementia was appropriate (Bondi et al., 1995; Ivnik et al., 2000; Jedynak et al., 2012). In addition, neuroimaging studies are revealing a variety of techniques that can detect signs of brain changes before the full presentation of AD (Jack et al., 1999; Kantarci et al., 2000; Reiman et al., 1996; Lowe, et al., 2007). By moving the point at which significant risk for AD can be identified to predementia status, research has challenged the nomenclature of the field.

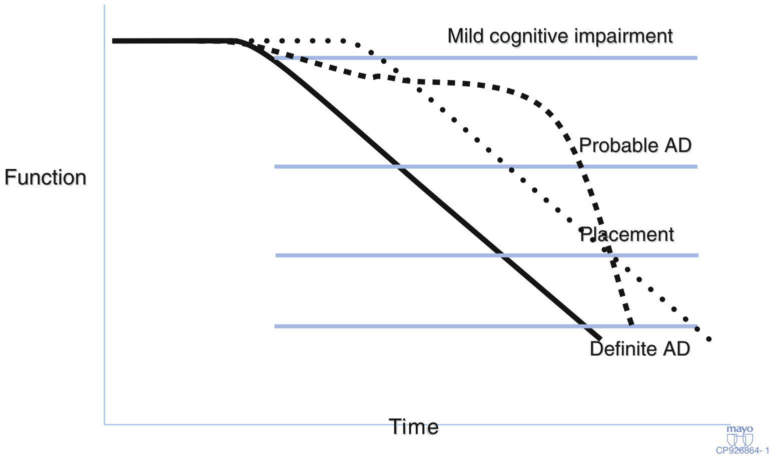


Fig. 1.1 Theoretical course of decline in Alzheimer's disease. *Solid line* reflects typical course. *Dashed line* represents desired outcome of early intervention, a prolongation of higher functioning, and a short course of significant functional impairment prior to death. The *dotted line* represents an alternative possibility, i.e., a delay in the onset of illness, but also a delay in mortality so that there is no reduction of functional impairment

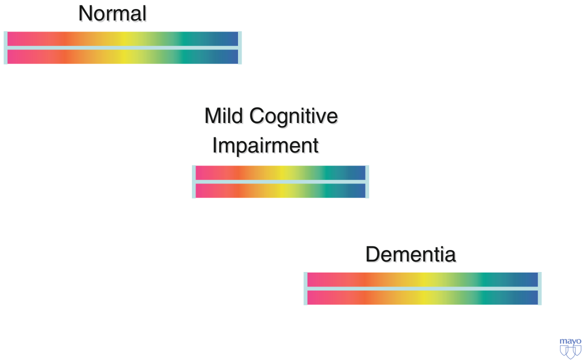


Fig. 1.2 Hypothetical cognitive continuum reflecting the overlap of Mild Cognitive Impairment with low functioning normal elderly and high functioning dementia

A variety of new diagnostic terms have been offered to help describe this predementia boundary zone between normal aging and AD (Smith et al., 1996). MCI (Albert et al., 2011; Petersen, 2004) has recently gained wide acceptance as an important clinical concept and as a target for potential therapeutic intervention. As suggested in Fig. 1.2, MCI refers to the overlap in cognitive function that could represent the lowest end of normal cognitive function or the earliest signs of clinically probable AD. Many studies have shown that people with MCI have a high (but not absolute) risk of progressing to a full dementia syndrome. Figure 1.3 represents fairly typical data regarding rate of conversion from MCI

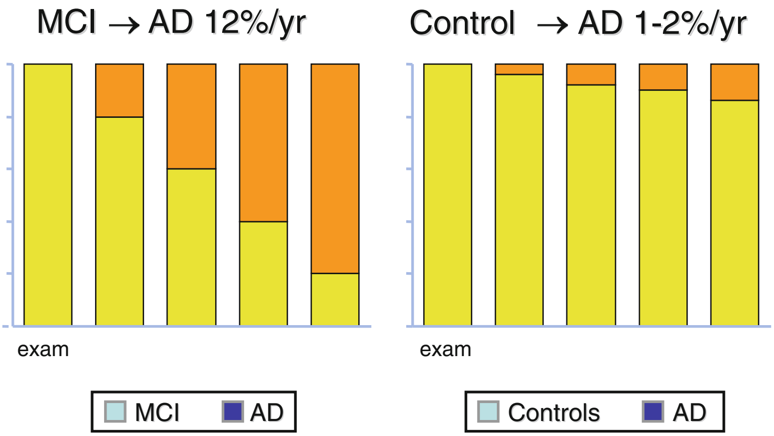


Fig. 1.3 Conversion to full dementia in mild cognitive impairment (MCI) vs. normal older adults. One to two percent is the commonly reported dementia incidence in older adults. Data adapted from Petersen et al. (1996), by permission of authors

to dementia. About 12% of persons with MCI will progress to full dementia each year, so that after 4 years almost 50% of a group of people who started with MCI will have developed dementia. As can be seen from Fig. 1.3, this is as much as ten times the rate of normal older persons. This significant increase in risk for dementia among people with MCI has led to the acceptance of the diagnosis in both research and clinical settings.

Use of Genetics Testing in Early Diagnosis of Alzheimer's Disease

The trend towards early detection has also been spurred by the identification of genes associated with AD. So far, four gene mutations have been identified and associated with AD (Petersen, 2002). It is likely that more genes will be found and more ways in which genes associate with AD will be discovered. At this time, however, it is reasonable to discuss the four known genes as either causative or susceptibility genes.

Causative genes. At the time of this writing, there are three genetic mutations that appear to have a causative link to AD. These genes are the APP gene on chromosome 21, the Presenilin 1 gene on Chromosome 14, and the Presenilin 2 gene on chromosome 1. These genetic mutations occur in only about 100 families. Thus, it is estimated that these genes explain less than 5% of all the AD present in the world today. These gene mutations are deemed causative because whenever the genetic mutation is present and the carrier of the gene lives to the age of risk, he or she invariably develops dementia. Moreover, members of the family who live through the age of risk without developing dementia are not carriers. All of the AD causative gene mutations are associated with early onset (AD occurring before the age of 65). The identification of these genes significantly demonstrates that AD can have a genetic cause, so it is possible that a portion of the common late onset form of AD will have a genetic cause as well.

Susceptibility genes. In addition to genetic mutations with apparent AD causation, at least one genetic variation has been identified that increases AD susceptibility. This is the Apolipoprotein E gene on chromosome 19 (Strittmatter et al., 1993). This gene has three common forms labeled E2, E3, and E4. People who possess the E4 genotype are at increased risk for developing AD. However, unlike causative genes, some people with the E4 genotype do live through the age of risk without developing AD. Moreover, over 45% of people with late onset AD do not carry the E4 genotype. Thus, the E4 genotype is neither necessary nor sufficient for development of AD. Still, inheriting one E4 gene increases risk for displaying AD approximately four times, and inheriting two E4 alleles increases risk roughly 16 times. Identifying such a significant increase in risk for AD may justify intervention in E4 carriers before they show signs of dementia.

Family dynamics and genetic counseling in neurodegenerative diseases. Knowledge of causative and susceptibility genes offers great promise for our early detection and prevention efforts in AD. The early diagnosis in a person with some equivocal evidence of cognitive decline can be facilitated by knowledge of his/her genes (Roses, 1997). Whole populations that show no evidence of cognitive decline but have genetic risk can be studied (Reiman et al., 1996) and even entered into prevention trials. However, the identification of these genes is a two-edged sword for caregivers. A majority of AD caregivers are family members. At the time of symptom onset in affected persons, over 40% of caregivers are spouses and at least 40% are the children of the affected person (Smith, Kokmen, & O'Brien, 2000). The genetics of AD is of substantial relevance to these caregivers. Pursuing genetic information about the affected person will reveal information about AD risk in his or her children (and siblings).

As a result, emerging genetic information now places AD in closer proximity to genetic neurodegenerative disorders such as Huntington's disease (Burgess, 1994). In disorders with a clear genetic cause, the recognition of disease in a family member immediately places all of the remaining family members at significantly elevated risk (sometimes as much as 100%) to also develop that disease. This has a broad and sometimes devastating impact on these families. The incidence of suicide in Huntington's disease families, for example, is significantly higher than that of the general population (Farrer, 1986). Family members of persons with Huntington's disease face agonizing decisions regarding genetic testing on themselves. With the increasing recognition of causative and susceptibility genes, AD families may face similar challenges. The emergence of this genetic information has produced a heretofore nonexistent literature on genetic counseling in AD (Tibben et al., 1997).

Already a number of consensus panels have addressed the issue of Apolipoprotein E genetic screening for non-affected family members (Anonymous, 2001; Relkin, Kwon, & Gandy, 1996). These consensus panels have typically argued against widespread screening, primarily because susceptibility genes impart risk, but there is no definite knowledge about the development of dementia in a given person. Nevertheless, the availability of genotyping to establish risk brings families to the point where they must confront their own risk and make decisions about their own health care in ways that previously were nonexistent. Certain medical–legal complications may ensue. In the future, health and long-term care insurance providers might limit coverage for people identified to be at genetic risk for dementia. Furthermore, genetic risk might impact a person's employability, especially someone in his 50s or 60s.

Early Diagnosis and Family Dynamics

Family dynamics and denial in diagnosis. Family members play a key role in seeking diagnosis in dementia (Boise, Morgan, Kaye, & Camiciolo, 1999). But the average interval between families' awareness of initial symptoms and initiation of diagnostic evaluation is 2–3 years (Smith, O'Brien, Ivnik, Kokmen, & Tangalos, 2001). Confusion about normal age-related memory change vs. abnormal memory decline is a common component of this delay. However, Wackerbarth and Johnson (2002) found that in about 70% of cases where formal diagnosis is eventually sought, the leading cause of the delay was difficulty accepting the decline of the person with AD. This difficulty accepting the diagnosis is a form of denial, which is a common first reaction to any loss, including death or catastrophic illness (Kubler-Ross, 1969).

By definition, MCI does not include impairments in daily function. Clear evidence of impairment may only be present on neuropsychological tests, and family members may vary in the degree to which they accept the credibility of such tests. Without evidence of impairment in day-to-day function, overcoming denial may be even more difficult. Conversely, MCI diagnosis may be less threatening to affected persons and their families. Often, affected persons and their families will admit memory problems are present even when they will not accept the diagnosis of AD. If family members will acknowledge that memory problems are present, they may accept a diagnosis like MCI as well. Since an MCI diagnosis may be sufficient to initiate medication intervention (Petersen et al., 2004) and mobilize the family, this diagnosis may serve as an intermediary to help ease the family into acceptance of AD. However, all of this speculation remains to be evaluated.

Early diagnosis and duration of caregiving. A variety of factors contribute to caregiver burden, including frequency of disruptive behaviors, level of functional impairment in the affected person, and amount of informal support received by the caregiver (Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000). Duration of caregiving may also contribute to caregiver burden, but evidence for this is equivocal. Some studies suggest a correlation with duration of caregiving and burden (Sugihara, Sugisawa, Nakatani, & Shibata, 1998), while others suggest burden declines after initial diagnosis (Grafstrom & Winblad, 1995), especially as caregivers develop a sense of mastery. It is not clear early diagnosis would thrust caregivers into providing care for longer periods of time. Aneshensel, Pearlin, Mullan, Zarit, and Whitlatch (1995) note variable patterns of association between symptom recognition, diagnosis, and provision of care. In the modal pattern, symptom recognition and diagnosis are closely linked, but care provision is delayed. Only in about one in five cases did diagnosis and assumption of hands on care co-occur.

What Is Needed?

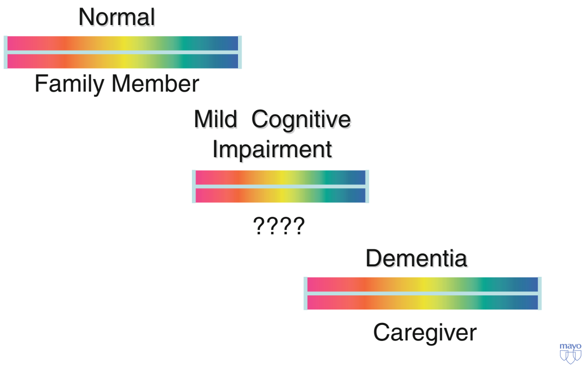
Research

As noted, early detection and prevention in AD are relatively new concepts. Thus, the greatest needs are in the area of research. Though the research questions are many, we pose three preliminary queries. In terms of early diagnosis and family dynamics, the answers to these questions will inform what is needed in terms of practice, education, and policy.

When do family members become caregivers? Research is needed to provide a clearer understanding of the impact of earlier diagnosis on family/caregiver systems. The current research focus on the transition from normal status to a person with AD needs to parallel studies on a spouse, child, sibling, or friend's transition to caregiver. It seems likely that between the existing family role and the caregiving role, there is a period of "concerned family member" that may be associated with its own forms of burden and distress or ambivalence (see Fig. 1.4). This may or may not correspond exactly to the period of denial between onset and diagnosis alluded to above.

In an effort to provide pilot data addressing these questions, we collected data from two focus groups. These focus groups were composed of husbands, wives, and daughters participating in caregiver support groups. These groups included caregivers supporting affected persons in a full range of living situations with a full range of impairments. Some of the caregivers were still providing care at home while others had placed their affected person in a care setting. Some of the affected were still in MCI stages, others had advanced dementia, and one affected member had recently died. We first asked them to specify age of onset, age of diagnosis, and age of placement (if applicable) for the affected person. Once they had established these milestones, we asked them to specify a relative point in time when they first became a caregiver. We declined to define the term caregiver for the focus group members. Thus, the estimate of caregiver-role acquisition was an entirely subjective decision by the caregivers. This differs from prior research (e.g., Aneshensel et al., 1995) in which caregivers reported when they first "started helping him/her do things she/he couldn't do…." Figure 1.5 reflects the modal placement of "caregiving onset" produced by the two groups. Note that male focus group members typically placed the onset of caregiving after diagnosis. However, subsequent questioning suggests that factors of functional loss were more important than timing of diagnosis in determining

Fig. 1.4 Does the transition from family members to caregivers parallel the transition from normal cognitive function to dementia?



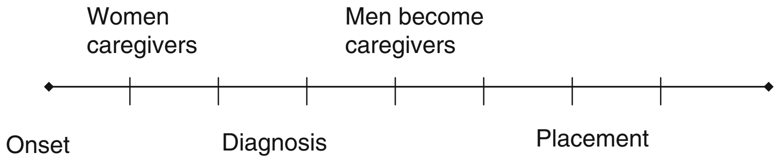


Fig. 1.5 Alzheimer's timeline. Preliminary results of focus groups of husband, wife, and daughter caregivers. Women in focus groups more often reported assuming the caregiver role before diagnosis than men

when caregiving begins. Female caregivers were more likely to view caregiving as having begun after the onset of illness but before diagnosis was made. For women, it was clearly functional problems, not diagnosis, that contributed to the assumption of the caregiver role. However, in the case of the women, a more minor functional impairment seemed to elicit "caregiving." These results are clearly quite preliminary. Despite the small groups, the participants nevertheless displayed variability in their responses to this process. These groups of caregivers may be biased in a number of ways, including the fact that they are participants in caregiver support groups. Nevertheless, this focus group exercise provides preliminary evidence that functional impairment rather than diagnosis drives the assumption of the caregiver role. As described above, this suggests early diagnosis is more likely to benefit than further burden caregivers.

Does early identification reduce morbidity in the person with Alzheimer's disease at the expense of increasing burden on caregivers? We need to consider the possibility that early identification could actually increase the burden of caregiving. The focus group data presented above suggest that the people's perception of when caregiving begins is associated with functional status of the affected person. If early detection leads to early intervention and early intervention delays functional decline, then caregiving would also be delayed: a positive outcome for caregivers. However, these issues would best be addressed by a prospective empirical study of the association of early diagnosis and caregiver burden.

Does early diagnosis lead to more or fewer transitions? Improvements in early detection abilities have occurred simultaneously with an expansion in the continuum of care options for older adults. An expanded continuum offers better-tailored options for persons affected with AD, but also more decisions. Early diagnosis may lead to earlier scrutiny of the behavior and functional status of the affected person. It is not clear if this early diagnosis also leads families to access care options sooner. If they do access care options sooner, caregivers and affected persons may then face more care transitions along the continuum. Anecdotal evidence suggests that these transitions are difficult for the affected person and draining for caregivers. More transitions may result in more burden.

Conversely, early detection may enable caregiver systems to anticipate needs sooner, gather information before "hands-on" care needs are overwhelming, and include the affected person in decision making. For example, many residential providers have developed "in-house" continua to enable aging in place. If affected persons and their families have early knowledge of high risk for dementia, they may seek to transition to aging-in-place communities while the affected person is still mildly impaired and more adaptable. In these settings, affected persons might begin in independent living with in-home support, transition to assisted living, and ultimately have skilled nursing home beds available to them if needed. Studies of the impact of early diagnosis on residential transitions are needed.

Practice

Both dementia specialists (Petersen et al., 2001) and primary care providers (Shah, Tangalos, & Petersen, 2000) appear to be embracing the concept of MCI or early diagnosis. Yet, many general practitioners remain unaware of this concept or see little utility in it. For the diagnosis of MCI to gain broader acceptance, clinicians will need to understand the risk for dementia associated with MCI *and* perceive a positive impact on outcomes related to making the diagnosis. Conversely, leaders in this area have cautioned that this not become a convenient vehicle to sidestep diagnosis of AD, even when AD is present. Families may embrace MCI diagnosis to avoid confronting AD.

Since most cognitive skills are still present at early diagnosis, advocates promote early diagnosis as a means to permit affected people to participate in care planning. There is strong evidence that persons mildly affected with dementia can participate in planning their own care (Feinberg & Whitlatch, 2002). Practically speaking, this generally includes residential, medical, legal, and financial planning. Whether families really do discuss these matters with the person in the early stages is uncertain, even if the affected person is still capable of contributing to the decision-making process. Nor is it clear who should lead families through these delicate discussions: physicians, social workers, mental health providers, clergy? Establishing practice standards in this arena seems important.

Education

There are numerous resources available to families of persons diagnosed with AD. The Alzheimer's Association provides extensive education and support to persons wanting to know about AD. Other resources include the Alzheimer's Disease Education and Referral Center (ADEAR), the Family Caregiver Alliance, and the National Institute on Aging's network of Alzheimer's Disease Research Centers. In addition, there are books, brochures, articles, web sites, education classes, and support groups in many communities to assist families dealing with a diagnosis of AD.

But when the diagnosis is MCI or "mild dementia" where do families turn? What should they think, and feel? How should they respond? Is this a devastating diagnosis, or a relief to the family? Is it useful or reasonable to deluge them with information on AD? Does receiving education on the stages of AD and caregiving strategies precipitate early symptoms of burden for the family or help them prepare and develop mastery? This needs further exploration before education standards in early detection are codified.

Educational efforts could be adequately tailored to address a diagnosis of MCI. This may include support groups for people with MCI and their family members, accessible information about the latest research findings and clinical trials involving MCI, and information that assists the family in openly and effectively planning for the future. Education should focus on coping with day-to-day issues related to the symptoms of MCI. For example, efforts could shift to topics related to issues of maintaining work/employment, safe driving, and proactive tools for coping and compensating for memory deficits. This kind of an educational approach could assist in delivering a powerful and positive message to people diagnosed with MCI and their families, possibly minimizing early feelings of burden.

Policy

Current medicolegal policy struggles to accommodate the concept of risk. Policies are most functional when dichotomies exist (e.g., guilty or not guilty, competent or incompetent, sick or well). However, prevention and MCI diagnoses deal in probabilities, not dichotomies. A person diagnosed with MCI does not have dementia but does have a high probability of developing dementia. Current Medicare policies do not provide adequate coverage for services and interventions for people with dementia (Fillit, Geldmacher, Welter, Maslow, & Fraser, 2002) let alone people with MCI. This may create economic barriers to early intervention with a major impact on public health.

While some see early diagnosis as a significant positive advance, there may also be disincentives to pursuing early detection. The person at risk for AD may also be at risk for losing rights and privileges. The diagnosis of cognitive impairment could lead to restrictions on employment, driving, ability to modify medical and financial advance directives, and access to long-term care or other insurance. Thus, an affected person and her or his family face a dilemma. Do they pursue early diagnosis to access the potential benefits of treatment and risk loss of independence and insurability as a consequence? Or do they avoid diagnosis and access to treatment to also avoid losing rights and privileges? Do early detection and intervention slow the course of illness (i.e., reduce morbidity) sufficiently to justify the stigma that may be associated with the diagnosis? As a matter of public health, disincentives to early detection should be minimized. If early detection can in fact reduce morbidity, policies should protect those that pursue early detection.

Future Directions

Current justifications for early diagnosis include enabling affected persons to participate in clinical trials, plan for their own care, and permitting caregivers to receive education to anticipate impending changes and challenges. Yet to date, no studies have suggested any significant benefits of AD therapies for early diagnosed persons. And although affected persons' participation in care planning may mitigate family disagreements over issues such as life sustaining efforts and dispersement of estates, current data suggest families are not necessarily engaging in this practice. And MCI-specific educational materials remain undeveloped. Importantly, evidence that early diagnosis improves long-term outcomes for affected persons or their caregivers does not (yet) exist. This type of research is clearly needed.

As noted in the introduction, currently 4 of 10 persons receiving the diagnosis of dementia are living alone at the time of diagnosis. Efforts at early diagnosis may lead to a larger number of cases wherein the affected person has been identified but remains alone in their home. Early diagnosis may thrust new concerns about safety and day-to-day function on unprepared family members. Prior research has shown that safety concerns may have great impact on decisions to relocate persons with dementia (Smith, Tangalos, Ivnik, Kokmen, & Petersen, 1995). Technology will afford increasing options for managing these safety concerns.

With the support of the Mayo Foundation and the Minnesota Department of Human Services, we conducted a "telemedicine" demonstration project. This project involved the placement of two-way interactive video equipment in the homes of mildly impaired AD patients. This equipment allowed a personal care assistant (PCA) to contact the person affected with AD. These PCAs made contact with the affected persons multiple times daily according to their medication schedule. Preliminary evidence suggested that the recipients of this service had no problem accepting or interacting with the equipment and improved accuracy in their medication self-administration. (Smith, Lunde, Hathaway and Vicker, 2007). This technology helps to address a major problem for early intervention strategies involving medication. That problem is the paradox of memory impaired people needing to self-administer medications to prevent further cognitive decline. This simple intervention with currently available technologies is likely a small foreshadowing of "smart house" technologies (Barucha et al., 2009) that may help maintain persons with early to moderate dementia in their own homes. It remains to be demonstrated that such technologies will reduce caregiver worry, i.e., caregiver burden.

Emerging data suggest the future will also bring public health initiatives to prevent AD. These initiatives may parallel public health initiatives in stroke, heart disease, and cancer, focusing on diet and healthy lifestyle practices that reduce risk. In addition, people identified as carriers of susceptibility genes may be directed to therapies, including antioxidant diets, physical and cognitive exercise, amyloid modifying medication, and possibly even vaccinations (Schenk et al., 1999). In the future, early diagnosis of an affected person will likely generate a plan for the family caregivers to begin their own preventative treatments, even as a plan for caregiving is developed for the affected member.

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Chapter 2
Psychosocial Interventions to Address the Emotional Needs of Caregivers of Individuals with Alzheimer's Disease

Mary Mittelman

Alzheimer's disease (AD) poses unique difficulties for many families. The time from the onset of symptoms of the illness to death is typically 5–15 years. The person with the illness experiences increasing cognitive and functional impairments, and ultimately becomes entirely dependent on others for survival. While it is possible to describe the symptoms that generally accompany the disease as it progresses, it is not possible to predict when or if a specific symptom will arise in any individual, or how long it will be before the symptom disappears as the severity of the illness increases.

Why Is Caring for a Relative with Alzheimer's Disease Emotionally Stressful?

Unlike many other illnesses, AD erodes the ability to interact with others, making it more difficult for the ill person to express gratitude towards those providing care. The characteristics and symptoms of AD change over time, so that family caregivers must continuously learn new strategies for interacting with the person with dementia, modifying the environment to be dementia friendly and coping with the changing needs for care. Regardless of how well informed family caregivers are, they generally find the emergence of new symptoms distressing. As the disease progresses, caregiving requires more and more time and effort, and at least through the middle stages, becomes increasingly stressful. As a result, people who care for relatives with dementia are more likely to sacrifice jobs, social, and other leisure time activities than those who care for relatives with physical illnesses.

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The primary stressors that derive directly from caregiving can be conceptually divided into two domains: those related to direct provision of care such as assistance with activities of daily living and medication management, and those related to behavior problems caused by the illness. Emotional symptoms associated with dementia such as irritability, apathy, depression, and anxiety and behavior problems such as agitation have been consistently found to be more stressful than cognitive and functional problems for caregivers (Croog, Sudilovsky, Burleson, & Baume, 2001; Haley, Levine, Brown, & Bartolucci, 1987; Schulz, O'Brien, Bookwala, & Fleissner, 1995; Smith, Williamson, Miller, & Schulz, 2011). Moreover, these symptoms, especially agitation and incontinence, are so difficult for family members that they frequently precipitate nursing home placement of the person with dementia (Coehlo, Hooker, & Bowman, 2007; Cohen et al., 1993). While care recipient and caregiver characteristics have independent effects on nursing home placement (Yaffe et al., 2002), caregivers' subjective experiences of their relatives' problem behaviors are at least as important as the behaviors themselves in predicting institutionalization (Fisher & Lieberman, 1999). This has important implications for effective comprehensive treatment strategies for dementia, as caregiver appraisal of symptoms is amenable to psychosocial intervention (Mittelman, Roth, Haley, & Zarit, 2004), while the behavior problems themselves are often more intractable.

How Does the Severity of Dementia Affect the Emotional Impact on the Caregiver?

In the early stage of AD, the main problems for the person with the illness relate to difficulties with memory. In this stage, repetitive questioning and getting lost in unfamiliar places force changes in lifestyle and can be exasperating and upsetting to caregivers. The person with dementia, however, can still carry out many activities on his or her own.

The middle stage of AD is particularly difficult for caregivers. It is during this stage that behavioral problems such as agitation are likely to become prominent. It may appear to the caregiver that their relative's personality has changed, as behavioral problems make the person with dementia behave in unfamiliar ways. Some of the symptoms of agitation may appear to be acts of deliberate hostility and aggression towards the caregiver. During this stage, the person with dementia becomes increasingly incapable of communicating verbally, and motor functioning begins to become significantly impaired. Severely compromised long- and short-term memory limit his or her ability to initiate or participate in social, recreational, and daily activities, which can lead to major changes in the character of his or her relationships with family members and friends.

In the later stages of the illness, the person with dementia becomes increasingly incapable of carrying out basic activities such as toileting, bathing, eating, and ultimately even sitting up or smiling. There are aspects of this stage that are also emotionally stressful for family members such as the time when their relatives no longer recognize them. Care needs shift during this stage from managing difficult behavior to assistance with basic functioning, which is not as stressful for many family caregivers.

The Impact of the Illness on the Relationship Between Caregiver and Care Receiver

It is not only the illness itself that is stressful but also the impact of the illness on the relationship between the person with AD and the person who has become, as a result of the illness, not only husband, wife, or adult child but caregiver as well. The progressive nature of the disease causes a change in the quality of the relationship, affecting ways of communicating and supporting each other, and undermines the bond between the caregiver and the ill relative. Family caregivers frequently become disheartened, feeling powerless to bring meaning and spirit back into the lives of their loved ones who are losing the ability to participate independently in the productive and pleasurable activities that had previously been a source of gratification and identity. Contradictory perceptions about the amount of help and protection the person with the illness needs can lead to conflict between the care recipient and the caregiver and create strain between them, which in turn contributes to the risk of caregiver depression (Lyons, Zarit, Sayer, & Whitlach, 2002).

Caregiving and Risk of Mental Illness

Research suggests that caring for a person with dementia can have a serious impact on a caregiver's psychological health, social life and career, and relationship with the person with dementia (Donaldson, Tarrier, & Burns, 1998; George & Gwyther, 1986; Schulz, Visintainer, & Williamson, 1990). Caregivers of relatives with dementia are at elevated risk for depression, anxiety, anger, and hostility (Bodnar & Kiecolt-Glaser, 1994; Livingston, Manela, & Katona, 1996; Pinquart & Sörensen, 2003a, 2003b; Sorensen, Duberstein, Gill, & Pinquart, 2006). Estimates for rates of specific psychiatric disorders among dementia caregivers vary widely, with rates of depression ranging from 23 to 85% and of anxiety between 16 and 45% (Brodaty & Donkin, 2009). Many dementia caregivers experience an episode of anxiety or depressive disorder for the first time during their caregiving years (Schulz et al., 1995), which is evidence of the especially stressful nature of caring for a relative with dementia.

Risk of Depression Among Caregivers of Relatives with Dementia

Depression is the most researched mental illness associated with caregiving. One review stated that 22% of dementia family caregivers meet diagnostic criteria for a depressive disorder when structured clinical interviews are used (Cuijpers, 2005). The increased risk of new episodes of depressive disorders among caregivers of relatives with dementia does not appear to be related to family history of depression or previous episodes of depression (Dura, Stukenberg, & Kiecolt-Glaser, 1990).

While some caregivers consistently report high levels of symptoms of depression, many others are episodically symptomatic. Moreover, caregivers prone to recurrent depression are more likely to report inadequate social support and stressful life events than episodically depressed or never depressed caregivers (Redinbaugh, MacCallum, & Kiecolt-Glaser, 1995). In longitudinal studies, the number of caregivers who were episodically symptomatic ranged from 32% (Alspaugh, Stephens, Townsend, Zarit, & Greene, 1999) to 41% (Schulz & Williamson, 1991). In a 2-year longitudinal study of caregivers (Schulz & Williamson), only 14% of caregivers of relatives with dementia were consistently symptomatic, while 41% were episodically symptomatic. Thus, estimates derived from cross-sectional studies may seriously underestimate the number of caregivers with risk of future episodes of depression.

Several population-based studies suggest that disturbing behavior of the person with dementia is the most significant predictor of depression in the family caregiver (Chappell & Penning, 1996; Clyburn, Stones, Hadjistavropoulos, & Tuokko, 2000). Cognitive theories of depression suggest that it is the appraisal of the behavior rather than the behavior itself that is the strongest predictor of depression, Indeed, in this study, caregivers who perceived the care recipients as most burdensome were at highest risk of depression (Clyburn et al., 2000). Not all behaviors have the same effect on caregivers. A longitudinal study in which both caregiver depression and care recipient behavior were assessed every 2 months for an 18-month period failed to find an increase in caregiver depression with severity of behavioral symptoms, but found that aggressive behaviors were more stressful and more associated with depression than other symptoms of agitation (Danhauer et al., 2004). Self-efficacy for symptom management is associated with reduced symptoms of burden and depression in caregivers (Gallagher et al., 2011). Depression in caregivers has consequences for their impaired relatives as well, as they are more likely to place them in nursing homes if they themselves are depressed (Whitlatch, Feinberg, & Stevens, 1999).

Placing the person with AD in a nursing home may not alleviate the stress of caregiving. Several studies of spouse caregivers showed that those who had placed their husbands or wives in nursing homes expressed significantly higher levels of sadness and guilt than home caregivers (Rudd, Viney, & Preston, 1999; Skaff, Pearlin, & Mullan, 1996). While relatives experienced relief from feelings of overload and tension, other indicators of stress such as evaluations of their role and feelings of well-being are not diminished by placement (Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001; Zarit & Whitlatch, 1993).

Are All Family Caregivers at Equal Risk of Psychological Distress?

There are many factors that influence the risk of psychological distress among caregivers of relatives with AD. The relationship of the caregiver to the care recipient, gender and age, race and ethnicity are examples of the background factors that affect the impact of caregiving.

Whether the caregiver is a spouse or adult child affects the type and amount of stress. The psychological impact of caregiving appears to be greater for spouses than for other caregivers (Baumgarten et al., 1992; Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002). Spouse caregivers are generally elderly themselves. As a result, they are at higher risk of poor physical health than younger caregivers, which adds to the strain of caregiving. Moreover, poor physical health has been identified as a risk factor for depression in caregivers (Lawton, Moss, Kleban, Glicksman, & Rovine, 1991).

For spouse caregivers, the social and emotional losses associated with having a husband or wife with dementia are more important than the amount of care required. In contrast, for adult child caregivers, for whom other life roles compete for time, the amount of care and the time required to provide that care can be stressful, regardless of the particular tasks that must be accomplished.

Elderly spouse caregivers of people with dementia run a higher risk of social isolation than adult child caregivers. The social networks of many elderly people have diminished in size, due to the death of friends and relatives and to the loss of workplace relationships after retirement. As a result, spouse caregivers may have placed greater reliance on the companionship and emotional support of their husband or wife with dementia than younger caregivers. The caregiving spouse can become socially isolated when dementia erodes the ability of the ill spouse to understand his or her needs, to communicate effectively, or to participate in activities they may have formerly enjoyed together. These problems can be exacerbated by the fact that many spouse caregivers feel that they must provide all the care for their ill spouse. In addition, family members and friends may not be used to offering help or providing emotional support for the caregiver.

People who care for a parent, as opposed to a spouse with dementia, face different caregiving challenges. Adult child caregivers are more likely to have multiple responsibilities, including jobs, marriage, and child rearing. They must also face the emotional challenge of the role change associated with caring for their parents who formerly were in the position of having to care for them. Sometimes adult child caregivers find themselves, because of a sense of filial obligation, to be spending more time in the presence of parents than they would have if their parents were not ill. This can cause resentment, anger, and bitterness. Other family members of adult child caregivers—their own spouses and children—may resent the time spent caregiving. If the person with AD lives with the adult child caregiver, this may cause additional problems due to the family members having to give up physical space. In the middle stages of the illness, behavior problems caused by the illness can be especially difficult for all family members who are living with the person with dementia, but may not feel the same filial obligation as the adult child caregiver.

Gender affects the impact of caregiving. Many studies have found that female caregivers report significantly more symptoms of depression than male caregivers (e.g., Baker & Robertson, 2008; Mittelman et al., 1995; Mittelman, Roth, Coon, & Haley, 2004; Pruchno & Resch, 1989). One study compared the effect of caregiving on male and female spouse caregivers and found that the mental health of wives who are caregivers for their husbands with dementia appears to be more affected than that of husbands caring for their wives, although there is no difference between husbands and wives caring for a spouse who has a physical illness (Hooker, Manoogian-O'Dell, Monahan, Frazier, & Shifren, 2000). One possible explanation for this finding is that a woman's psychological well-being is more dependent on the emotional quality of the marital relationship than a man's, and dementia inevitably changes the quality of the relationship.

Race and ethnicity affect the impact of caregiving. Studies investigating the relationship between race and ethnicity and the caregiving role suggest that non-White caregivers may not experience the same levels of stress and depression as White caregivers, although the impact of race and ethnicity is clearly complex, and dependent at least in part on other factors such as acculturation, education, and income. In an analysis of the REACH II data, which included more than 600 caregivers, of whom one third were non-Hispanic White, one third were African-American, and one third were Hispanic, it was reported that the African-American caregivers had significantly more role strain than the other groups (Hilegman et al., 2009), and that White caregivers had more intrapsychic strain. Non-White caregivers also are more likely to hold strong beliefs about filial responsibility and to use prayer, faith, or religion as coping mechanisms (Connell & Gibson, 1997). Cultural values also affect the mental health impact of caregiving, with increases in sense of family obligation being associated with decreases in both mental and subjective physical health (Sayegh & Knight, 2011).

Personality affects the impact of caregiving. Personality traits may influence an individual's reaction to the caregiving role, and response to an intervention. For example, neuroticism, defined as having a tendency towards experiencing negative emotions such as worrying, being nervous and insecure, and hypochondriacal (Costa & McCrae, 1985), predisposes caregivers to psychological distress and to appraising situations as especially stressful (Bookwala & Schulz, 1998; Hooker, Monahan, Bowman, Fraizer, & Shifren, 1998). On the other hand, what have been called "resilience factors"—personal mastery, self efficacy, and coping—appear to be protective (Harmell, Chattillion, Roepke, & Mausbach, 2011) and can be the targets of psychosocial interventions to reduce risk of morbidity associated with caregiving.

Caregiver strain affects the risk of physical illness and mortality. Caregiving has deleterious effects on physical health and mortality (Haley, Roth, Howard, & Stafford, 2010; Vitaliano, Scanlon, & Zhang, 2003), which may be particularly salient for caregivers who report a high level of strain, For example, Schulz and Beach reported that after 4 years of follow-up, participants who were providing care and experiencing caregiver strain had mortality risks that were 63% higher than noncaregiving controls; caregivers who did not report subjective strain did not show elevated mortality (Schulz & Beach, 1999). Thus, alleviating the stress of caregiving and preserving the mental health of family caregivers may have implications for their physical health and risk of premature mortality.

Social Support and Emotional Well-Being of Family Caregivers

Stress theory suggests that the size of the effect that caregiving has on psychological well-being is determined not only by the characteristics of the caregiver and the objective extent of the primary stressors but also by subjective factors, principally the caregiver's appraisal of the situation as challenging or harmful and by whether he or she has adequate resources, including social support, for coping with the stress (Lazarus & Folkman, 1984). While behavior problems associated with AD have a major impact on family caregivers, considerable individual differences have been reported in caregivers' reactions to these problems (Haley et al., 1987; Teri et al., 1992; Zarit, Todd, & Zarit, 1986). Thus, one caregiver may view a problem such as asking the same question over and over again as a minor annoyance, while another caregiver will find this behavior to be extremely upsetting.

The number of people who are providing social support does not appear to have an effect on caregiver depression. Rather, it is the quality of support from family and friends that is related to depression among caregivers (Roth, Mittelman, Clay, Madan, & Haley, 2005). Criticism or upsetting interactions with family and friends is related to a higher risk while positive support is related to a lower risk of depression. Family conflict is more prevalent among these caregivers than among other caregivers (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999), perhaps because caring for people with dementia is so emotionally demanding.

While cognitive and functional decline associated with AD can severely affect the quality of life of family members, they often are reluctant to seek assistance. Some family caregivers feel they can or should provide all the care for their ill relative alone. Many family caregivers expect their relatives to know the kind of help they need and to offer it without their having to ask. Others are unwilling to accept help or try to hide their relative's illness. However, as the symptoms of the disease become more severe, it becomes more and more difficult to include the person with AD in social activities. As a result, family caregivers, and the relatives for whom they care, can become increasingly socially isolated if they shoulder the burden of care alone.

Ironically, the more disturbing the behaviors of the person with dementia, the less help and support the caregiver is likely to receive from family members and friends (Clyburn et al., 2000). Thus the caregivers who needed help the most receive the least, potentially increasing their risk for depression.

How Can Psychosocial Interventions Help Family Caregivers Cope with the Emotional Consequences of Caregiving?

Stress and coping models proposed in the Alzheimer's disease caregiving literature (e.g., Haley et al., 1987; Pearlin, Mullin, Semple, & Skaff, 1990; Schulz, Gallagher-Thompson, Haley, & Czaja, 2000) and general stress and coping theories (e.g., Lazarus & Folkman, 1984) suggest that by improving caregivers' ability to cope and master the caregiving situation, and by enhancing support, it would be possible to avoid or ameliorate the negative emotional consequences of caregiving. Research in the past two decades has given empirical support to this hypothesis, and suggested that psychosocial interventions can be effective treatments for the emotional and mental health consequences of caring for a relative with AD. While there are effective pharmacological treatments for clinical depression, for the many family caregivers who suffer from symptoms of depression insufficient for a clinical diagnosis, psychosocial interventions may be more appropriate. These interventions may reduce the risk of symptoms increasing to a clinically significant level and do not have the disadvantage of potential unwanted side effects. For those with clinical depression, psychosocial interventions can be of additional, or perhaps synergistic, benefit when used with medications.

Studies of psychosocial interventions to improve mental health outcomes, most notably depression but also anxiety and anger, have reported modest to moderate success. The degree to which these interventions have had demonstrated effectiveness appears to depend on many factors, including the intensity and type of intervention (Schulz et al., 2002). The diversity and variability in caregiver problems suggest that interventions that provide a range of services designed to improve family support and provide group support to alleviate the burden of caring for relatives with AD can have the greatest impact on caregiver well-being (Kennet, Burgio, & Schulz, 2000; Zarit, Orr, & Zarit, 1985). It seems reasonable to presume that psychosocial interventions that provide individually tailored education, counseling, skills training, and support over long periods of time would be most effective, given the duration of the illness and its emotional impact.

While many intervention studies have not demonstrated improvements in mental health of caregivers, a meta-analysis of psychosocial interventions for caregivers of relatives with dementia showed that they have, on average, small but meaningful effects on reducing burden and depressive symptoms (Pinquart & Sörensen, 2006; Sorensen, Pinquart, & Duberstein, 2002); among studies reviewed, psychoeducational and psychotherapeutic interventions were the most consistently effective.

Interventions that included both supportive and cognitive components appeared to be of greatest value in improving psychological well-being (Cooke, McNally, Mulligan, Harrison, & Newman, 2001). Generally, these interventions focused on emotions, isolation, difficulties managing behavior problems, and reducing the physical burden of care. They also strove to alter caregivers' appraisals of their ill relative's behavior by improving knowledge, beliefs and skills related to caregiving (Hepburn, Tornatore, Center, & Ostwald, 2001).

Individual interventions appear to be more effective than group interventions. They are more flexible and are therefore better able to address each caregiver's specific needs. They can also take place at a time and place most convenient for the caregiver, which is an important consideration for those who must find alternative supervision for the person with dementia who may not safely be left alone.

Examples of Interventions with Proven Efficacy

Some researchers think that it is best to develop interventions for caregivers with significant psychological morbidity. Others think that it will be most useful to take a preventive approach and develop interventions for all family caregivers of people with AD, since the illness is so stressful that it appears to cause diagnosable mental illness, particularly depression, among significant numbers of people who had no prior history of such illness.

Examples of Studies of Interventions to Help Caregivers Whose Emotional Distress Is Sufficient for a Diagnosis of Depression

In a study to compare two treatment modalities (Gallagher-Thompson & Steffen, 1994), a large proportion of caregivers of relatives with dementia who satisfied diagnostic criteria for a depressive disorder derived a clinically significant reduction in symptoms of depression from both brief (16–20 sessions) psychodynamic therapy and brief cognitive behavioral therapy. Results of the study suggested that psychodynamic therapy was more effective when the patient was in the early stages of dementia, while cognitive/behavioral therapy was more effective later in the caregiving career. This difference may be a reflection of the greater number of problem behaviors in patients in the middle stages of dementia that require an adjustment of attitude towards the patient and strategies for behavior management.

Another small randomized controlled trial of an intervention based on a cognitive–behavioral family intervention model also had a positive impact (Marriott, Donaldson, Tarrier, & Burns, 2000). All participants were diagnosed as psychiatric cases on the General Health Questionnaire (GHQ; Goldberg, 1978) at intake. The intervention consisted of 14 sessions divided into three components—caregiver education, stress management, and coping skills training. Each component was designed for the individual caregiver, based on his or her understanding of the illness, appraisal of the patient's behavior, and personal coping style. The intervention significantly reduced depression and psychiatric caseness on the GHQ; only 3 of the 11 caregivers in the intervention group were still cases at follow-up.

Examples of Interventions to Help Caregivers, Regardless of Psychological Morbidity, Withstand the Emotional Distress of Caregiving

One of the first interventions to demonstrate efficacy was developed in Australia in the late 1980s and included an intensive 10-day training program as well as periodic booster sessions and access to the services of a counselor. The availability of excess inpatient beds at a psychiatric facility made it possible for caregivers and patients to receive the intensive portion of the intervention while residing in the hospital. The main focus of the intervention was on training caregivers in problem solving and coping skills. The intervention responded to individual needs by making a counselor available after the formal training period for further advice. This study, in which caregivers were followed for many years, demonstrated the efficacy of the intervention to reduce caregiver stress. Moreover, an analysis of data covering an 8-year span after enrollment showed that caregivers who received the intervention were able to keep patients at home significantly longer than those who did not (Brodaty & Gresham, 1989; Brodaty, McGilchrist, Harris, & Peters, 1993). This study was extremely innovative and valuable as a demonstration of the possible benefit of psychosocial intervention. However, because of the residential aspects, it might be too expensive to replicate in other settings.

The REACH II intervention was evaluated in a large, multiethnic sample in five cities in the USA, with more than 600 caregivers. The intervention consisted of 12 in-home and telephone sessions over 6 months. Outcomes were measured at enrollment and at a 6-month follow-up. While the results differed by ethnic group and relationship of the caregiver to the care recipient, the intervention had an overall positive effect on quality of life, defined as a five-dimensional construct that included depression, burden, self-care, and social support and care recipient problem behaviors. In this study, the prevalence of clinical depression at follow-up was significantly greater among caregivers in the control group than among those in the intervention group (Belle et al., 2006). Because the study had only one follow-up assessment, the potential long-term efficacy of the REACH II intervention is unknown.

The NYU Caregiver Intervention (NYUCI) was evaluated in a randomized controlled trial, which was funded by the NIH from 1987 to 2010. The goals of the study were to investigate the effects of counseling and social support on the well-being of spouse caregivers of people with AD, and on the length of time they were able to care for them at home. The intervention was designed to enhance social support for the caregiver over the entire course of the illness, with a special emphasis on family support. The study enrolled 406 caregivers over a 9½-year period. There is no other longitudinal study that has followed such a large number of dementia caregivers participating in an intervention study for such an extended period of time. The study had an unusually high retention rate. Only 4.7% of caregivers refused to continue in the study while the patient was still living at home. Interview and questionnaire data were obtained at regular intervals whether the person with dementia lived at home, in a nursing home, or was deceased. Assessments continued for 2 years after the patient died.

Caregivers who participated in the NYUCI study were randomly assigned to an enhanced care treatment group or a usual care control group at intake. Those who were in the treatment group received two individual and four family counseling sessions within 4 months of intake, agreed to join support groups that met weekly, and could request what we named “ad hoc” counseling — continuous availability of counselors to caregivers and families by telephone to help them with new symptoms and the many crises associated with the disease. The structured counseling sessions occurred within a fixed period after caregivers enrolled and before the first follow-up assessment.

A priority of all aspects of the intervention was to increase the adequacy of support for the caregiver while still assuring that the caregiver's expectations were realistic. The focus of the individual and family counseling sessions was on diminishing the negative aspects of family involvement with caregiving, while enhancing the positive supportive aspects. Counselors also provided resource information and referrals for auxiliary help, financial planning, and management of patient behavior problems.

The NYUCI is unique in several ways. One innovative component of the intervention is the systematic involvement of other family members in addition to the spouse caregiver. Another unusual aspect of the intervention is that it is not time limited. Caregivers can access support and counseling for an unlimited time, whether the patient is at home, in a nursing home, or deceased.

While the primary aim of the NYUCI is to improve formal and informal social support for the caregiver, it also provides education for caregivers and family members, and strives to engender understanding of the abilities and limitations of the person with the illness and an accurate appraisal of problematic behavior resulting from the illness. The methods used in the intervention are documented in detail in *Counseling the Alzheimer's Caregiver, A Resource for Health Care Professionals* (Mittelman, Epstein, & Pierzchala, 2003). Web-based training for prospective counselors is being developed and should be available by 2014.

The intervention has demonstrated efficacy. It improved the spouse caregiver's satisfaction with his or her social network within 4 months of entering the study. It also had a significant effect on depression; the difference in number of symptoms of depression (as measured by scores on the *Geriatric Depression Scale* Brink et al., 1982) between caregivers in the usual care control group and those in the enhanced care treatment group gradually widened, and were statistically significant by 1 year after enrollment (Mittelman et al., 1995). After 1 year, 29.8% of caregivers in the enhanced treatment group had symptoms of depression sufficient for a possible diagnosis of clinical depression, compared with 45.1% of those in the control group (Mittelman, Roth, Coon, et al., 2004). Caregivers in the control group became more and more depressed while those in the treatment group remained the same. This suggests that, for most caregivers the intervention, rather than reducing depression, acted as a preventive treatment. The intervention had equal impact on depression in female and male caregivers, despite the fact that female caregivers entered the study considerably more depressed than male caregivers, on average. Of special interest is the continuing impact of the intervention. The improvements in depression in the group receiving counseling and support compared to those in the control group were still detectable more than 3 years after the caregivers enrolled in the study (Mittelman, Roth, Coon, et al.). The effects of the intervention on depression lasted through the nursing home placement and death of the person with dementia, even though these transitions may have occurred years after the six individual and family counseling sessions (Gaugler, Roth, Haley, & Mittelman, 2008; Haley et al., 2008). This finding makes it clear that a sustained intervention with an array of services (counseling, support, and ad hoc intervention) is critical in reducing depressive symptoms in caregivers.

The effects of the intervention on depression and reaction to behavior problems were largely through improving the caregiver's satisfaction with social support (Roth et al., 2005). Individuals in the enhanced treatment group reported higher levels of satisfaction with their social support network over at least the first 5 years after enrolling in the study than those in the support group. Higher levels of emotional support, more visits, and having more network members to whom they felt close were all individually predictive of improvement in social support network satisfaction (Drentea, Clay, Roth, & Mittelman, 2006).

We also measured personality traits using the NEO personality profile (Costa & McCrae, 1992). We found that more neurotic caregivers had higher levels of depression than those who were less neurotic, and were more likely to become increasingly depressed over time (Jang, Clay, Roth, Haley, & Mittelman, 2004). Nevertheless, regardless of the level of neuroticism, the intervention was equally effective in managing depression, helping the more neurotic caregivers avoid increasing levels of depression and reducing the symptoms of depression among caregivers who were less neurotic. This suggests that even caregivers with difficult personality traits may benefit from individualized interventions such as the one developed at NYU.

The NYUCI also had significant and substantial effects on caregivers' reactions to the problem behaviors associated with the illness, despite the fact that it did not have any effect on the frequency of the behaviors themselves (Mittelman, Roth, Haley, et al., 2004). The stress involved in caring for a relative with AD has a cumulative effect over time, increasing the risk of both morbidity and mortality. The caregiver's appraisal is a key intervening variable linking stressors and negative outcomes and deserves greater attention as a target of interventions.

The NYUCI had a small but significant effect on self-rated health of the caregivers and on the number of new illnesses they reported (Mittelman, Roth, Clay, & Haley, 2007). Most spouse caregivers are older adults, and many are vulnerable to the negative consequence of the prolonged role of caring for a husband or wife with dementia. Taken together, the effects of the NYUCI on stress, depression, and physical health suggest that supportive interventions can have a substantial impact of the cost of these negative outcomes to the health care system.

The NYU study also demonstrated that counseling and support enable caregivers to postpone or avoid placing their relatives with dementia in nursing homes (Mittelman, Ferris, Shulman, Steinberg, & Levin, 1996; Mittelman et al., 1993; Mittelman, Haley, Clay, & Roth, 2006). In the most recent analysis, published in 2006, which included all 406 participants and modeled the risk of nursing home placement for 12 years after entry into the study, the estimated median difference between the treatment group and the control group in time from enrollment to nursing home placement was 557 days. Improvements in caregivers' satisfaction with social support, reduced number of symptoms of depression, and response to behavior problems of the person with dementia collectively accounted for 61.2% of the intervention's beneficial impact on placement (Mittelman et al., 2006).

Psychosocial Interventions Currently Widely Available to Caregivers of Relatives with Alzheimer's Disease

Support groups for people who are caring for relatives with AD have become increasingly available. Some are led by health care professionals and others by trained volunteers. There are many support groups that are affiliated with the local chapters of the Alzheimer's Association. While research suggests that interventions such as support groups, when used alone, generally do not lead to significant improvements in depressive symptoms (Bourgeois, Schulz, & Burgio, 1996), they provide other benefits to many caregivers. They can provide a continuing source of emotional support. They make it possible for caregivers to meet with others who are in the same situation. Sometimes it is easier to reveal negative emotional reactions to peers one can expect to empathize than to discuss them with family and friends who the caregiver fears may condemn them for these feelings. Caregivers can also learn techniques to cope with specific problems that have worked for others who have had them.

Educational workshops, have been conducted for many years under the auspices of the Alzheimer's Association and elsewhere, and have helped caregivers cope with the ongoing burden of caregiving that can lead to depression and/or burnout. In recent years, recognizing that the needs of caregivers for counseling and support are unpredictable and may occur at any time, the Alzheimer's Association has been providing access to a telephone helpline, 24 h a day, 7 days a week.

As a result of the research that has demonstrated the effectiveness of psychosocial interventions in the management of chronic diseases such as AD, there is beginning to be an awareness of their value. A Web site, the National Registry of Evidence-Based Programs and Practices (NREPP), is maintained by the Substance Abuse and Mental Health Services Administration. In recent years, federal funding has been made available to states through the Alzheimer's Disease Supportive Services Program of the Administration on Aging, for demonstration projects to make evidence-based interventions available to the community. Other funding sources are encouraging further research to improve existing interventions and to develop and evaluate new ones. These efforts should increase public awareness of the importance of supportive psychosocial interventions.

Summary and Conclusion

Alzheimer's disease is one of the most feared illnesses associated with old age. It slowly robs its victims of cognitive and functional capacity, independence, and dignity. Family members are generally loath to remove relatives with AD from their homes, but find it very difficult to provide adequate care without enormous emotional cost to themselves. Those who ultimately choose to place their relatives in nursing homes do not necessarily experience a reduction in stress. While depression is the most frequently studied outcome of caregiving, anxiety, anger, sadness, and even disgust are emotions experienced by many people who are caring for relatives with AD.

Psychosocial interventions can alleviate many of the emotional consequences of caregiving. Education and counseling can make caregivers aware of the causes of their relatives' symptoms, the probable course of the illness, how to interact with other family members to maximize cooperation and minimize conflict, and how to access appropriate services in the community. Family members of the person with the illness and his or her caregiver are an essential resource for emotional support and should be included, whenever possible, in supportive counseling and educational interventions. People with AD can survive for many years. Their care at home is costly, but current institutional alternatives do not provide a desirable solution for most families. The emotional cost associated with caregiving is also high, but can be reduced by providing adequate emotional and material support.

Until a cure for AD is found, the number of people who will have to shoulder the burden of caregiving can only grow, as the number of elderly people increases. Research over the past two decades has made it clear that interventions that respond to the individual needs of family caregivers, are available as needed and are not time limited, can help family members of people with AD and other chronic illnesses to withstand the emotional demands of caregiving. Estimates of the potential costs and benefits of caregiver interventions suggest that nonpharmacologic interventions, if made available, can offer significant savings to state and federal governments, regardless of the effectiveness of current drugs, and that failure to fund effective caregiver interventions may be fiscally unsound (Weimer & Sager, 2009). Widespread availability of these evidence-based psychosocial interventions can be both cost effective to the health and social care system and of enormous benefit to family caregivers and the people for whom they care.

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Chapter 3
Education, Training, and Support Programs for Caregivers of Individuals with Alzheimer's Disease

Connie Siskowski and Lisa Gwyther

Although the diagnosis of Alzheimer's disease is unique to the individual, its effects extend to every family member. The course of its journey is especially challenging because there is no single linear continuum of support over the course of care. And, there is no recipe book of care. Alzheimer's families seek information at different points in their caregiving careers or at different points in their family member's disease trajectory. Despite recognized diversity and the need to customize family support and education, most Alzheimer's families must ultimately identify and negotiate complex decisions, provide strenuous, intimate physical care, and learn to manage strong emotions, anxiety, ambiguity, and uncertainty. How this translates to practice is that education, training, and support programs must be continuously available, offered through a variety of mediums, and accessible from familiar and trusted local sources.

The Essence of Alzheimer's Family Care

Alzheimer's family care has been likened to "running a marathon without ever seeing the finish line" or "solving an equation with no constants." Paramount from the perspective of both the person with Alzheimer's disease and the caregiver is the

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knowledge that it is the individuals with whom they interact through their journey that shape their experiences (Cockerill et al., 2006). Although there are many studies of survival in Alzheimer's disease, only recently are there studies of survival among Alzheimer's family caregivers (Kiecolt-Glaser et al., 2003; Schultz & Beach, 1999).

The shift of residence from home to a facility provides no shield for the caregiver to be burden free. Studies continue to show that the majority of all nursing home residents have some form of dementia and that 70% of family caregivers continue to actively provide care. Although the direct caregiving tasks and responsibilities transfer to those responsible in the facility, the family caregiver of someone with Alzheimer's disease remains vulnerable to depression and anxiety and cardiometabolic effects with more pronounced effects among those who visit most frequently (Schulz et al., 2004; von Kanel et al., 2011).

While all family caregivers need information, education, training, and support, the identification of families who are most at risk for negative caregiving consequences should be the logical focus of professionals. Prioritization assists in the allocation of limited resources. Among Alzheimer's disease family caregivers who are most likely to be at risk are those who: (a) are older than 50 years of age, (b) have low income or low education, (c) perceive no choice in their caregiving role, (d) co-reside, and (e) provide a high level of care as evidenced by the amount of time spent caregiving and the extent of caregiving tasks, especially hands-on activities of daily living (Gwyther, 2005).

As the composition and complexities of families in the USA are changing, there is a growing emergence of children who are caring for family members with Alzheimer's disease. The first national study of this issue shows that the top diagnosis among 1.4 million caregiving youth is Alzheimer's disease (National Alliance for Caregiving [NAC] & United Hospital Fund [UHF], 2005). Children and grandchildren who are fulfilling this role are also at risk with interruptions in their education, missing school/after school activities, and/or not completing their homework (Siskowski, 2006). Although there is a paucity of research about caregiving youth in the USA, studies of "young carers" in the UK show that these children have an average age of 12 years, and incur negative ramifications of caregiving that mirror the adult family caregiver's physical, psychological, and financial caregiving consequences (Ryan & Fox, 2003).

Evidence for and Limits of Caregiver Education and Training

There are unique challenges in the care of an individual with dementia for which no one person is fully prepared prior to the experience. How family members react, their capacity to fulfill specialized care roles, and their responses to the caregiving role may ease the burden on the one family member who has the most responsibility. The need for caregiver education arises at the onset of diagnosis and may minimize and/or prevent multiple negative consequences of caregiving including immunosuppression, coronary heart disease, hypertension, anxiety, depression, exacerbation of chronic illnesses, and even premature death that may be related to hyperproduction of IL-6 among caregivers of persons with dementia. IL-6 is a proinflammatory cytokine that is typically associated with age-related conditions. The production of IL-6 was four times greater among stressed caregivers (Kiecolt-Glaser et al., 2003).

Research findings and meta-analytic studies of the effectiveness of caregiver education programs conclude that they have modest effects on knowledge about services, improvement of caregiver psychological and social well-being, and caregiver problem-solving abilities (Fortinsky, Kercher, & Burant, 2002). Multicomponent programs of caregiver support and education hint at cost effectiveness with findings of delayed institutionalization and reduced use of health care services (Brodaty, Green, & Koschera, 2003; Mittelman, Haley, Clay, & Roth, 2006).

Although there has been increasing attention to educating the general population about memory disorders and care using multimedia presentations, it does not appear that increasing public awareness with information about Alzheimer's disease is effective in building an education base and then translating the knowledge to understanding the person with the condition. A qualitative study of family caregivers conducted by Paton, Johnston, Katona, and Livingston (2004) indicates that the behaviors of individuals with Alzheimer's disease are thought by the majority of family caregivers to be in their control. The behaviors of persons with dementia can be understood as "unmet needs", anticipated, and "managed," but not necessarily "controlled"; this is the focus of most dementia caregiver education programs. When the caregiver accepts that there is no blame, shame, or stigma, it may be easier to overcome the traditional barriers to accepting warranted external help and home services prior to, and in the prevention of, caregiver exhaustion.

Educational Materials as a Form of Alzheimer's Family Support

The Alzheimer's practice literature supports the largely intuitive value and supportive benefits of education programs and materials (Toseland, 2004). Educational materials have the advantage of staying power with the potential for broad dissemination. They are published in a variety of media and formats that can easily be reproduced, downloaded, viewed, and passed among family caregivers, casting a broader net than programs that require time commitment, effort, or physical attendance. Educational materials in the public domain increase awareness of the issues, can be re-read or referenced as needed, and are available in multiple mediums for diverse audiences, such as the Internet-based "Powerful Tools for Caregiving" for use in the workplace.

There are comprehensive, well-indexed, and regularly updated practical books about Alzheimer's family care that range from *The 36-Hour Day* to *Learning to Speak Alzheimer's* for general audiences, to books targeting adult children, such as *Alzheimer's Solutions.* There are DVDs, interactive Web-based programs, free online video clips on driving from the Alzheimer's Association or from Terra Nova, brochures, pamphlets, newsletters, webcasts, and Web sites that focus on a range of family caregivers and family care contexts.

The reader or recipient of the information typically dictates the medium, content, and dissemination strategy. For example, adult children caregivers may seek educational materials on the Internet (www.aarp.org/caregive) or the Alzheimer's Association Carefinder (www.alz.org/carefinder) that assists in finding local options and knowing appropriate questions to ask. Public awareness documentaries, such as the *Complaints of a Dutiful Daughter* (1994) or *The Forgetting* (2008), have staying power. These resources are quite different from an earlier, equally effective fotonovella, *What is Happening to Abuelito?*, an Alzheimer's Association bilingual booklet for low-literacy, multigenerational Latino audiences that is illustrated in a culturally competent and appropriate soap opera story format.

The National Institute on Aging (NIA) has also produced valuable public references such as Caring for a Person with Alzheimer's Disease: Your Easy-to-use Guide from the National Institute on Aging (2009) and two attractive low-literacy booklets titled *Understanding Memory Loss* and *Understanding Alzheimer's Disease* (2006). Similarly, Journeyworks Publishing offers a low-literacy cartoon-style 1995 guide, *Caring for a Person with Memory Loss and Confusion: An Easy Guide for Caregivers.* There are topical books or brief pamphlets addressing identified major concerns of Alzheimer's families. Examples include NIA's English and Spanish 2002 booklets, *Home Safety for People with Alzheimer's Disease*, The Hartford's At the Crossroads: Conversations about Alzheimer's Dementia and Driving and The Calm Before the Storm: Family Conversations about Disaster Planning, Caregiving, Alzheimer's Disease and Dementia (2009) or AARP's 2003 free booklets in English and Spanish, *Steps to Success: Decisions About Help at Home for Alzheimer's Caregivers.* There are first-person narrative accounts with advice specific to spousal caregivers: *Your Name is Hughes Hannibal Shanks* (1996) and *A Curious Kind of Widow: Loving a Man with Advanced Alzheimer's* (2006); for adult children caregivers, The Alzheimer's Action Plan: A Family Guide (2009); and for young children, *When Meme Came to Live at My House* (1998) and *What's Happening to Grandpa*? (2004).

Although there is little research or evaluation of the use or behavioral impact of these materials, the sheer numbers of books (1,300) found on Amazon.com or links (2.48 million) at Google.com under "Alzheimer's care," the marketing hype about the number of hits on Alzheimer's personal and informational websites, and the burgeoning number of television and radio documentaries on this topic indicate that these materials are being widely disseminated. It is up to the consumer to determine the reliability and accuracy of information.

What is missing from the evidence base for practice in Alzheimer's care are specific protocols, guidelines, or evaluation tools to provide assistance in the selection of the right materials for a specific family. Each family approaches Alzheimer's disease with a different set of experiences; psychosocial, religious, and cultural norms; and literacy levels that complicate the care context. These factors impact the decision of the preferred intervention at a particular time or teachable moment along the caregiver's and/or care recipient's continuum or care trajectory.

Educational Interventions

A randomized controlled trial in four Alzheimer's demonstration states used an individualized family education intervention focused on targeting and dosing information so as not to overwhelm Alzheimer's family caregivers (Gitlin & Gwyther, 2003). Although findings from this study are unpublished, it is apparent that a shotgun approach to giving families a little bit about all aspects of Alzheimer's care at one point in time is probably not effective.

There are several ways to deliver or provide education for Alzheimer's caregivers (Toseland, 2004). Professionals can provide one-on-one teaching in the home (Cocoran, 2003); use a monograph, *Practical Skills Training for Family Caregivers*, from the National Center on Caregiving, Family Caregiver Alliance; or combine individual and family counseling and training from a health or human service agency base (Mittelman, Epstein, & Pierzchala, 2002; Mittelman et al., 2006). In these in-home or agency settings, counseling and education are offered in the context of service provision.

Education can be offered equally well in the framework of care coordination or case management programs (Austin, Chernesky, Gwyther, & Grube, 2000). In addition, the Alzheimer's Association and the National Chronic Care Consortium's care management project demonstrated excellent results from education offered in the context of chronic disease management (Bass, Clark, Looman, & McCarthy, 2003).

Caregiver education is also a major component of psychoeducational, time-limited, skillbuilding group interventions (Hebert et al., 2003; Toseland, 2004); community workshops or educational forums; community lecture series followed by discussion; and technology-based interventions, such as telephone-mediated groups (Bank, Arguelles, Rubert, Eisdorfer, & Czaja, 2006), computer-mediated groups, and videoconferencing. Furthermore, a dual form educational technique using telephonic coaching with a videotape series has proven to be successful for caregivers of individuals with Alzheimer's disease (Steffen & Mangum, 2003).

There have been other types of educational and intervention strategies, including an objective driving skills evaluation that can help both the care recipient and caregiving family make decisions about ongoing driving capabilities. These evaluations are available through memory disorder centers, occupational therapy programs, and in some states, the Division of Motor Vehicles. The testing includes neuropsychological components as well as the use of simulators in non-road tests. The impartiality of these tests assists the clinician to respond to the questionable reliability of caregiver requests for the person with Alzheimer's disease to cease driving (Reger et al., 2004). Thus, an independent resource along with professional clinician guidance assists all members of the family care team to make the important decision of when to stop driving. No longer driving a car, even though it is for safety reasons, is the equivalent to loss of independence and a signal of disease progression. It becomes a challenging, unrelenting, and uncomfortable issue for many caregiving families. Assurance of alternative affordable transportation may ease this crucial transition (A useful video is “Into the Other Lane: Driving and Dementia,” from Terra Nova Films 2010).

A role of the clinician, health care provider, or other professional caregiver is also that of a family educator, providing guidance as the disease progresses, and the line becomes finer for caregiver discernment about the ability of the person with Alzheimer’s disease to engage in the decision-making process and make informed decisions. Research shows there is a marked lack of accuracy in the caregiver’s ability to judge the capability of the care recipient to make decisions (Hirschman, Joyce, James, Xie, & Karlawish, 2005). Thus, the health care provider should offer education to assist caregivers in the assessment of both driving and other decision-making capabilities.

A Wide Variety of Support

The need for support services varies with the caregiver and family context; this includes employment status and preillness caregiver strength and resiliency. Among adult family caregivers, 73% report that praying is their greatest source of strength in helping them to cope (NAC & AARP, 2004). A qualitative study among both Catholic and Protestant caregivers of spouses with Alzheimer’s disease shows that spirituality and religion are an important source of support in coping with the stressful situation of caregiving (Stuckey, 2001). Providers who are involved with families in which there is a caregiving youth should be cognizant that the young person may not have a solid spiritual foundation upon which to draw inner strength and, therefore, may require access to counseling, spiritual resources, and/or education to learn coping skills.

By caring for themselves, family caregivers for persons with Alzheimer’s disease can concurrently benefit their care recipient. There is substantiation for improvement in care recipient mood as well as postponed nursing home placement when female caregivers of persons with Alzheimer’s disease improve their own mental health and physical well-being through exercise and dietary programs (King, Baumann, O’Sullivan, Wilcox, & Castro, 2002). In addition to better levels of fitness, the caregiver also shows improvement in sleep as a result of these interventions. Moreover, there is concomitant reduced psychological distress that is of mutual benefit to both the individual with Alzheimer’s disease and the family caregiver.

There is a broad spectrum of support services available to caregivers of persons with Alzheimer’s disease to augment their inner strength and fortitude. Each modality incorporates different objectives and offers unique features to address specific caregiver concerns or needs. A service may be as simple as a 24-h, 7-day-a-week toll-free help line that provides comprehensive information about in-home evaluation, care management, skillbuilding, fitness training, chore services, education, injury prevention, stress management, day care, respite services, and other topics.

The Alzheimer's Association 24-h Contact Center provides immediate access to skilled social workers who speak almost 40 different languages. The mere existence of a growing number of for-profit and nonprofit support services speaks to the recognition of and response to a need by both corporate America and various governmental agencies.

Over 20 years ago, callers to a help line service that specializes in Alzheimer's disease made an average of nearly four requests. They sought advice about home, day care, and support group services, as well as for general dementia information (Coyne, 1991). Today, these services still exist and are augmented by others, including those utilizing technology. The effective use of technological advances reduces the cost of care from the more expensive yet traditional one-to-one personal counseling intervention.

An automated interactive voice response intervention that was designed to assist caregivers of persons with Alzheimer's disease and disruptive behaviors is an example of a one tested form of support. The array of services provided include (a) telephonic stress monitoring and counseling, (b) information, (c) personal voice mail connections to dementia care specialists, (d) a voice mail telephone support group, and (e) a distraction call for the person with Alzheimer's disease. In an evaluation of this program, findings showed that women in the intervention group who had not yet mastered the skills of managing a loved one with this illness and caregivers with the highest levels of anxiety benefited the most from this modality (Mahoney, Tarlow, & Jones, 2003).

Marziali and Donahue (2006) documented the use of Internet-based psychosocial intervention. They provided information, videoconferencing, email communication, and facilitated on-line sessions for older caregivers of persons with neurodegenerative diseases. The results demonstrated a significant reduction in stress between an intervention group and a control group. Although the sample size was small and the control group experienced a 54% dropout after 6 months, the study provides evidence to support the use of technological support for these family caregivers. A pragmatic advantage to this approach is its convenience for the family caregiver, offering flexibility and ease of access in the comfort of home.

Each study reflecting new technologies or support services points to the need to use a targeted, individualized approach to address the family's health status and the caregiver's capabilities. The utilization of professional care managers to facilitate family involvement in the development of a care team approach, individualized guidance, recommendations for home safety, and local resources, including respite, is valuable for both the person with Alzheimer's disease and the caregiver. Care managers, located through the National Association of Professional Care Managers, may be hired privately or be offered through community resources. Alzheimer's family consultants, who are available through regional programs, also serve valuable roles as a sounding board, trusted advisor, and a referral resource for caregivers.

Support groups are among the most common types of activities to assist, educate, and empower family caregivers, and yet many caregivers do not participate in them. Caregivers who have never attended a support group rate themselves as less burdened than caregivers who have attended a support group, and have adequate personal support systems (Martichuski, Knight, Karlin, & Bell, 1997). Caregivers who do not attend support groups cite convenience as a primary reason. Virtual group caregiver support, available for all levels and types of caregivers, continues to evolve as technology advances and Internet usage and comfort with its security and capacities increase. Virtual groups address barriers to participation and also provide a resource for caregivers in rural areas, where in-person access is limited.

The REACH II (Resources for Enhancing Alzheimer's Caregiver Health) project, supported by the NIA, evaluated the effectiveness of a structured multicomponent intervention adapted to diverse individual risk factors and found that it could increase caregiver quality of life and reduce caregiver depression (Belle et al., 2006). This and other studies support the wisdom of matching caregiver needs to a skills oriented multicomponent intervention responses (Gitlin, Hauck, Dennis, & Winter, 2005; Gwyther, 2005).

In other parts of the world, including the UK and Australia, caregiver assessment is standard practice in the health and human services delivery systems. Evaluation results help to prioritize resource allocation. There is a global need for family caregivers to be able to continue in their role; no country has either the labor pool or financial resources to replace family caregivers if they were to abandon their commitment. There are current policy recommendations in the USA to encourage a shift to a similar practice by implementing national caregiver assessment (Feinberg, Wolkwitz, & Goldstein, 2006). Without a focus on a caregiver's capabilities or well-being, when there is a need for home care services, the health provider looks to how the family caregiver can assist in the accomplishment of health care related tasks rather than first evaluating the caregiver's capability and capacity. This expectation, without support for the caregiver, especially for the older spousal caregiver, may result in harm.

A study conducted in the UK was inconclusive on the relative effectiveness of individualized assessment and support, conventional personal support vs. technology-based support (computers or telephones), specific caregiver training, or multifaceted support strategies (Thompson & Briggs, 2000). However, the research cites the challenges of gathering specific outcome data because of the plethora of variables. Thus, there is neither a recommendation of one type of intervention over another, nor is there any evidence to discontinue a specific type. A multinational analysis reports that there are no universally recognized successful interventions to effectively reduce caregiver burden (Torti, Gwyther, Reed, Friedman, & Schulman, 2004).

People, and older learners in particular, can reach a level of understanding when stress is minimal and when they have the opportunity to practice in a non-threatening environment, such as the home. Sometimes simple environmental adaptations can increase the ease of day-to-day caregiving and household tasks. Gitlin et al. (2005) studied an occupational therapy intervention using six in-home sessions to assist families in space, efficiency, and safety changes to help the daily functioning of the person with dementia. The program demonstrated diminished caregiver burden at a statistically significant level ($p<0.05$). Follow-up therapy via telephone and an additional home visit were also part of the treatment plan. Evaluation was done at 6 and then at 12 months to determine the permanency of the changes. Results show somewhat effective maintenance of change; however, there was a need for more frequent professional contact and ongoing skill education.

The well-being of the caregiver is critical in the evaluation process as well as in the provision of assistance. As reported by Zanetti, Geroldi, Frisoni, Bianchetti, and Trabucchi (1999), a caregiver who is burdened perceives a poorer status of the patient and vice versa. More recent studies suggest a strong correlation between the caregiver's well-being and the patient's competencies in daily living activities (Berger et al., 2005). As deficits in independence as well as behavioral disturbances increase over time, the caregiver burden/depression intensifies. Thus, the practitioner must be aware of the caregiver's status –to fully evaluate the caregiver's reports of patient functioning, accompanied by information, education, and guidance based on the caregiver's needs at the time.

The provision and the use of regular respite by family caregivers is among the most needed of support services for persons caring for individuals with Alzheimer's disease. Respite can be obtained through a family/friend care team, volunteer services, adult day centers, paid in-home help, and through short- or long-term facility placement. Two keys to establishing successful respite care are to begin it early in the Alzheimer's care journey and to provide regular breaks. Findings indicate that in-home respite significantly reduces plasma epinephrine in stressed caregivers of persons with Alzheimer's disease (Grant et al., 2003). This reduction in epinephrine may reduce mortality among burdened caregivers.

The type of respite resources utilized should be responsive to caregiver needs and change as caregiving demands increase. The physician's encouragement of the family caregiver to utilize respite care promotes the use of this most beneficial resource, which is a strategy to maintain caregiver health and well-being.

Policy Initiatives

There are three main policy areas that should be included for future consideration regarding the education, training, and support of family caregivers: (a) promotion of the integration of health care with community support systems, (b) individual caregiver and family assessment with needs-driven flexible response, and (c) inclusion of benefits and supports for caregivers of any culture and any age.

All too often, there is no interface between the medical team and the community-based care team, which can be an extension of the clinician's eyes and ears to make more informed care decisions. Additional field input and research are needed in identifying family caregivers who are most at risk for negative health outcomes, along with the best practice packaging of individualized, multifactorial, multidisciplinary, and affordable approaches to deliver supportive interventions to persons with Alzheimer's disease and their caregivers. Such a package should include pharmacologic interventions for the person with dementia symptoms since they have been shown to reduce caregiver burden (Torti et al., 2004).

The extent of caregiver burden can influence the treatment modalities and the use of patient medications offered by the physician. In a study of individuals with Alzheimer's disease and their caregivers, Karlawish, Klocinski, Merz, Clark, and Asch (2000) found that when a caregiver's burden experience was lower, there was increasing importance of patient quality of life and the preservation of cognition and function. Thus, physician encouragement of early integration of support systems for the family caregiver and the minimization of the caregiving burden may maximize patient outcomes.

Research shows that there is a lack of consistency between what the mild-to-moderate stage Alzheimer's patients are willing to risk from a treatment perspective and what the caregiver thought the care recipient's choice for treatment would be. An informed family and an integrated family care team process with coordinated community care will promote the use of collective wisdom in creating and implementing a care plan. Policy that fosters the integration of successful education, training, and support practices avoids duplication and enhances the caregiving family experience. Health care delivery practitioners should routinely and seamlessly transition their care practice to incorporate community-based resources and maximize the family caregiving experience.

Integration of care incorporates the full spectrum of disease management along the continuum of the Alzheimer's disease journey. This occurs in concert with the family's wishes and understanding. Although there is a lower survival rate, studies shows aggressive end-of-life treatment for people with Alzheimer's disease and an acute illness at a rate comparable to people with other conditions with resultant caregiver confusion (Morrison & Siu, 2000). Health care providers who work in partnership with family caregivers can arrive at care team decisions for appropriate palliative end-of-life care.

Not only is caregiver assessment important for determining a family caregiver's present capacity and capability, it is also vital in examining the extent of preexisting health conditions. Both areas are important for identifying caregivers at greatest risk and allocating limited intervention resources. Preexisting illnesses, such as recurrent depression, cancer, hypertension, diabetes, and/or coronary disease are among those cited for their potential to increase caregiver health risk (Vitaliano & Katon, 2006).

Caregiver burden scales, or levels of care, use a formula based on time spent in caregiving and the number and types of caregiving activities that the family caregiver does. The incorporation of health parameters into these scales is logical to improve the identification and prioritization of caregivers and families at greatest risk. These factors are also critical in the development of an integrated and family-centered collaborative care approach to enhanced outcomes for both the care recipient and caregiver. They may also help a family determine which family member should or should not accept caregiving responsibilities.

Meeting the caregiving policy challenges of a nation that is rapidly becoming increasingly diverse and in which more and more youth are caregiving is daunting, including the development of neutral and universal language. The concept of support or "being there" in the room or residence with the care recipient, in addition to caregiving responsibilities and worries, warrants further research to determine caregiving effects. The Mahoney Caregiver Vigilance Questionnaire©, with its culturally neutral language, may assist in meeting needs for cultural understanding and acceptance (Mahoney, Jones, et al., 2003).

Policy makers need to consider supporting various social resources and cultural variances and expectations. There is increasing evidence in the value of using the arts as a medium of expression for people with dementia, thus providing family caregivers with an outlet not only for activity but also for communication and recognition of the capabilities of person who remains (Basting, 2006). Such mediums can bridge gaps in intergenerational care.

Although it would be potentially helpful, it is unlikely that caregiver education will become part of physician's and other health care professional's core curriculum in the near future. Communication is a two-way street. Specific programs, such as *Communicating Effectively with Health Care Providers*, offered through the National Family Caregivers Association network of workshop leaders, and the *Partnering with Your Doctor* workshop, offered through the Alzheimer's Association, are two avenues for caregivers to improve the way they hear and respond within a health care setting. The physician, who exhibits empathy, even by acting, is most likely to be an effective practitioner.

Federal policymakers are increasingly aware of the importance of supporting family caregivers and have proposed several bills to specifically assist caregivers of persons with Alzheimer's disease. These include increased funding of the National Family Caregiver Support Program, with revisions to give priority for resources for caregivers of persons with Alzheimer's disease. The Lifespan Respite Care Act signed in December of 2006 creates grants for state agencies and organizations to recruit and train respite care workers, provide respite as well as information and access to support services.

In addition, there are several bills that are pending which, if passed, would assist individuals and families dealing with Alzheimer's care. Examples include the Ronald Reagan Alzheimer's Breakthrough Act and the 2011 National Alzheimer's Project Act. The Alzheimer's Disease Supportive Services Program Evidence-Based Caregiver Interventions and Innovations Programs build on the 1993–2006 Alzheimer's Demonstration Grant to States Program to encourage the development of consumer-directed respite services, caregiver interventions and systems change activities that are responsive to Alzheimer's families. Other general caregiving bills, such as the Family and Medical Leave Enhancement Act and the Military Family Support Act, would also be inclusive of caregivers of persons with Alzheimer's disease. There is no existing bill to include education, training, or support services for a growing group of unrecognized long-term care providers: children.

What's Ahead?

Directly parallel to the rising numbers of persons with Alzheimer's disease is an increase in the numbers of family caregivers of all ages, including caregiving youth. Effective pharmacological interventions that slow disease progression contribute to an extended duration of caregiving. Technological advances are already playing a major role, and will continue to do so at a rapid pace, to increase caregiving family safety and to provide choice in the selection of therapeutic modalities that are appropriate for a particular family, and promote caregiver health. The epitome of comprehensive care is the prevention of negative consequences when caregiving for a person with Alzheimer's disease. The development of accurate assessment, evaluation, and intervention tools and services, and the determination of appropriate packages of education, skill-building, and support programs to promote the best quality of life for a caregiving family are the challenge for the future.

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Part II
Issues in Providing Quality Care

Chapter 4
Developmentally Appropriate Long-Term Care for People with Alzheimer's Disease and Related Disorders

Steven H. Zarit and Allison M. Reamy

Long-term care for older adults, particularly programs designed for people with Alzheimer's disease and related disorders, is characterized by wide extremes. At one end of the continuum are poorly run care programs and facilities that challenge the integrity of the people being served, while at the other extreme are exciting approaches that use innovative ways of providing care to people with dementia that address quality of life, not just custodial needs (see Beck, 2001; Woods, 1996 for reviews). These latter programs are of particular interest, as they advance the way we care for older adults. However, such programs often have a short life span, disappearing when funding ceases or when the people involved in their development move on. A contributing factor is the paucity of research on quality and outcomes of long-term care. Without a foundation of empirical evidence that demonstrates that these innovations are essential for the health and well-being of people with dementia, it is difficult to argue that funding should be made available to support their continuation, let alone wider adoption of their practices.

Therefore, despite the best efforts to disseminate creative solutions in dementia care, most community and institutional settings remain immune to these developments, or adopt in the most superficial way whatever the flavor-of-the-month in care happens to be, whether it be a locked unit for people with dementia, calendars on the wall, culture change, or pets and plants. As a result, much of the long-term care that older people with dementia receive falls in the middle of the continuum of care on quality. It is often uninspired, and sometimes even detrimental, to their well-being. No one in long-term care deliberately sets out to provide bad care, but lack of knowledge, skills, and resources among staff, as well as penny-wise pound-foolish

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approaches by administrators, sometimes found in the for-profit sector, have combined to keep care at a level that is at best unimaginative, and at worst fails to give sufficient attention to basic human medical and psychosocial needs. Over the years, repeated calls have been made to improve the quality of care in nursing homes and other institutional settings, and the occasional scandal will prompt short-lived flurries of investigations and reforms. Yet, while a web of state and federal regulations assures that most of the time facilities will provide a reasonably clean and reasonably safe environment, most settings provide care that often fails to rise above lackluster. The vast historic gap between platitudes and quality of care that has historically characterized long term care (Kahn & Zarit, 1974) remains as wide as ever, particularly in the subset of nursing homes cited for care deficiencies (Wunderlich & Kohler, 2001).

This chapter will explore concepts and examples of developmentally appropriate care for people with Alzheimer's disease and other types of dementia, with the goal of contributing to the discussion of how to raise the overall quality of care that people with dementia receive. We begin with an exploration of the nature of developmentally appropriate care for dementia. Next, we examine some promising approaches in community-based programs and then in institutional programs.

What Is Developmentally Appropriate Care?

The criteria for diagnosis of Alzheimer's disease and other dementias have received extensive attention over the years, with task forces and committees formulating guidelines and standards for diagnosis and patient treatment. Apart from medical guidelines, however, little effort has been made to develop standards of care, or to define developmentally appropriate care for people with dementia (see Cherry, Vickrey, Schwankovky, Plauché, & Yep, 2004, for an exception). The development of such standards is clearly a daunting challenge, since Alzheimer's disease is a moving target. People with the disease initially experience mild, insidious changes in areas of cognition; they do not differ very much in their everyday functioning from individuals without the disease. Over time, however, there is an inexorable progression, though at a rate that varies from one person to the next, until near the end there is massive, global cognitive impairment. People suffering from moderate to severe dementia typically have difficulty reasoning, and may have trouble learning and remembering basic routines. With only limited awareness of their difficulties, they may at times stubbornly resist help or assistance. They may, for example, insist they can leave their place of residence, whether home or institution, when they are no longer safe to be on their own. They may even try to exit, or they may become combative or agitated when prevented from doing so.

Developmentally appropriate care needs to reflect these changing capabilities of people with the illness in a manner that reconciles their disabilities with their remaining abilities and particularly their identity as adults. A developmental approach would take into account the person's current abilities, build on strengths, and, where possible, help each person find ways to compensate for limitations. Such personalized care would not necessarily involve fragmenting programs into ever-smaller and more refined definitions for each disease stage, but some specialization of programs and activities by severity of the illness that would tailor programming to meet specific needs of people. As the examples that follow suggest, the issue of how best to group people with dementia should continue to evolve.

Definitions of appropriate care may depend on whose perspective we use, the person with Alzheimer's disease, the family, staff at a program or facility, medical personnel, or policy makers. In initial stages of illness, evidence suggests that we can ask the individual with dementia himself or herself (Feinberg & Whitlatch, 2001; Whitlatch, Feinberg, & Tucke, 2005). However, beyond the initial manifestation of the disease, people with Alzheimer's disease, or other types of dementia, cannot be effective advocates for themselves; they are dependent on other stakeholders to define appropriate care. As Kitwood (1997) so aptly observed, the result has often been that we lose sight of the person with dementia and create environments that are dehumanizing and degrading, even while espousing noble platitudes and good intentions.

A developmentally appropriate program would be built around the perspective of people with the disease, despite this perspective being imperfectly understood. The emphasis that Kitwood (1997) and others (e.g., Brod, Stewart, Sands, & Walton, 1999; Woods, 1999) place on recognizing the personhood in those suffering from dementia has to be the guiding principle of a care system. Some specific elements of a person-centered approach include respecting the individuality of persons with dementia, taking into account their past and current preferences, respecting their personal and cultural identity, and finding ways of giving them a voice in program decisions and in their daily life (Woods). Research guided by a person-centered perspective would give consideration to quality of life as people with dementia might define it, and explore their emotional and spiritual side, rather than just cognition and behavior (Woods). As Kitwood (1997) wrote,

> Memory may have faded, but something of the past is known; identity remains intact, because others hold it in place; thoughts may have disappeared, but there are still interpersonal processes; feelings are expressed and meet a validating response, and if there is a spirituality, it will most likely be of the kind that Buber describes, where the divine is encountered in the depth of I-thou relating (p. 69).

The strength of these precepts is in the assertion that people retain a basic humanity, despite their debilitating illness. Accumulating evidence demonstrates that individuals with dementia do in fact retain a meaningful sense of self that they can articulate, particularly in early stages of illness (Reamy, Kim, Zarit, & Whitlatch, 2011; Whitlatch et al., 2005). However, the limitation to such person-centered approaches is that they do not provide a specific blueprint for how to handle a particular person or situation or how to design a program or environment. It is too easy, given the progressive cognitive difficulties of dementia, to depersonalize, medicalize, and objectify the individual. Under the pressure of a person with dementia who is agitated and threatening staff or other residents, an overworked staff person in a long-term care facility may be hard-pressed to think about the personhood or individuality of a given elder. Most people who work in long-term care would likely endorse Kitwood's principles, but the key is to develop an empirically validated set of care strategies and approaches that embody these principles at every point along the course of the disease.

The prospect for advances in medical treatment of Alzheimer's disease and other dementias means that opportunities for intervention may change in unforeseen ways. For example, if progression of the disease is slowed, it may become possible to develop a new array of interventions to maintain or enhance functioning of people with dementia and enable them to remain at home and in control of their own care for much longer periods of time. Whatever medical gains might be made, there will be an ongoing need for creating a body of practical knowledge that implements person-centered principles at the individual and program level. This approach would involve a multifaceted and multidisciplinary effort, some of which is already ongoing, to identify creative approaches for the care of people with dementia, and to evaluate those approaches systematically to determine that they are reaching their objectives. By combining innovation with careful evaluation, practice knowledge in care could be built systematically, just as in the development and evaluation of new medications. In doing so, new approaches to care can gain credibility and acceptance and lead to effective dissemination of both the principles of care and a how-to-guide for implementing those principles.

Even as the person with dementia has to be at the center of the care system, we also should not lose sight of the personhood of other important players in the care process. Family caregivers must be able to balance the demands placed on them with their own well-being. Most notably, the role and circumstances of care assistants and nurse's aides, the people who provide most of the hands-on care, need to be considered. It is hard to imagine that person-centered care could be consistently implemented when the people who deliver that care hold poorly paid positions with few benefits and minimal opportunity for career advancement.

We will now turn to discussions of developmentally appropriate care in two contexts: the community and institutions. Community-based efforts are further broken into early stage interventions and interventions in the middle and later stages of dementia. This is followed by a discussion of the specific barriers to providing developmentally appropriate, person-centered care in institutions and, despite these barriers, innovative approaches to institutional care. We conclude with a discussion of future directions in providing developmentally appropriate care for individuals with dementia.

Community-Based Programs

Early Stage Programs

Early stage intervention represents a window of opportunity to hear the voice of people with Alzheimer's disease. People whose symptoms are still mild can understand what is happening to them and reflect on their future. They may benefit from opportunities to gain information and discuss their concerns about the disease frankly with their family or with other early stage patients. They may also be able to develop plans for the future that reflect their preferences and values for the type of assistance they will receive later on in the disease (Whitlatch, Judge, Zarit, & Femia, 2006). Early stage patients themselves recognize this opportunity and have been advocating their inclusion in organizations such as the Alzheimer's Association and Alzheimer's Disease International. Heightened emphasis among physicians on making a diagnosis as early as possible will increase the need and potential for early stage programs.

Memory Club is an example of a growing number of early stage programs for community-living people with dementia and their family "care partners" (Gaugler et al., 2011; Zarit, Femia, Watson, Rice-Oeschger, & Kakos, 2004). Developed by Rice-Oeschger and Watson, Memory Club is a ten-session, psychoeducational program that includes structured topics and speakers, as well as providing time for informal discussions among participants. Each session is divided into parts, in which persons with dementia and care partners meet both together and separately. Topics for sessions includes: medical information, emotional issues around diagnosis, communication within the care partner–person with dementia dyad and with family and friends, the role of support, finding comfort and strength, community resources, and planning for the future.

Goals for Memory Club are to provide information about the disease and community resources, as well as build feelings of support as a way of dealing with the emotionally difficult problems facing each dyad. Information creates a foundation for understanding Alzheimer's disease, as well as the treatments and resources available to help people with the disease and their families. The leaders use group process to build support among participants and to address feelings and communication. The portions of the sessions when people with dementia and care partners meet separately are particularly helpful in creating cohesion and support and helping people raise issues they cannot talk about with their partner. The joint sessions, in turn, are useful for working on communication issues within the dyad, and between the dyad and their wider network of family and friends.

Another possibility in working with early stage patients is to include them in evaluations of outcomes of services and interventions. Interviews with persons with dementia and their care partners who participated in Memory Club revealed both similarities and differences in their perceptions of and satisfaction with the program (Gaugler et al., 2011; Zarit et al., 2004). Care partners gave very high ratings to all features of the program, including the quality of information provided and opportunities to exchange ideas with people experiencing the same problems. They also liked the structure of the sessions and felt they had enough time to interact with their relative. People with dementia were also very positive in their ratings of different features of the program, though they did not endorse items as strongly as their care partners. They gave their highest ratings to the leaders of the group and the information they received, and the lowest, surprisingly, to learning from other people in a similar situation and feeling understood by other group members.

Participants also completed assessments of selected areas of functioning prior to and after completing Memory Club. Care partners had no changes in mood over time, but persons with dementia reported fewer negative feelings after completion of the group (Zarit et al., 2004). In more recent work, care partners reported having increased confidence for managing memory loss and feeling better prepared for what lies ahead (Gaugler et al., 2011). The classes also prompted them to take tangible steps in planning for the future.

This example is noteworthy for a couple of reasons. It demonstrates the possibility of involving people with dementia in discussions of their disease and its implications for the future (see also Clare, 2002; Kuhn, 1998; Moniz-Cook, Agar, Gibson, Win, & Wang, 1998; Whitlatch et al., 2006). It also demonstrates the possibility of involving people with early dementia in the evaluation process (Logsdon et al., 2010; Menne & Whitlatch, 2007; Whitlatch et al., 2005). While persons with dementia gave generally positive responses to Memory Club, they also pointed out features of the programs that they did not like. The overall results show that the program has a high degree of acceptability among participants and is reaching its main goals (providing information and opportunities to discuss dementia-related issues and building support). Both care partners and persons with dementia were able to face head on the difficult issues that lie ahead for them and felt that they made gains in understanding the disease, the choices they face, and their emotional reactions. It further demonstrates the potential different needs of care partners and persons with dementia when coping with the early signs of illness. More recent evaluations have shown promising results for similar approaches (e.g., Logsdon et al.).

Community-Based Programs in Middle and Late Stages

Much of the emphasis in community-based care in the middle and later stages of dementia has been focused on family caregivers. Caregivers are often given training to reduce stress and improve their skills in managing the person with dementia. A common goal is to encourage caregivers to increase respite use. Respite can include having someone come into the home to stay with the person with dementia, or out-of-home programs such as adult day care and overnight respite. When provided in adequate amounts, respite has positive benefits for family caregivers, reducing care-related strains and improving well-being (Zarit, Stephens, Townsend, & Greene, 1998). Less work has been done, however, on the effects of respite care on people with dementia (see Zarit, Gaugler, & Jarrott, 1999, for a review). There is reason for concern. People with dementia may adapt poorly to some changes, or may reject assistance. It is not known if adverse effects would emerge during a temporary placement in overnight respite, or if a daily transition from home to adult day care might be stressful for some people. Recent work suggests that adult day care use is associated with decreases in behavior and sleep problems for people with dementia (Zarit et al., 2011), but more research that focuses on mood and quality of life is needed.

At the core of the discussion of benefits of respite to the person with dementia is the quality of programs. The challenge, of course, is that it becomes more difficult to glean preferences and concerns directly as dementia progresses. Cognitive deficits also limit the range of activities persons with dementia can participate in or that they might experience as meaningful. One of the dilemmas adult day care and other respite providers face in planning activities is how simple each activity could be without becoming demeaning or childish. The suitability of simple activities may depend on the attitude of staff. Treating clients in respectful ways and recognizing their individual preferences may go a long way in involving people with dementia in meaningful activities.

One approach to involving people with middle to late stage dementia in meaningful activities is to obtain information about their preferences from their families (Teri, Logsdon, Uomoto, & McCurry, 1997). However, such reports may not be wholly accurate, given evidence of discrepancies between caregivers and individuals with dementia when reporting on individuals' with dementia values (Reamy et al., 2011). Thus, while caregivers' suggestions are an important piece of the puzzle, there is also a need to confirm which activities are engaging and enjoyable through systematic observations of the interactions or activities that take place in a respite program. Direct observation of client–staff interactions and of client behavior during particular activities offers a window into the quality or developmental appropriateness of respite programs. As an example, Jarrott and Bruno (2003) conducted an observational study of intergenerational activities for people with dementia enrolled in an adult day care program. People with dementia exhibited more positive emotion during intergenerational activities than during other activities and compared to a control group that did not participate in intergenerational activities. There were also more person-centered interactions during intergenerational activities than during typical activities. These results suggest both the promise of intergenerational programming, and the efficacy of observational methods as a way of evaluating the appropriateness of activities.

A consistent theme in the literature is that familiar settings and activities will support remaining competencies. One innovative approach is home day care, a program developed in Scotland in which private persons invite people with dementia into their home on a regular basis (Mitchell, 1999). Activities follow a normal social pattern, for example, serving tea and lunch, conversation, games, and outings.

Community-based programs vary widely in their philosophy, programming, staffing patterns, funding sources, and available resources. State regulations address issues of safety and staffing patterns, but offer little guidance about the type of programming and activities that may be most beneficial. Despite these challenges, the examples provided in this section demonstrate programs for people with dementia that appear to work, and it would be meaningful to further evaluate, replicate, and expand such models in care.

Institutional Care

Barriers to Developmentally Appropriate Institutional Care

Care of people with dementia places special burdens on residential care settings, such as nursing homes and assisted living facilities, given the characteristics of moderate to severe dementia and the high percentage of residents in institutional care having dementia or general cognitive impairment. Individuals with moderate to severe dementia may attempt to escape the facility or may wander into other residents' rooms, and even take items from those rooms. At times, they may become agitated or combative toward staff or other residents. Their limited speech and understanding makes interactions with staff more problematic, and typical efforts to gain social control often do not work. Add to this mix staff shortages and inadequately trained staff, and it becomes clear why care in many institutional settings is at best uninspired and at worst demeaning and deficient. Implementation of developmentally appropriate care needs to address simultaneously what the standards of care in residential settings should be, as well as the reasons why new ideas for improving care are not disseminated or implemented widely. Understanding why innovations in care are not adopted and disseminated is an important step toward reform of the system.

Several factors contribute to the resistance of institutional settings to innovation. First, residential facilities often lack the resources to achieve better quality of care. Staff shortages and turnover are rife, and it challenges the most skilled and dedicated administrators to maintain an adequate number of staff. Staff training is one obvious strategy for improving the quality of care, but high rates of staff turnover dilute the potential benefits of training (Smyer, Brannon, & Cohn, 1991). Improvement in the quality of care over the long term will depend on being able to attract and retain committed, trained staff at every level. The issue of how to pay for this effort is by no means trivial, and will require considerable effort to address, particularly given the projected growth in the number of older people over the next 40 years.

But, lack of resources is only part of the problem. There is often no institutional support for change. The best facilities all seem to have a key person, whether the administrator or head nurse, who has a vision of what good care involves, and makes sure that it is implemented on a daily basis for each patient. Innovations do not have to occur from the top down, but someone at the top has to understand and support change. A critical challenge is how to attract and retain people with the knowledge, skill, and imagination to implement high quality care, as well as to train more people with a vision of what dementia care can be. One of the best places we have visited has had continuity of leadership for more than 20 years, but this stability is more the exception than the rule.

An additional barrier is that, as a result of regulation and tradition, nursing homes and some other types of residential settings are structured like mini-hospitals. Following the pattern of acute care hospitals, nursing homes are organized in a hierarchical and bureaucratic way, in which routine health care and safety needs receive the greatest emphasis, and in which there is little flexibility in the system to accommodate residents' individual preferences and choices. One notable example is the nearly universal use of shared rooms. Putting two or more people into a room comes from a hospital model; the indignities associated with a lack of privacy can be endured for a short period of time, but this arrangement makes no sense on a long-term basis.

The impact of the hierarchical, bureaucratic model in institutional settings is made most strongly on personal autonomy. Autonomy is one of the core features of personhood, yet institutional settings often act in ways that undermine the autonomy of residents. The hierarchical structure of nursing homes and other institutional settings, and the primacy given to medical and quasi-medical routines, results in a potentially high level of staff power over residents, and the staff can directly or inadvertently engage in behaviors that erode a resident's self-confidence and self-esteem (Goffman, 1961; Kahn & Zarit, 1974; Persson & Wästerfors, 2008). In this structure, residents are at the bottom of the hierarchy, and they are typically regarded as helpless and dependent (Baltes, 1994). The staff often believe that residents are unable to comment accurately on their own needs and preferences, even when objective measurement of competency indicates otherwise (Simmons & Schnelle, 2001). Furthermore, these staff members often act based on a folk logic or ritualistic perspective in care, acknowledging resident preferences only when they align with the institutional routines on hand (Persson & Wästerfors, 2008; Ulsperger & Knottneurs, 2011). Compounding the problem is staffing patterns; the individuals with the least training, nurse's aides spend the most time with residents, and those with the greatest training, nurses, and doctors spend the least time in actual contact with residents (Wunderlich & Kohler, 2001; Smyer, Brannon, & Cohn, 1988).

Parmelee and Lawton (1990) proposed that institutional care is governed by the autonomy–security dialectic. Both autonomy and security are basic needs, but the balance between them can be easily upset, particularly for frail older adults who are trying to hold onto a diminishing degree of control over what happens to them. In an institutional setting, there is an emphasis on security over autonomy. The institution will try to minimize risks by controlling personal decisions in areas such as diet, mobility, and exercise. Expressions of autonomy raise the risk of an adverse event, such as a fall. People living on their own can make decisions about how much risk to take in a particular situation, but institutional settings try to minimize these kinds of risks. Bureaucratic routines also give little opportunity for expression of personal preferences and values in areas such as diet, activities, and even sleep and waking cycles. We all uncritically accept a nursing home telling an 85-year old she cannot sleep late if she wants to, because it upsets the routines of staff, though none of us would want that for ourselves. According to Lawton and Nahemow (1973), an optimal environment is one that challenges an individual to function at his or her best. In an institutional setting, however, challenges may be seen as risky or inconvenient, with the result that residents are bored, restless, and demoralized.

These institutional practices also reinforce dependency. The pioneering work of Margret Baltes and her colleagues (Baltes & Horgas, 1997; Baltes & Reisenzein, 1986; Baltes & Wahl, 1992) found that the staff members were guided in interactions with residents by "dependency-support scripts." Detailed behavioral observations revealed that the staff was most likely to give residents support and attention when they engaged in dependent self-care behaviors, and to ignore or punish residents who were more independent or attempted to direct their own activities. Residents themselves reported compliancy with this help and not performing activities even when they were still able to do so (Wahl, 1991).

This combination of an emphasis on security over autonomy and dependency-support scripts undermines a person's remaining areas of independent functioning and competency and leads to what Kahn (Kahn, 1975; Kahn & Zarit, 1974) characterized as excess disability. This refers to a process by which a person develops greater disabilities than are warranted by his or her underlying medical conditions. Although there may be several pathways leading to excess disability, Kahn believed that the way in which institutional settings restrict opportunities for autonomous, self-directed behavior was the most dominant influence on their development. Residents who cannot exercise independence and choice in carrying out everyday activities and are reinforced for their dependent behaviors become increasingly dependent, and as a consequence, may suffer a loss of mobility and function.

These threats to autonomy, as well as the other adversities of institutional life, have a differentially greater impact on people with dementia. They are the most vulnerable, because they cannot advocate effectively for themselves, and their efforts to communicate their needs are often ignored. Despite federal guidelines, psychotropic medications remain in widespread use in institutional settings, particularly for people with dementia.

Part of the difficulty encountered in the care of people with dementia has to do with the fact that the design of the setting does not accommodate the impairments of people with dementia. The most obvious example is a locked unit. People with dementia who are mobile are often not aware of their own limitations or the need to stay within a designated area, and they might wander off. Indeed, wandering is a reason that some people end up in a nursing home in the first place. But with person–environment fit, what was previously a problem becomes potentially adaptive, since residents can get exercise and maintain some autonomy over their activity by being able to walk freely within the unit.

As noted, the dilemma has not been a shortage of ideas; rather, the typical nursing home or assisted living facility has just been remarkably slow to adopt innovations. There are institutional, cultural, psychological, and political barriers to improving institutional care. Despite extensive practice-based knowledge and the occasional research trials of innovative care techniques, it is dismaying to see how little has changed (Beck, 2001). Even simple procedures that have a direct impact on quality of life, such as prompted voiding to help people remain continent, cannot be sustained in many facilities (Schnelle et al., 2002).

Innovative Approaches to Institutional Care

Against this backdrop of low expectations, it is all the more remarkable that some innovative programs have been able to provide high quality care to people with dementia. New approaches to residential care have attempted to create settings that can accommodate the behavior of people with dementia without fostering excess disability and dependency. Many of these new programs have been guided by the concept of the therapeutic environment (Cohen & Day, 1994; Lidz & Arnold, 1990; Regnier, 1994). The therapeutic environment includes architectural design, as well as staff-resident interactions and activities. In contrast to the medical model, which is primarily oriented around medical needs and tasks, a therapeutic environment is designed to support autonomy and build upon remaining competencies of people with dementia, as well as other residents of a setting. Underlying this approach is the belief that while we can do little to change the contribution of the "person" with dementia in person–environment interactions, as just mentioned it is possible to modify the environment in ways that produces a different, and potentially better, outcome (Zarit & Zarit, 2006).

The most prominent examples of therapeutic environments are special care units for dementia. These units may be housed within traditional nursing homes or in assisted living facilities. Although there is no consensus on what constitutes "special" Alzheimer's care (Holmes et al., 1994; Maslow, 1994), some common features are typically found that address the limitations of people with dementia through environmental support or prosthetics and through program and staff training (Boling & Gwyther, 1991; Hiatt, 1991; Zimmerman & Sloane, 1999; Zimmerman, Sloane, Williams, et al., 2005). These common features can be grouped into four core and two special characteristics.

The first core feature is the use of architectural and design features that facilitate appropriate behaviors. A review of the environmental intervention literature supports the use of unobtrusive safety measures, varying the ambiance, size, and shape of spaces, providing single rooms, maximizing visual access, and providing stimulus control with periodic availability of bright lights (Fleming & Purandare, 2010). In addition, it may be beneficial to have facilities look more like a home, for example, use furnishings and decorations from the resident's own home, replace fluorescent lighting with traditional lamps and bulbs, and add plants and pets, as well as have homes be small in size, and/or provide outside space, but the evidence is a bit more limited on this front (Fleming & Purandare). An important feature that has received more attention in Europe than the USA is the use of single rooms, which increases opportunities for privacy and autonomy and removes conflict between roommates as a stressor (Malmberg & Zarit, 1993).

The second core characteristic is a program of activities that is developmentally appropriate for people with dementia. Activities are used to engage people in meaningful ways, as well as head off problems due to inactivity and boredom. Although much of the activity in residential settings is organized in groups, it is clear that some people will need to be engaged in a one-to-one situation or a group of two or three other residents at most. In a typical setting, activities often take place only during the day shift, but they should be made available during evenings and weekends as well. Activities that are familiar, such as gardening or food preparation, are more likely to engage people than tasks that are not part of well-established habits.

The third core characteristic is a trained staff and management team that understands the principles of dementia care and agrees on how to implement them. One approach is to train all staff on a unit, including dietary and maintenance personnel, to work in a therapeutic way with residents. Staff need to be selected on the basis of their ability to interact with people with dementia. Staff should also be dedicated to a unit, not rotated, because rotation creates difficulties for memory-impaired residents to sustain relationships. Staff–resident ratio is likely to be greater than on ordinary units, though there has been little research to estimate how much staff might be needed.

A fourth core element, which is not usually featured in a prominent way, is involvement of the family. Most family members who were assisting a relative with dementia in the community remain involved with that person after placement (Gaugler, Anderson, Zarit, & Pearlin, 2004; Zarit & Whitlatch, 1992). Often, families provide the same types of assistance as they had prior to placement, such as dressing and feeding. Their role within the facility, however, is ambiguous, and there is considerable potential for misunderstandings between staff and family members (Looman, Noelker, Schur, Whitlatch, & Ejaz, 2002). Programs can address this problem by viewing families as a potential asset that can contribute to care in important ways. To facilitate family involvement, however, facilities need to teach them the "rules of the game," show them how that unit functions, who performs what jobs, who to bring complaints to, and how families can be involved (Zarit & Zarit, 2006).

These core characteristics have typically been addressed in the literature, but two special features have received less attention. The first feature is how the unit addresses terminal care. As the disease progresses, people with dementia may become bedridden and need a different kind of care than what is available in a typical "special" unit, which is oriented toward the ambulatory patient. This care involves a different set of staff skills, as well as helping families make end-of-life decisions in an informed way. Some special care units move people off the unit for late stage care. This approach leads to a more efficient use of scarce resources—ambulatory residents reside in the dementia unit while bedridden residents receive more intensive nursing service. It can, however, raise concerns among family members that their relative is no longer receiving "special" care for his or her needs. Allowing people to remain in place provides continuity for residents and their families, but doing so may impose strains on staff who are oriented toward providing activities and not heavy basic care. To address this dilemma, a facility could create a "special" late stage unit oriented to the special needs and demands of terminal care in dementia.

The other special feature concerns the need for medical personnel, doctors, and nurses to have geriatric and dementia training to provide optimal care (Institute of Medicine, 2008). Such things as recognizing risks and signs of overmedication, understanding the role of behavioral symptoms in medical disease, and knowing how to provide palliative care to late stage patients are critical. The lack of good medical care can lead to excess disability in even the best-run therapeutic units.

Despite the extensive expansion of special care units, only a relatively small amount of research has been conducted that documents how well special care works compared to ordinary care settings, and which features of special care might be most important. In a pioneering study, Rovner, Steele, Shmuely, and Folstein (1996) randomly assigned residents into special care or an ordinary nursing home unit. Special care included dementia-appropriate activities, psychotropic medication management, and conducting educational rounds. After 6 months, residents in special care had significantly fewer behavior problems and lower rates of medication and restraint use than people in the ordinary unit. In another study, systematic use of psychosocial interventions was found to reduce use of antipsychotic medication by almost one half (Fossey et al., 2006).

In the largest study to date, Zimmerman, Sloane, Heck, Maslow, and Schulz (2005) examined both methodological issues in assessing quality of life of residents receiving dementia care and differences between assisted living and nursing homes. Findings suggest that type of setting (assisted living/nursing home) had less effect on outcomes than specific features of the settings. Among factors related to better quality of life were the use of specialized workers for dementia care, better training of staff in dementia care, more involvement of staff in care planning, and more encouragement of residents to engage in activities (Zimmerman, Sloane, Heck, et al.).

Many initiatives in residential care in this country have drawn upon models developed in Europe, particularly the UK, the Scandinavian countries, and the Netherlands (Regnier, 1994, 2002). One such model is the Swedish group home for dementia (Malmberg, 1999; Malmberg & Zarit, 1993). This approach has many features similar to special care units, but it differs in important ways. Facilities are typically small, consisting of five to seven residents in a unit, with two units typically linked together (e.g., on different floors of the same building) to facilitate sharing of staff. Residents' apartments open to a common area where there are kitchen, dining, and recreational areas. Activities are built around typical home and leisure tasks, such as setting a table and loading a dishwasher. Staff ratio is very high by United States standards—one staff member for every three residents during the daytime, one to five or six in the evening, and one to ten at night. The most notable difference, however, is the effort to preserve residents' autonomy. A resident signs a lease for an apartment in a group home. Legally, the apartment belongs to the resident, and he or she may go inside and shut and lock the door. Each person, of course, has his or her own apartment, which is furnished and decorated with the resident's own belongings. As with other dementia programs, definitive evaluations of group homes have not been conducted, but observation of the facilities suggests that residents are able to function well in this setting, with few behavioral disturbances (Malmberg & Zarit). Unfortunately, this model is being phased out, partly due to cost concerns, but also as a result of a shift in philosophy away from small-scale and dementia-specific units.

A similar model has emerged in the USA, the Green House. The Green House project seeks to alter both the structural and operating features of a medical model nursing home and improve the person-centered quality of care. In many ways the model mirrors the small group homes in Sweden with six to ten residents in a facility living in private rooms that enter to a common living space (the Convivium). However, it takes on some distinct characteristics and is not restricted wholly to individuals with dementia, but rather provides nursing level care for any elder with such a level of need. Homes are built in towns, or cities, within neighborhoods, taking on the shape of the surrounding residential communities (e.g., free-standing home or apartment complex), and are run independently with a small direct care staff entitled the Shahbazim, meaning "universal workers." The traditional hierarchy of staffing personnel in nursing homes is flattened. Staff members are certified nursing assistants who have received training for their new role; they manage menu planning, meal preparation, laundry and light housekeeping, personal care, and communications with clinical team, families, and the community. The staff provides care 24 h a day with a staffing ratio of 4 h of care per elder per day. Additionally, a clinical team works with the Shahbazim and provides care as required. Further, there is a Guide who acts as a coach to the Shahbazim, helping with operations and ensuring quality of services in one or more homes. Lastly, there is also a Sage who is a local elder volunteer who acts as a coach, mentor, or trusted advisor to the Shahbazim, assisting with development and continued growth of the self-managed care team. Ultimately, individuals move into these homes and live the remainder of their lives within the intentional community (NCB, 2009; Thomas, 2004).

The Green House project is a relatively new undertaking, with the first homes built in 2003, in Tupelo, Mississippi (Rabig, Thomas, Kane, Cutler, & McAlilly, 2006). As a result, the evaluation of their efficacy is still underway and has only been evaluated with a quasi-experimental design (i.e., residents not randomly assigned) comparing Green House outcomes to existing institutions. However, initial findings are promising. When comparing Green House outcomes to two other nursing homes in the Tupelo area, four important empirical findings have been reported: the Green House is a feasible undertaking with environmental design features that meet the goals of the builders (Cutler & Kane, 2009; Rabig et al., 2006), it results in positive effects on elders' quality of life (i.e., autonomy, improved privacy, dignity, relationships; Kane, Lum, Cutler, Degenholtz, & Yu, 2007), it positively affects family members of elders in the homes (i.e., increased engagement; Lum, Kane, Cutler, & Yu, 2008), and it increases staff supervision and staff attention to residents by 1.5 h per day compared to normal nursing homes without increasing staff hours (NCB, 2009; Rabig et al., 2006). Although limited in scope, these results offer some compelling evidence that the Green House project is improving the person-centered quality of care for individuals with dementia, and also for other elders. Furthermore, conceptually the project appears to address the problem of quality in long-term care from a holistic perspective. The project integrates staffing changes (e.g., diminishing the hierarchy and increasing training), mandates environmental changes that elicit a more "homelike" atmosphere, and pushes the envelope of culture change. And, ultimately, such a model deinstitutionalizes the "total institution" of long-term care. However, realistically, implementing a full-scale system reform of taking down all long-term care facilities and rebuilding Green Houses is not practical. It is still a new undertaking and unclear if all residents benefit from such a form of care. Furthermore, there are gaps in how staff may systematically assess the values and preferences of adults to ensure that needs/values are being met and the model has not been fully evaluated for its effects on resident functioning. Further systematic evaluations are necessary to understand the true value of such an innovative model.

Directions for the Future

In the end, innovative programs for people with dementia in community and residential settings provide the foundation for principles and guidelines for developmentally appropriate care. Basic principles of care include:

- *Treat people with dignity and respect.* Probably everyone in long-term care would agree with this precept, but putting it into practice, particularly with people suffering from dementia, may require more clear definitions and standards than are currently available.
- *Allow people with dementia personal control and autonomy.* The paradox of locked units is that residents can have more autonomy within the unit, because it is secured. The autonomy provided in Swedish group homes goes beyond anything found in the USA. How much autonomy is needed to counteract the typical institutional pressures needs to be determined.
- *Provide structured and meaningful activities.* Despite all the rhetoric about quality of life, many programs in the community and in residential settings fail to engage people with dementia in meaningful activities. It is a challenge to devise ways of involving people with cognitive deficits and to address the variability in levels of ability within any group. Nonetheless, a well-conceived activities program represents a promising approach for improving daily life for people with dementia.
- *Provide appropriate medical care.* Modern principles of geriatric care need to be implemented on a consistent basis in nursing homes and other long-term care settings. There is nothing more discouraging to staff, residents, and families than to have a uninterested or inexperienced physician trying to deal with the complex medical problems of persons with dementia.
- *Involve the family*. Typically, the family has been an afterthought in much of the long-term care system. Integrating families and helping define their role and

participation in care can be a valuable resource to staff, as well as for persons with dementia.

- *Use the opportunity created by early diagnosis for examining developmentally appropriate care.* People with early stage dementia can give us valuable insight into their preferences and needs and help us think in new ways about how to plan care for the full course of the illness.

As has been emphasized throughout this chapter, significant barriers stand in the way of improving quality of care for people with dementia. Many committed and creative people, however, are making the effort to improve the lives of older persons with dementia. We need new ways of encouraging and supporting their efforts, as well as evaluating their programs to document what they have accomplished. Through careful evaluation of innovative projects, it will be possible to argue for increasing the resources needed to provide the right kind of care and assistance throughout the course of illness.

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Chapter 5
The Economics of Caring for Individuals with Alzheimer's Disease

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The devastation of Alzheimer's disease (AD) is well known. It robs victims of cognitive ability and eventually steals their ability to function independently. To manage this loss of independence, individuals with AD receive care from a wide variety of sources. Most patients with AD prefer to live at home for as long as possible before disease progression makes home living difficult or impossible and the patient is institutionalized. Although preference of home living and the need to curb high cost of institutionalization concur with each other, the care provided at home comes at tremendous cost to the family and friends of AD patients both financially and also in terms of human cost. Estimating the economic value of the system of care at home for the AD patient is difficult. In this chapter, we will explore economic issues associated with caring for AD patients. Models of cost estimation will be reviewed. Sources, distribution, who pays for the costs of care, and factors that affect costs of care will be discussed. The perspectives of the payer and of the caregiver will be addressed. The human costs of care and cultural differences will be explored. Early diagnosis and treatment and their effect on caregiving cost will be discussed.

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Who Provides Care for AD Patients

As estimated 5.4 million Americans currently have AD (Thies & Bleiler, 2011). The incidence of AD is expected to climb almost one million persons a year. By 2050, it is estimated that 11–16 million Americans will be afflicted with this disease. The vast majority of these AD patients live in the community. At least 80% of the care for these patients is provided by family members, friends, and other unpaid caregivers. More than half of the caregivers (56%) are over age 55, married (66%), have less than a college degree (67%), are white (70%), and live with the AD patient. More than half are the primary breadwinners of the household (55%), and nearly half are working full or part time. Because AD is strongly associated with aging, and because life expectancy is higher for women than men, more than two-thirds of patients with AD are women. Adult children are the primary caregiver of many AD patients because many spouses of AD patients are themselves elderly and cannot provide the level of care their spouses need without substantial help from their children. Traditionally, women have provided most of the care, although in recent decades, the proportion of male caregivers has increased. More than half of the AD caregivers are helping their mother (36%), mother-in-law (11%), father (8%), or father-in-law (2%) (National Alliance for Caregiving and Alzheimer's Association, 2004). In all, 26% of family caregivers have children 18 or younger living with them. These caregivers are sometimes referred to as the "sandwich generation" as they simultaneously provide care for two generations.

In 2010, 14.9 million family and other unpaid caregivers of patients with AD and other dementias provided an estimated 17 billion hours of unpaid care, representing an average of 21.9 h of care per caregiver per week (Thies & Bleiler, 2011). Compared to non-AD care, the care of AD patients is often more complicated because of issues unique to dementia, such as those arise from the impaired memory, cognition, judgment, and behavioral and psychological problems, and therefore often is more time consuming, more physically and emotionally challenging, and takes a heavier toll on the caregivers. Compared to 16% of non-AD caregivers, 23% of AD caregivers typically spend 40 or more hours a week providing care (National Alliance for Caregiving and Alzheimer's Association, 2004). Two-thirds of AD caregivers help with one or more activities of daily living (ADLs), and are considerably more likely than other caregivers to help with the most difficult ADL tasks, including dealing with incontinence (32% vs. 13%), bathing (35% vs. 25%), and feeding (28% vs. 18%).

Like other caregivers, many caregivers of AD patients (44%) are employed. Their work life often is more heavily affected than non-AD caregivers. Among non-AD caregivers, 17% report working fewer hours because of their caregiving responsibilities, 16% report having taken time off work without pay to provide long-term care, and 31% report having rearranged their work schedule (Center on an Aging Society, 2005). Among AD caregivers, while 13% report working fewer hours or taking a less demanding job, two-thirds report taken time off work without pay because of their caregiving responsibilities, and 14% report giving up work entirely or choosing early retirement (National Alliance for Caregiving and Alzheimer's Association, 2004).

The economic consequences of reductions in hours and leaving the job market are tremendous, particularly for women, as women were more likely than men to leave their jobs entirely once they began care. The amount of lost wages due to leaving the labor force early because of caregiving is estimated at $142,693 for women, compared to $89,107 for men. Women also are estimated to lose an additional $131,351 in Social Security benefits compared to $144,609 for men (MetLife Mature Market Institute, 2011).

Given the heavier burden placed on them, it is not surprising that AD caregivers often report emotional and physical problems which themselves have economic consequences. AD caregivers report high or very high levels of emotional stress (61%) during the course of caregiving (Thies & Bleiler, 2011). They are more likely than non-AD caregivers to use physician care, emergency room care. They also are more likely than non-AD caregivers to use supportive services such as transportation services (24% vs. 17%), meals on wheels (18% vs. 12%), and adult day care (16% vs. 2%). Yet, almost half of the AD caregivers who report unmet needs (44%) have not used any support services.

On the other hand, even with such demanding caregiving responsibilities, many aspects of caregiving still can be rewarding. Some studies suggest caregivers feel useful and proud, or experience personal growth or an enhanced relationship between the care recipient and other family members (Amirkhanyan, 2003).

Challenge of Valuing Caregiving

Components of Costs

Attempts to estimate total costs associated with AD caregiving must take into account all components of care, including direct, indirect, and intangible costs. Direct costs refer to expenses incurred by the health care system in treating AD or trying to prevent the onset of AD. These may include imaging, laboratory and neuropsychological tests, pharmacological agents, physician visits, inpatient care, home care, and institutional care. Indirect costs are imputed values of resources lost due to the illness, including premature deaths, patient and caregiver lost productivity, unpaid caregiving time, and time patient and caregiver spent waiting for treatment. Resources needed for the patient in additional years of life that result from treatment or interventions also must be included into the cost estimates. The assessment of the value of unpaid, informal caregiving time, often provided by family members or friends, presents serious measurement issues.

Intangible costs, those related to pain and suffering endured by patients and families, psychological burden of caregiving, and deterioration of patient and caregiver quality of life (QoL), are difficult to evaluate. There is a lack of a systematic approach to estimate intangible costs, and controversy exists as to whether they should be included in economic analyses of caregiving in AD. Nonetheless, they are a significant component in assessing total disease costs considering the scope of caregiving impact on patients and their families.

In order to allocate resources efficiently, it is critical to understand when, where, and how much is spent on managing the disease. The perspective, or the economic viewpoint from which analyses are performed, determines the range of costs included in analyses. Alternative perspectives include those from the society, public payers (e.g., Medicare, Medicaid), private payers (e.g., private insurance companies), and patients and their families. To estimate the total costs of the disease, analyses should be performed from the perspective of the society.

Assigning Dollar Value to Care Delivery

The monetary values on the resources used in caring for patients with AD have been estimated using top-down and bottom-up analyses. In both types of studies, the first steps in the analyses are identification and measurement of resources used. Top-down, also known as prevalence-based estimates, base conclusions on the number of patients served. It multiplies average per-patient costs by disease prevalence rates to arrive at an overall cost estimate. By contrast, bottom-up estimates derive total cost estimates from summing itemized expenses from measurements of each relevant resource utilized (e.g., work activity). Each type of study has its advantages and disadvantages. Studies using the top-down methods are generally less labor intensive to perform. However, prevalence rates of AD used in different analyses vary considerably, resulting in substantial variation in total cost estimates. Combining utilization and cost data from different sources requires particular care. Costs available in one data source may not correspond to categories of resources utilized in another data source. Bottom-up studies are typically time-consuming to perform, especially when complex cost items are involved. Generalizability of the results also depends critically on the representativeness of the data. However, these studies usually are more detailed. Taken together, these studies allow a more comprehensive view of the economic impact of caregiving that will generate testable hypotheses and yield information that ultimately affects public policy.

Several factors account for the considerable variability in the estimates of AD costs across studies. First, there are geographical and time differences in the pricing of medical and health care services. Analyses performed in different time periods and different geographical regions represent prices of medical services in that time period and place and may not be directly comparable. To compare results from different studies, relevant components of the Consumer Price Index (CPI) can be used to adjust for inflation across time. Purchasing power parity (PPP), which reflects the purchasing power between different economies, can be used to adjust prices across countries. However, despite corrections for geographical and time differences in computing costs, there often are sufficient intrinsic differences in costs in different times and geographic areas that make it impossible to directly compare results from different studies with reasonable accuracy. Second, diagnostic criteria differ across studies and over time. Some studies follow the International Classification of Diseases (ICD); others use the Diagnostic and Statistical Manual of Mental Disorders (DSM). Within studies that utilize DSM, different editions also have been used depending on what was current. Still other reports do not clearly identify diagnostic criteria. Differences in study methodology, e.g., study population, disease severity, and study design further increase the variability of cost estimates.

Health Utilities

Health-related quality of life (HRQoL) is an important indicator in assessing disease burden, especially for chronic diseases such as AD. HRQoL estimates the relative desirability of estimated health states, incorporating multiple domains of health perceptions, impairments, and social, psychological, and physical functioning. They can be used in cost-effectiveness analyses to inform decisions on resource allocation.

Generic preference-weighted instruments such as the Health Utilities Index (HUI) and the EuroQol have been recommended for measuring HRQoL and have been widely used in clinical studies (Gold, Siegel, Russell, & Weinstein, 1996). The HUI is a set of three recently developed classification systems that measures the overall health status and HRQoL of individuals, clinical groups, and general populations. Each system uses a generic, preference-based, multiattribute health-status classification method on a conventional 0–1 scale, with 0 indicating being dead, 1 indicating full health, and negative values indicating states that are worse than death. Each subsequent version differs from the earlier version by modifying attributes and allowing more flexibility for capturing high levels of impairment. For example, studies show that HUI3 is more sensitive than HUI2 to capture more severe stages of AD and patients' AD stage has been reported to substantially affect HRQoL (Neumann, 2005; Neumann et al., 2000). The EuroQol was developed through reviewing existing classification systems and testing in adult samples in Western Europe. It consists of five dimensions of health (mobility, self-care, usual activities, pain/discomfort, anxiety/depression), with three levels within each dimension (no problems, some/moderate problems, extreme problems) (EuroQol Group, 1990). A recent study using EuroQol to measure patients' HRQoL reported that dependency upon others to perform ADL was the main factor affecting HRQoL (Andersen, Wittrup-Jensen, Lolk, Andersen, & Kragh-Sorensen, 2004).

A criticism of the generic health state classification systems is that systems that are sufficiently general and simple to be applied across all diseases and interventions may lack sensitivity to important differences in health status that are specific to particular diseases or interventions. This shortcoming may be particularly true for AD. Several studies examined the feasibility of using general preference weighted instruments among AD patients and caregivers. One study comparing HUI2 and HUI3 found that both measures discriminate well across AD stages (Neumann et al., 2000). Compared with HUI2, HUI3 yielded lower global utility scores for patients with AD, and more scores for states judged worse than dead. Results suggest that HUI3 may yield substantially different results from the HUI2, particularly for persons who have serious cognitive impairments such as AD. Another study reported that HUI2 may not adequately capture differences in the burden of caregivers of those with AD (Bell, Araki, & Neumann, 2001). To date, generic health state classification systems have not been well validated in AD, and information on health utilities in AD are scarce. Development of condition-specific preference-weighted instruments may provide ways to better estimate HRQoL in AD.

Costs of AD and Factors that Affect Costs

Costs of AD in the Community and in Nursing Homes

Although estimated cost of AD varies substantially, common themes emerge in many studies. Regardless of living situations, most studies report a more than threefold increase in the cost of care for AD patients than those without AD (Thies & Bleiler, 2011). Among AD patients, total cost is mostly estimated to be higher for institutionalized patients than those living in the community (Oremus & Aguilar, 2011). A recent review reported an estimated annual total direct cost of $42,072 (2010 dollars) per patient for all patients with AD, compared to $13,515 for non-AD patients. Among AD patients, total direct cost was estimated at $24,250 for patients living in the community, and $68,964 for those who are institutionalized (Thies & Bleiler, 2011). Approximately two-thirds of all patients living in nursing home have some degree of cognitive impairment, including about 40% who had a formal diagnosis of AD, with the rest having mild cognitive impairment. Differences in total direct cost between community-dwelling and institutionalized AD patients are reduced when caregiving costs by unpaid caregivers for those in the community are included in cost estimations. When patients are institutionalized, much of the costs of AD caregiving shift from indirect to direct. A recent report by the Alzheimer's Associated suggests that unpaid caregivers provide an average of 21.9 h of care per week for their loved ones with AD, amount to an annual per patient cost of $13,668 if this care were valued at $11.93 per hour (Thies & Bleiler, 2011).

Medical management problems often are cited as a main reason for the higher direct costs among AD patients. Compared with non-AD patients, a greater risk of medical complications for AD patients has been linked to higher rates of hospitalizations among patients with severe AD living in the community (Albert et al., 1999; Guijarro et al., 2010). Most studies also report longer lengths of hospital stay for patients with AD (Kane & Atherly, 2000). The most common reasons for hospitalization of AD patients include syncope, fall and trauma (26%), and ischemic heart disease (17%) (Thies & Bleiler, 2011).

People with AD and other dementias make up a large proportion of all elderly people who receive nonmedical care. For example, more than a third of older adults who receive home health services and about a half of those who receive adult day care services are cognitively impaired (Hyde, Perez, & Forester, 2007). One study showed that at early disease stages of the disease, few patients use any nonmedical care; however, as patients reach mild to moderate levels of dependence, nonmedical care use began to increase rapidly and becomes an increasingly large component of AD care cost (Zhu et al., 2008).

Who Pays for AD Care?

Who pays for care differs substantially for those with and without AD and for those living in different care settings. Nearly all people who have AD are eligible for Medicare, which pays for about half of the total cost of care for beneficiaries with and without AD. In 2004, average total per person cost from all sources for Medicare beneficiaries with AD or other dementias was estimated at $42,072, almost three time as high as $13,515 for Medicare beneficiaries without AD (Alzheimer's Association, 2009). Because of the disproportionately high use of nursing home and other long-term care services among AD patients, the second largest payment source among AD patient was Medicaid, accounting for 20% of total cost of care ($8,419), almost nine times as high for non-AD patients ($915, or 7%) of their total care. For non-AD patients, on the contrary, the second largest sources of payment were from private insurance ($1,869) and out of pocket ($2,442), together accounting for 22% of the patient's total cost of care, although both were lower than their counterparts for AD patients ($2,354 from private insurance and $3,141 from out of pocket).

Among individuals with AD, care cost differs substantially by setting. In 2004, average total per person cost for those living in the community was $24,250, compared to $68,964 for those facility-dwelling beneficiaries. Much of the difference is due to the substantial differences in Medicaid payments associated with long-term care. Because of increased limitations in independent functioning that accompany progressive cognitive decline, AD patients are much more likely to use long-term care services provided in nursing homes or in the community (e.g., home care services). About half of all Medicaid beneficiaries with AD and other dementias are nursing home residents, and the rest live in the community (Thies & Bleiler, 2011). Among nursing home residents with AD and other dementias, 51% relied on Medicaid to help pay for their nursing home care. In 2004, among individuals with AD, Medicaid paid $19,772 (in 2010 dollars) for those living in a long-term care facility as compared with $895 for those living in the community (Alzheimer's Association, 2009).

The financial burden of caring for patients with AD weighs heavily on the families of the afflicted individuals and increases with disease progression. One study estimates annual out-of-pocket costs at $1,350 for persons without dementia, $2,150 for those with mild or moderate dementia, and $3,010 for those with severe dementia (Langa et al., 2004). Important components of out-of-pocket costs include premiums for Medicare and private insurance (45%) and payments for hospital, physician, and other health care services that were not covered by other sources

(31%) (Nonnemaker & Sinclair, 2011). Before the implementation of Medicare Part D Prescription Drug Benefit in 2006, out-of-pocket costs were increasing annually for Medicare beneficiaries (Neuman, Cubanski, Desmond, & Rice, 2007). In 2003, prescription medications accounted for about one-quarter of total out-of-pocket costs for all Medicare beneficiaries (Nonnemaker & Sinclair, 2011). After its implementation, out-of-pocket costs for prescription drugs for many Medicare beneficiaries were reduced. In all, 60% of all Medicare beneficiaries were enrolled in a Medicare Part D plan in 2010, and the average monthly premium for Medicare Part D is $41 in 2011, with wide variations (The Henry J. Kaiser Family Foundation, 2011b). However, the largest component of out-of-pocket costs for people with AD remains the cost of facility care. Among AD patients, compared to community-dwelling individuals, out-of-pocket costs are nine times as high for facility-dwelling beneficiaries ($21,272 vs. $2,929).

Large out-of-pocket costs for families of AD patients may result in a number of problems. These include decreased access to necessary health care services, decreased use of medications, and ultimately, decreased health status and quality of life for AD patients and their caregivers. Income and asset data are not available for people with AD or other dementias specifically, but 47% of older adults had incomes that were less than 200% of the federal poverty level in 2009 ($21,660 for a household of one) (The Henry J. Kaiser Family Foundation, 2011a). Policies that aim at reducing out-of-pocket costs for long-term care also are a pressing issue that would have considerable impact on AD patients and their families.

Factors that Affect Costs

Several important factors that influence the cost of AD have been identified in the literature. Patients' disease severity, cognition, and function have been reported in various studies to increase the cost of caring for those with AD (Hill, Fillit, Thomas, & Chang, 2006; Zhu et al., 2006a, 2006b, 2008). More recently, there is increased awareness that behavioral and psychological symptoms of dementia (BPSD) are highly prevalent among AD patients and increase both direct and indirect costs of caring for patients with AD (Beeri, Werner, Davidson, & Noy, 2002; Murman et al., 2002; Zhu et al., 2006a, 2006b). Behavioral disturbances in AD patients are qualitatively different from those in other diseases. They are frequently a source of distress for the caregivers and a main reason for institutionalization (Zarit & Zarit, 1983). Almost two-thirds of dementia patients were institutionalized because of behavioral problems such as combativeness, angry outbursts, and/or wandering (Chenoweth & Spencer, 1986).

The presence of comorbid conditions has been consistently shown to significantly increase the cost of caring for patients with AD (Frytak et al., 2008; Kunik et al., 2005; Taylor, Schenkman, Zhou, & Sloan, 2001; Zhu et al., 2006b). The effects of comorbidities are particularly important in AD patients as the majority of them have at least one comorbid condition, and as many as two-thirds have three or more comorbid conditions (Thies & Bleiler, 2011). In 2004, 26% of beneficiaries with AD have coronary heart disease, 23% have diabetes, and 16% have congestive heart failure (Alzheimer's Association, 2009). A study reported that each comorbid condition in AD patients was associated with disproportionately higher cost ($10,435) than in patients without AD ($526) (Bynum et al., 2004; Fillit, 2000; Frytak et al., 2008; Murman, Von Eye, Sherwood, Liang, & Colenda, 2007). These higher costs suggest that detecting comorbid conditions for patients with dementia is difficult, and management of the patients' comorbid conditions as cognition worsens may be compromised.

Recent studies suggest that patient dependence, conceptualized as the level of assistance required by the AD patient, may be a promising construct that integrates different domains of AD progression (McLaughlin et al., 2010). Patient dependence, as measured by the Dependence Scale, has been shown to characterize broad ranges of disease severity, to decline over time, associated with patient cognition and function, and can be easily measured regardless of care settings (Brickman et al., 2002; Stern et al., 1994). Studies also have shown that it correlates well various components of cost of care (Zhu et al., 2008). It should be noted, however, that patient dependence also is influenced by factors other than AD severity, for example, comorbid conditions, environmental factors, or level of dependence before onset of AD. Current reports of patient dependence have been based on reports by informants, in most cases the patient's primary caregiver. The validity of informant report and the congruence to assessment from independent observers is yet to be established.

Value of Caregiving Time

Family members caring for loved ones with AD allocate tremendous amount of time providing care to the patient with AD. Most of this care is unpaid for. However, it is extremely costly from the perspectives of both individual and society. The value of informal caregiving has been estimated at $10,400–$34,517 per patient per year in 1996 (Oremus & Aguilar, 2011).

Several issues arise when measuring the amount of time caregivers spend providing care. Instruments developed for measuring caregiving time often require that caregivers estimate the amount of time spent helping or supervising patients either at specific points in the day or on a typical day. Caregivers may find it difficult to quantify accurately the amount of time that is spent in caring activity, as opposed to time spent in household activities that would have demanded their attention prior to the onset of caregiving, e.g., cooking, cleaning, and grocery shopping that they may have always done. Time spent on these activities prior to the onset of caregiving should not be attributed to patient's illness (Moore, Zhu, & Clipp, 2001; Zhu, Moore, & Clipp, 2003). Categorizing time into caregiving or performing chores also may be difficult when much of the caregivers' activity is jointly performed, i.e., work done by a caregiver while care or supervision is simultaneously being provided to the patient. A more accurate way of estimating informal caregiving costs may be time and motion studies in which diaries kept in caregiver and non-caregiver control households are compared in terms of recorded time spent on household chores (McDaid, 2001).

Most of the studies to date have estimated the value of caregivers' time using either the market cost approach or the opportunity cost approach. The opportunity cost approach estimates the value of caregiver's time in its next best use, for example, an average hourly wage of individuals with similar characteristics (age, gender, education). The market price of informal caregiving is estimated by what would have been paid in the market for equivalent services (e.g., home health aide). Sensitivity analyses have often been performed using alternate wage rates such as regional or national average wage rates or minimum wages. Often the opportunity cost approach is the preferred method of estimating the costs of informal caregiving time. However, the opportunity cost approach may undervalue time for many of the caregivers who are retired, unemployed, or never have been in the labor market because their next best alternative use of time is unpaid. It also does not take into account the value of lost leisure time or of people who are retired for whom there may be no appropriate market wage data. On the other hand, market prices also may not accurately reflect caregivers' opportunity cost of time. It also disregards caregiver preferences (McDaid, 2001). One study comparing the estimated caregiving costs using both approaches suggests results using these two different methods are similar (Moore et al., 2001; Zhu et al., 2003).

A third approach to evaluate the caregivers' time is the contingent valuation method, in which respondents are asked to state their preferences, or willingness-to-pay (WTP) in a hypothetical scenario (Nocera, Bonato, & Telser, 2002). This method has been used in a number of studies in estimating the value of informal care (Konig & Wettstein, 2002; van den Berg et al., 2006). A recent study of AD caregivers from several countries suggested average willingness to pay for a 1-h reduction in caregiving time between 59 and 144 Euros per month ($73–142 per month using 2010 PPP) (Gustavsson et al., 2010). The amount the caregiver is willing to pay is associated with the caregiver's income but not necessarily with disease severity or burden. Contingent valuation method is sensitive to a number of methodological issues, including which, when, how, and to whom questions are posed (Diener, O'Brien, & Gafni, 1998). Four commonly used methods include (1) open-ended questions, in which respondents are simply asked to state their maximum WTP; (2) payment cards, in which respondent choose a maximum WTP from a range of amounts given; (3) bidding games, in which respondents are asked to accept or reject an offer, and depending on the answer the offer is either increased or decreased until the respondent states that maximum WTP is reached; and (4) dichotomous choice, also known as the take-it-or-leave-it-offers, in which the respondents are given a bid for which they can either accept or reject. The sample average of maximum WTP is then estimated by altering the bid in different groups in order to generate a demand curve for the group. The open-ended question, though straightforward, is often difficult for the respondent, especially when no guidance of the amount is provided. Responses to the payment cards are limited to those stated in the cards given to the respondents and are associated with a range bias. The bidding game has been shown to be associated with a starting point bias. The dichotomous choice method is similar to market transactions but no maximum WTP is directly obtained from the respondent and there is a risk of overestimation because of respondents' tendency to take the offer.

Another important issue in valuing caregiving time is the question of whether unpaid caregiving (i.e., informal caregiving) is a substitute or complement to formal, paid care (Nordberg, von Strauss, Kareholt, Johansson, & Wimo, 2005; Pezzin, Kemper, & Reschovsky, 1996). If formal and informal care are substitutes, then policies that lead to increased utilization (and costs) of one type of care will result in decreased utilization (and costs) of the other. On the other hand, if formal and informal care are complementary, then policies that lead to increased utilization and costs in one type of care will increase utilization and costs of the other type of service. Taken together, results in the literature are mixed, possibly because neither formal care nor informal care is a homogeneous product. Some types of formal services (e.g., help provided by a home health aide with dressing, feeding, and bathing) are similar to care provided by informal caregivers and may be a substitute for formal care; others (e.g., hospitalizations, medical care) are not and may be a complement for formal services. After institutionalization, much of the patient's care is shifted to paid facility employees. However, many informal caregivers continue to provide bedside care such as feeding the loved ones and legal and financial management.

AD caregiving represents a staggering cost to businesses. Caregivers report financial strain from having to give up work as well as personal distress about having to leave the work force. An Alzheimer's Association report on the costs to US businesses finds that the total cost for AD caregiving by employed workers to be approximately $36.5 billion dollars (Koppel, 2002). This total amount represents absenteeism of caregivers for AD patients ($10.2 billion), productivity losses associated with absenteeism ($18.0 billion), replacement costs of caregiver workers leaving their jobs ($6.3 billion), insurance for those on leave and worker replacement fees ($1.9 billion), and additional usage of employee assistance programs by employed caregivers ($63.6 million) (Koppel). The costs to businesses have not been included in most studies of AD costs and further indicate the devastating impact of AD on all aspects of society.

Human Cost of Care

Caregivers of AD face substantial difficulties socially, financially, emotionally, and physically during and after the course of caregiving (Morse, Shaffer, Williamson, Dooley, & Schulz, 2012; Schulz & Martire, 2004; Schulz et al., 2010; Smith, Williamson, Miller, & Schulz, 2011). More than 80% of AD caregivers report frequently experiencing high levels of stress and almost half report suffering from depression: although two-thirds of all AD caregivers report high levels of stress, they also report substantial amount of satisfaction associated with caregiving. Understanding the mechanisms related to caregiver burden and satisfaction and finding ways to reduce burden and enhance satisfaction are central to lowering the overall cost of AD.

A number of key characteristics of patients that influence caregiver stress have been identified, including the types of personal care tasks required, the hours of care each day, and the amount of supervision needed, and whether the caregiver lives with the patient (Torti, Gwyther, Reed, Friedman, & Schulman, 2004). Behavioral characteristics of the dementia patient have been consistently shown to be a primary source of caregiver stress, often more burdensome than patients' physical or cognitive problems. Behaviors such as aggression, agitation, and wandering are strongly associated with caregiver burden and depression (Bullock, 2004; Gaugler et al., 2011).

Caregiver burden has been reported to be associated with care recipient characteristics (e.g., behavioral disturbance), caregiver characteristics (e.g., coping ability), or external characteristics (e.g., financial resources) (Mohamed, Rosenheck, Lyketsos, & Schneider, 2010; Rymer et al., 2002). Several factors have been proposed that may mediate the degree of burden experienced by caregivers. These include caregiver personality and coping style, social support, care recipient impairment, and caregiver–care recipient relationship. It is important to understand these variables as they may directly or indirectly affect outcomes such as caregiver health and institutionalization of the care recipient. An active, problem-focused coping style has proved to be beneficial in managing the stress related to caregiving in both men and women, and has been associated with positive caregiver health outcomes over time (Gallagher et al., 2011; Gitlin, Winter, Dennis, Hodgson, & Hauck, 2010). Moreover an optimistic personality coupled with a sense of mastery has also been associated with mental and physical health in caregivers of AD patients (Hooker, Monahan, Shifren, & Hutchinson, 1992).

Caregivers' own characteristics often influence caregiver burden than characteristics of a patient's illness (George & Gwyther, 1986). In particular, female caregivers are more depressed and socially isolated than male caregivers. Younger caregivers, often daughters, are more burdened than older caregivers (spouses), as are those with less educational attainment, lower income, and less availability of assistance (Torti et al., 2004).

Considerable research has documented the benefits of social support for caregivers. Studies have shown that perceived social support may reduce both stress and sense of burden (Etters, Goodall, & Harrison, 2008; Goode, Haley, Roth, & Ford, 1998; Montgomery, Kwak, Kosloski, & O'Connell Valuch, 2011). Social participation is associated with greater caregiver life satisfaction; however, social networks can be a source of stress if they are perceived to be inadequate. A low level of social support is not only related to sense of burden, but also associated with poor physical health and increased psychiatric problems for the caregiver (Etters et al., 2008). The social support a caregiver receives may in turn be mediated by the degree of behavioral impairment in the care recipient. Social opportunities once shared as a couple may now be limited.

Care provision may affect caregivers' own health and increase caregivers' own health services and costs, and in turn make it more difficult for caregivers to provide effective care (Schulz & Sherwood, 2008). On the other hand, caregivers may also derive satisfaction from the caregiving experience. Feelings of gain or satisfaction may include elevated self-esteem, a sense of greater purpose and meaning in one's life, and heightened self-efficacy stemming from the caregiving role (Gallagher et al., 2011). A recent study found that the vast majority of AD caregivers (81%) reported both caregiving burden and satisfaction (Sanders, 2005). Only a minority (19%) reported only caregiving burden. Good caregiver/care recipient relationship (measured in terms of warmth and criticism) has been found to delay institutionalization (Karlawish, Casarett, Klocinski, & Clark, 2001; Spruytte, Van Audenhove, & Lammertyn, 2001). Caregivers who could identify at least some benefit of caregiving and those who found meaning in caregiving reported less burden and less depression (Cohen, Colantonio, & Vernich, 2002; Gallagher et al., 2011).

Considerable efforts have been made to develop a range of support services for family caregivers to reduce caregiver burden. Results of these interventions have been mixed. The most promising findings suggest that a relatively comprehensive set of support services from multiple dimensions, provided at sufficient intensity and targeted to specific needs, are more likely to produce positive effects. For example, the early studies from the Medicare Alzheimer's Disease Demonstration and Intervention Program showed that providing caregivers with case management and subsidized community services did not substantially reduce caregiver burden or depression (Newcomer, Spitalny, Fox, & Yordi, 1999; Newcomer, Yordi, DuNah, Fox, & Wilkinson, 1999). In the REACH study, one of the largest randomized trials examining effective interventions for caregivers of dementia with ethnically diverse background, caregivers in the intervention group scored significantly lower on caregiver burden after 6 months of treatment, although no single intervention demonstrated significant improvement over another (Hebert, Dang, & Schulz, 2007; McGinnis, Schulz, Stone, Klinger, & Mercurio, 2006). Findings suggest that interventions be individualized to caregivers' background and should target subgroups who may responded more favorably than others. More recent examination of specifically designed management protocol for care managers working with caregivers targeting specific areas of needs lowered burden among caregivers in the intervention groups (Montgomery et al., 2011). To facilitate the interpretation of the effects of intervention for dementia caregivers, more research is needed to establish the clinical cut points on key caregiver measures (Gaugler, Mittelman, Hepburn, & Newcomer, 2010).

Cultural Differences

The nation's racial and ethnic minority populations have been growing at much faster rates than the population as a whole. Burden from caregiving may be experienced and expressed differently among people of varying backgrounds. Increasing diversity nationally and internationally makes understanding the differences in coping with AD increasingly important. A growing body of research has examined possible differences in the way various racial and ethnic groups approach caregiving and differences in perceived burdens and satisfactions between groups (Torti et al., 2004). The consistency of findings across studies, geographic regions, cultural differences, and health care delivery systems is striking. Results show some striking consistencies in studies from various nations. For example, noncognitive, behavioral disturbances of patients with dementia result in increased caregiver burden and that female caregivers bear a particularly heavy burden across cultures. Caregiver burden influences time to medical presentation of patients with dementia, patient condition at presentation, and patient institutionalization. On the other hand, research on racial and ethnic minority caregivers suggests that between group differences may reflect underlying differences in cultural values related to caregiving, family networks, or socioeconomic status. For example, in Asian cultures where cultural norms encourage familial obligation, patients present substantially later in the course of their dementia for medical attention than in Western countries (Chow et al., 2002; Pang et al., 2002). Understanding these cultural values and potential barriers can affect the availability, accessibility, and acceptability of formal care services for different groups. To the extent that some groups may experience more burden and stress, particular attention needs to be paid to culturally sensitive programs of education and support.

Early Diagnosis and Treatment

Most patients with AD are diagnosed in primary care settings. However, delayed or missed diagnoses, particularly at early stages of the disease, are common. Many patients were not diagnosed until disease symptoms were moderate or severe, behavioral problems become pronounced, or when medical emergencies occur. About half of the patients who met standard diagnostic criteria for dementia do not have a diagnosis of dementia in their medical record (Boustani, Peterson, Hanson, Harris, & Lohr, 2003; Bradford, Kunik, Schulz, Williams, & Singh, 2009), and those who were diagnosed were more likely to already be in moderate or severe stages of dementia. One study shows that as few as 9% of patients with mild dementia were diagnosed (Bradford et al., 2009). In studies performed in academic centers, average time from diagnosis to death ranged from 6 to 9 years; however, in nonacademic clinical settings, average time from diagnosis to death was reported to be as short as 3–5 years (Fillit et al., 2006).

Studies show that although currently there is no cure for AD, the majority of patients and families prefer to be informed about the disease (Carpenter et al., 2008). Sensitive and accurate disclosure, taking into consideration of the patient and family's ethnic, cultural, religious background, may confer many benefits. It helps patients and their loved ones understand what is happening, provides an opportunity for patients and their loved ones autonomy in pursuing desired activities, facilitates management of the disease symptoms, helps families plan for the future, and may potentially reduce excess cost associated with the disease (Fillit et al., 2006).

There is evidence that pharmacological treatments for symptoms of dementia to stabilize or slow the progression of mild to moderate AD decrease the time caregivers spend helping with ADLs, reduce the stress associated with carrying out these tasks, and delay the need for institutionalization (Sano, 2004, 2010). Treatment seems to be most effective when administered early in the disease. In open-label extension studies, patients who received placebo during the double-blind phase of the clinical trials and subsequently received ChEI treatment during open-label extension phase never achieved the same level of performance as patients who received ChEI therapy throughout the study. Studies also show that interruption in treatment can result in a loss of cognition and function that may not be recoverable, or may result in the development of behavioral problems (Fillit et al., 2006; Sano, 2004, 2010). Together these studies provide evidence on the benefits of early and continued pharmacologic treatment of AD for the patient and caregiver. The effect of our current approaches on AD prevention and treating individuals prior to symptom onset on caregiving is worth noting. If individuals with amyloid who are currently healthy do not have disease symptoms for 10–20 years, and if we assume that effective disease treatment becomes available in 5–10 years, their effects on AD caregiving will only become apparent in the long run.

Concluding Thoughts

The incidence and prevalence of AD are likely to rise as the population continues to age, and the already staggering costs of caring for patients with AD in both the community and nursing homes also are likely to increase. Because of the progressive, chronic nature of AD, caring for patients with AD represents a formidable challenge to their caregivers, who must cope with the knowledge of the inevitable decline over time of their loved ones who suffer from the disease. Providing care to those with dementia may be emotionally and physically stressful. Compromised caregiver health may increase the risk of their own frailty in later life and lead to higher medical costs for the caregiver, affect their ability to continue caring for their loved ones, and institutionalization of the patient.

How caregivers cope with this stress is important when considering the economics of caregiving. On the other hand, caregivers also may derive feelings of gain and satisfaction from the caregiving experience. While less extensively studied, the presence of the positive aspects of caregiving is also important to measure in order to obtain a more comprehensive understanding of the caregiving experience. It may also be important to measure the positive aspects of caregiving from an economic point of view to the extent that resilient caregivers who experience a sense of purpose, connection, or well-being in their caregiving role may be less likely to be plagued with physical or emotional ills and less likely to institutionalize the care recipient.

These data also suggest a critical role for the physician, who needs to recognize the family members as the primary care providers and help them in that role.

The Alzheimer's Association and the aging networks are available to provide information, support, and services for families of AD patients. For most families, the caregiving role does not begin in the doctor's office or a hospital, when a diagnosis is made or a crisis occurs. However, at that point, the physician can begin to play a critical role, by assessing the family care environment, identifying the needs of both the patient and the caregiver, and making the connection between the family and the community agencies available to help.

Tax proposals which would provide important financial help to those caregivers whose loved one is their spouse or dependent for tax purposes may not reach many of the caregivers who are making significant financial sacrifices in terms of out-of-pocket expenses and reduced earnings in order to provide care. Other mechanisms, including direct funding of services for both the caregiver and the care recipient, are needed to provide the assistance and support these families need. Policies that aim at reducing out-of-pocket costs for long-term care also are a pressing issue that would have considerable impact on AD patients and their families.

The impact of AD on the caregiver is an important issue for the treatment of patients with AD. The emotional and physical toll of caring for an AD patient can increase health risks for the caregiver and increase medical costs for the household. As caregiver burden increases, patient-risk thresholds are reached sooner, and the likelihood of placement in a nursing home occurs earlier in the disease. Alleviating caregiver burden may be a factor in delaying nursing home placement. Interventions that improve patients, functional and behavioral symptoms, and thus reduce the demand for assistance from caregivers, could prove beneficial for patients, caregivers, and society. The currently available ChEIs have pharmacologic differences, and it is important to evaluate each agent's ability to reduce the burden of care. With such high stakes for families and society as a whole, it will be critical to examine the effect of ChEI therapies on caregiver burden in randomized, controlled trials of these agents.

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Chapter 6
Faith and Spirituality: Supporting Caregivers of Individuals with Dementia

Karen Meier Robinson

The number of Americans currently afflicted with Alzheimer's disease (AD) will reach crisis proportions in the future. The current number of approximately 5.4 million Americans is predicted to quadruple by the year 2047. One in eight people over age 65 have the disease, and nearly half have it by age 85. Someone new is diagnosed with the disease every 69 s (Alzheimer's Association, 2011). Caregivers face stressful challenges in providing care for relatives with dementia, as average length of caregiving exceeds 8–10 years.

The purpose of this chapter is to present a comprehensive overview of faith, spirituality, and caregiving for persons with Alzheimer's disease. Current status and future directions of spirituality and caregiving are explored, and implications for research, education, and social policy related to these concepts are identified. Conceptual, theoretical, and empirical knowledge regarding spirituality and caregiving is reviewed, integrated, and interpreted in the context of caregiving for persons with dementia. Additionally, the important role of clergy, spiritual care of persons with dementia, and racial, cultural, and ethical considerations are explored. In this chapter, the term spirituality will be used (instead of religiosity) because spirituality encompasses a more holistic concept (Pesut, Fowler, Taylor, Reimer-Kirkham, & Sawatzky, 2008; Sessanna, Finnell, Underhill, Change, & Peng, 2011).

A distinct body of research is developing on spirituality's effect on caregivers' health (Hebert, Dang, & Schulz, 2007). The concept of spirituality has evolved beyond religious considerations to encompass holistic, multidimensional perspectives that are integral to maintaining the well-being of caregivers (Farran, Paun, & Elliott, 2003). A deeper understanding of spirituality enhances the potential for professionals to identify spiritual needs of caregivers and incorporate spiritual caregiver interventions into practice.

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Current Status

Over the last 25 years, more research has focused on mind, body, and spirit interactions and their effect on caregiver health and well-being. Findings vary somewhat from study to study according to dimensions studied and measures used. Faith and belief systems have been found to influence caregivers' perceptions of health and illness and direct their perception of caregiving burden (Spurlock, 2005). Increasingly recognized among researchers, spirituality is an underexplored area related to caregiving of individuals with dementia.

Conceptual Framework

Recent literature has begun to address the importance of religious and spiritual factors in health care. However, there is considerable confusion as to the differences among terms that are often used interchangeably—belief, faith, religion, and spirituality. This confusion can cause great misunderstanding. Belief and belief systems represent the broadest concept, including religions, spiritualities, and philosophies. Faith is the intellectual and emotional acceptance of and involvement in a belief system. Religion is the formal institutionalization of a belief system. Spirituality is defined as a belief system that focuses on intangible elements that impart vitality and meaning to life events (Maugans, 1996; McSherry & Cash, 2004). Throughout history, religion and spirituality have been intertwined; in most societies, spirituality is expressed through organized religions. However, disagreement exists among researchers about the degree to which spirituality is linked to religiousness (Clarke, 2009; George, Larson, Koenig, & McCullough, 2000). The major difference between the concepts is that religion is linked to formal religious institutions, whereas spirituality does not depend upon institutional context (Pargament, 1997; Pesut et al., 2008). Thus, the distinctive character of religion is in its institutional identity and collective reinforcement.

A growing body of research has investigated the relationship of caregiving to spirituality and religion, particularly related to health and emotional well-being in caregivers (Spurlock, 2005). Operationalizing and measuring spirituality is a challenge because of the complex, multidimensional character of the concept (Berry, 2005). However, many established, well-tested scales exist to measure specific religious variables, including dimensions of religiosity (Mull, Cox, & Sullivan, 1987), intrinsic religious motivation (Hoge, 1972), and Christian and church orientation (Payne, 1982). The spiritual Well-Being Scale (Ellison, 1983) is a widely accepted, frequently used tool that attempts to provide a general measure of spirituality, addressing both its religious and existential components. With evolution of spirituality toward a more existential perspective, many scales measuring spiritual perspective (Reed, 1987), purpose in life (Crumbaugh, 1968), and self-transcendence (Reed, 1991) specifically address variables related to spirituality. For a review of literature on spiritual and religious measures used in nursing journals between 1995 and 1999, see Kilpatrick et al. (2005).

The work of Frankl (1963, 1969) is central to our current understanding of spirituality. Frankl used his experiences as a prisoner in a Nazi concentration camp during WWII to develop an existential theory that identified people as spiritual beings (Carson & Green, 1992). He proposed that the reason some persons survive difficult situations and others do not is that the survivors rise above difficulties to create meaning from the experience. The construct of "finding meaning" is rooted in the existential concept of person's ability to find meaning through suffering and rests on four assumptions (Farran, Miller, Kaufman, & Davis, 1997, p. 317). The first assumption is that people have the ability to make choices in how they see or respond to a difficult situation, such as caregiving; second is that personal and philosophical values shape a person's response to a difficult situation; third, people hold responsibility for choosing the right action and conduct. Assuming responsibility for another is doing the right thing, or doing what the situation demands, regardless of doing what one prefers on an individual level. The fourth assumption is that people have the capacity to find provisional and ultimate meaning. Provisional meaning refers to the day-to-day events that provide a sense of purpose. Ultimate meaning refers to some philosophical or spiritual power that could provide greater purpose in a difficult situation (Farran, Keane-Hagerty, Salloway, Kupferer, & Wilden, 1991; Frankl, 1963, 1978; Pearlin, Mullan, Semple, & Skaff, 1990). For some people, allowing caregiving to fulfill this sense of purpose helps them to transcend the everyday difficulties of the experience.

Reed's (1991) definition of self-transcendence includes the capacity to reach out, to extend oneself beyond personal concerns, and to take on broader life perspectives and activities in order to make meaning of life situations. Coward (1991) built on Reed's work by exploring self-transcendence in women with advanced breast cancer and in persons with AIDS (Coward & Lewis, 1993).

The most commonly used framework to guide caregiving research is the Stress/Coping Framework, which suggests that background variables, stressors, and resources determine how caregivers respond to stress (Pearlin et al., 1990). Two ways in which resource variables may influence stress outcomes are : (a) a main effect and (b) interaction or "stress moderating" models (Miller, Campbell, Farran, Kaufman, & Davis, 1995). Even the comprehensive model of caregiver distress (Pearlin et al., 1990) included a positive psychological resource variable similar to finding meaning. This positive resource, management of meaning, is a type of coping strategy consisting of a reduction in expectations, use of positive comparisons, and search for a larger source of explanation of the illness. The major difference between *management of meaning* and *finding meaning* is that *management of meaning* is primarily a cognitive process such as decreasing expectations and using positive comparisons (Pearlin et al.). On the other hand, *finding meaning* is not only cognitive in nature but also transformative in nature. Persons create meaning by transforming how they think and feel about a situation, thus creating a new way of experiencing the situation (Farran et al., 1997).

Research

The experience of caregiving for persons with AD confronts the caregiver with end of life issues. Robinson and Kaye (1994) used Reed's (1991) framework to hypothesize that relationships between spiritual perspective, social support, and depression would be stronger in caregiving wives than in noncaregiving wives. Findings provided partial support for this hypothesis. Although the Pearson correlations did not attain significance, the magnitude of the direct relationship between spiritual perspective and perceived social support was notably larger in the caregiver group. Differences were clearly evident in reference to outcome variables of depression, global satisfaction with support, and perceived availability of the support network.

Not surprisingly, spirituality has emerged in stress and coping studies as an important coping mechanism or resource for persons with chronic illness. Many studies have demonstrated the relationship between aspects of spirituality and enhanced ability to cope with stress and illness (Coward, 1991, 1994). Spiritual variables have also been found to be significant to the well-being of persons facing end of life issues (Reed, 1991). Caregivers of persons with dementia were found to rely on spirituality as a coping mechanism (Kaye & Robinson, 1994; Robinson & Kaye, 1994). Feelings of comfort and strength drawn from religious faith and practices support caregivers and promote emotional well-being (Rabins, Fitting, Eastham, & Fetting, 1990). Caregivers used prayers and religious coping frequently; they perceived prayer and trusting in God as effective coping mechanisms (Stolley, Buckwalter, & Koenig, 1999). Support was found for the hypothesis proposed by Chang, Noonan, and Tennstedt (1998) that spiritual coping influenced caregiver distress indirectly through the quality of the relationship between caregiver and care recipient. Caregivers who used spiritual beliefs to cope with caregiving had a better relationship with care recipients, which was associated with lower levels of depression and role submersion.

Robinson and Kaye's (1994) conceptual framework extended the familiar stress and coping perspective (Lazarus & Folkmans, 1984) of spirituality that is commonly invoked to conceptualize research on spirituality-related variables. The authors suggested that spiritual perspective does more than just moderate negative outcomes of the stress of caregiving. Instead, spirituality may be integral to the positive experience of caregiving. Coping conveys more of a reactive stance to stress. Spiritual perspective may transform the stressful experience to generate new and positive experiences that otherwise may not have evolved. It is limiting to view spirituality as a coping strategy and response to a stressful situation which then becomes dormant when the situation is over. Spirituality might be better understood as a basic human phenomenon that is sustained throughout life and that occurs in various observable behaviors (Reed, 1994). A variety of theoretical models are needed to explain how spirituality transforms the stressful experience to enhance well-being.

Spiritual behaviors and caregiving. Spiritual behavior has been identified in several caregiving studies as an important variable aiding caregivers who are coping with a caregiving situation. Kaye and Robinson (1994) reported that 77% of caregivers talked about spiritual matters with family/friends once per week. Additionally, 88% read spiritual-related materials once per week.

One of the most important spiritual coping resources in caregiving appears to be prayer (Gwyther, 1995; Spurlock, 2005; Stolley et al., 1999). Robinson and Kaye (1994) reported that 94% of caregivers engaged in private prayer every day. Of the caregivers, 94% thought that forgiveness is an important part of spirituality. Anger associated with grief and loss in the caregiving experience may elicit feelings of shame (Teusink & Mohler, 1984) and guilt (Rabins, Fitting, Eastham, & Zabora, 1990). A spiritual perspective becomes therapeutic when caregivers perceive forgiveness from God and reframe their caregiving as a positive experience. Spiritual perspective may affirm a sense of wholeness and well-being in the experience of caregiving (Farran et al., 2003). If spiritual care, and consequently church involvement, is increasingly seen as beneficial for people with dementia and their caregivers, a better understanding of clergy's role in caregiving appears to be vital.

Practice

A vital aspect of ministering to caregivers and persons with dementia seems to have been nearly overlooked in the literature. Several suggestions about what could and should be done by clergy in dementia care are discussed in the literature, ranging from kind words to the family after the Sunday service to the organization of extensive adult day care services. Little is known about the opinion of the clergy who are asked to put these suggestions into practice.

Role of clergy in dementia care. Theology serves as an important foundation and provides valuable guidance for chaplains providing pastoral care to persons with dementia and their families. Sapp (1999) reflects on theological doctrines found in Hebrew-Christian scriptures and traditions that can help us "see the image of God"; human nature as a psychophysical unity; the dependence of all persons upon God's mercy; the centrality of community; and God's judgment of personal worth by standards very different from those of our culture. The first and most helpful concept is human creation "in the image of God." According to Sapp (1999), the clear intention of the creation story found in Genesis was to "convey the uniqueness of human beings and their relationship to their Creator" (p. 30). Creation in the "image of God" denotes uniqueness for humans that convey special dignity and worth even for those whose cognitive function is greatly diminished.

The psychophysical nature of human beings refers to the dual nature of humans involving a body and soul. Our society places value on and views clarity of thought and the ability to perform complex cognitive operations as sources of human dignity and dismisses as useless those who are no longer able to perform such functions. Society devalues such persons and does not treat them with the respect that is due to all human beings. According to the Creation story, God affirms the goodness of humans regardless of disease.

Another characteristic our society values more highly than cognitive functioning is autonomy. Americans pride themselves in being an “independent” people. The negative side of this self-reliance is an abhorrence of dependency. From God’s perspective, we are totally dependent throughout our lives on God to sustain us. Everyone is equally dependent from God’s perspective.

The fourth basic concept is the importance of community. God sees humans not as disconnected individuals but as people linked through community and changing over time in ways over which little control is possible. The community of faith remembers for persons with dementia by continuing to treat them as God’s beloved children. In a real sense, this community will remember for them, not allowing anyone to be lost from the community of faith.

The last theological concept is related to God’s different standards. Acceptance of the gospel does not require a person to have great intelligence or wisdom, nor great wealth. Indeed, salvation cannot be earned by any means. God judges by very different standards than those in our materialistic society (Sapp, 1999).

Clergy support for family caregivers. Several studies were found on the role of clergy in dementia care concentrating on clergy support for family caregivers (Ries, 1993; Robinson, Ewing, & Looney, 2000; Stuckey, 1998). Ries (1993) and Robinson et al. (2000, a replication of Ries’s study) choose a quantitative approach, asking family caregivers to judge the appropriateness of possible aspects of pastoral involvement in dementia care. A wide range of caregiver expectations of clergy involvement in dementia care and limited satisfaction with their actual performance was observed. The main emphasis of the questionnaire was placed on caregiver perceptions of the role of clergy in dementia care. Another questionnaire attempted to examine clergy knowledge and perceptions in offering support to AD families (Robinson et al.). Findings suggested the need for more educational opportunities for clergy.

In a qualitative study, Stuckey (1998) investigated the nature of the caregiver–clergy dyad by interviewing 19 caregivers and their 18 perspective clergy or clergy groups. With regards to clergy perceptions of their role in the care of persons with dementia and their relationship with caregivers, the study focused on exploring differences among Christian denominations. Caregivers and clergy of all denominations faced difficulty in “determining when churches should become involved with the family caregiving situation” (Stuckey, p. 31). Stuckey points out “clergy did not want to become involved in parishioners’ lives unless they were invited in. however, caregivers were often ambivalent about issuing an invitation” (Stuckey, p. 31).

In doctoral dissertation, Matthes (2001) explored the role and extent of involvement of Anglican parish-based priests in the care of older people with dementia and their families. Findings indicated that priests regard the involvement of clergy in dementia care as important but only a few see it as a priority. The majority saw their role primarily as supporting the family. Some did not see a role for themselves in the care of persons with dementia at all. Of the ten areas of possible involvement in dementia presented in a questionnaire, the priests identified “contribution to the public debate about dementia, counseling, and practical help as least important” (Matthes, p. 4). Considerable differences were found in role perceptions among individual priests. Surprisingly, counseling and practical help were not viewed as important yet caregivers suffer from high rates of depression and anger (MacNeil et al., 2010).

Spiritual care among persons with dementia. Scientific investigations into the relationship between spiritual care and well-being among persons with dementia have been problematic, mainly because "quality of life" and "well-being" are difficult to measure in persons with dementia (Bond, 1999). However, anecdotal accounts of the beneficial impacts of religion and spirituality on persons with dementia have been discussed by a number of authors (Killick, 2006). Post (2000) states that "persons with dementia continue to respond to their faith and inner needs through long-remembered rituals that connect them with the present" (p. 138). Other authors have noted similar responses: "sometimes the patient who has not spoken coherently for several years will suddenly blurt out a prayer or a hymn; such deeply learned material is the very last to disappear" (Mooney, 2004; Murphy, 1997, p. 3).

Several additional articles were found that identify the importance of spirituality for persons with dementia. Richards (2000, p. 3) believes that the heart of spirituality is communicating "soul to soul" by connecting with what is still left for a person with dementia. Enhancing what remains rather than dwelling on what has been lost will aid communication. Bell and Troxel (1999) identified several positive attributes of people with cognitive impairment that focused on their strengths. Many strengths related to aspects of the spirit. For example, a person with AD may still be compassionate and concerned about others. In order to build on strengths, one must be aware of the spiritual or religious history of the person and family.

In order to connect, one must be "present," if only for a short time. Being "present" means to be "with" the person with dementia and to assume that there is something special to communicate. In order to be receptive in communication, usual expectations must be changed to a sense of valuing each moment as a gift of sharing. A smile, a touch, a nod of the head may be very meaningful communication (Bell & Troxel, 2001). In order to relate spirituality, knowing what provided a sense of purpose and meaning over a lifetime must be discovered. Richards (2000, p. 4) suggested determination of what gave a sense of meaning and purpose in the past and a focus on how that might be applied in the present. Care providers must be aware of the spiritual and religious history of the person, and family must know what spiritual practices were important to the person (Hide, 2002). How might these practices be available now as the person struggles with dementia? A spirit of gentleness and kindness remains when this spiritual connection has occurred. Care providers must remember that a message of love and concern is communicated through this gentleness of spirit.

The diagnosis of an irreversible degenerative dementia results in inadvertent negative attitudes and beliefs that "there is nothing anyone can do." Kitwood's (1997) book, *Dementia Reconsidered: The Person Comes First*, identified that a sense of hopelessness and helplessness surrounding "palliative care" can result in depersonalization or a "malignant social psychology" in long-term care (McCurdy, 1998, p. 83). This pessimistic attitude is insidious because it does not intend to create a “malignant” atmosphere. Rather, the negative philosophy (Post, 2000) resulted from staff attitudes of anxiety and lack of awareness of possible alternatives in providing care for persons with a diagnosis of irreversible decline (Higgins, 2005). The concept of palliative care may be responsible for attitudes of “keeping the patient comfortable” which translate into insensitivity and abandonment. Once solution to overcome this negative attitude was to see those who provided care as making or seeking meaning in care situations (Roger, 2006).

Education and Training

Robinson et al. (2000) found that clergy experience a lack of knowledge about care of persons with dementia and support for caregivers. A variety of training packets, information brochures, and practice guides were found to help provide this education (Ryan, Martin, & Beaman, 2005). The purpose of this material was to increase awareness about dementia among clergy and church groups and to give general advice about how to improve church-related dementia care (Gwyther, 1995; Hall, 2000; Wainright, 1995). Several articles were also found about different forms of dementia care provided by religious organizations (Stuckey, 1998; Uwakwe, 2000; Wentrobe, 1999), and two booklets were found that provided inspiring daily reflections followed by a related caregiving tip. Messages for caregivers described caregiving situations, solutions, and always included an inspirational message (Cain & Russell, 1995; Roche, 1996). Bell and Troxel (2001) elaborated on the need to see the providers of long-term care from a spiritual perspective. Care was enhanced when caregivers took care of their own spiritual needs first. Spiritual self-care involves maintaining “your own faith traditions, taking time to keep a journal, play a musical instrument or be outdoors” (p. 38). Bell and Troxel spend a substantial part of their article describing the ways in which caregiving staff can be trained, supported, and helped to maintain hope, openness, and receptivity to spending time in the company of persons with dementia. Stuckey (2003) summarized four major themes that consistently emerge regarding the role of religion and spirituality in the AD experience: (1) spiritual support for those with AD; (2) relationships as spiritual connections; (3) hope and meaning; (4) and cultural and ethnic considerations. These same themes surface whether among persons of Christian, Jewish, Eastern, or nonreligious background. More emphasis is needed on the premise that for persons with AD, the disease does not diminish the spirit (their very soul) (MacKinlay, 2002). All persons are entitled to respect, dignity, and to being offered spiritual nurturing. Topics related to spiritual care need to be included in mandatory continuing education for long-term care staff.

In her book *Forget Me Not: The Spiritual Care of Alzheimer’s Disease*, Everett (1996) notes that traditional religious services employ an abundance of cognitive-based expressions of faith (e.g., reciting scripture, listening to sermons, and responsive reading). She suggested that worship can and should be a multisensory experience using touch, music, and even nature as pathways of connection to someone with AD. For example, research demonstrated that persons with AD have a reduced capacity to detect odors (Bacon-Moore, Paulsen, & Murphy, 1999). However, the use of aromatherapy among persons with AD suggested odors can have a calming effect (Brooker, Snape, Johnson, Ward, & Payne, 1997).

Social Policy and Advocacy

Several national programs exist that hold promise to offer support to caregivers. Social policy needs to focus on strengthening these programs. One such program is Robert Wood Johnson *Faith in Action* program. *Faith in Action* programs were initiated by small seed grants to help communities meet their identified needs. The strength in *Faith in Action* programs is the flexibility and range of services and populations served by local programs. Services provided are nonmedical in nature, with the emphasis on neighbor helping neighbor.

Still another movement that may be very helpful to caregivers is the development of parish nurse programs. Parish nurses attempt to integrate faith and health in their faith group. They serve as health educators, personal health counselors, referral agents, developers of support groups, and trainers of volunteers (Biddix & Brown, 1999). Parish nursing was defined as the practice of "holistic health care" within a "faith community, emphasizing the relationship between faith and health" (Bergquist & King, 1994). Parish nursing was founded by Reverend Granger Westberg in Illinois in the mid-1980s and has been recognized as a specialty by the American Nurses Association since 1998 (Metzger, 2000). The key element that separates parish nursing from other types of nursing is the fundamental belief in the relationship between spirituality and health.

A funding problem exists for both these programs because after initial seed grants are over, both types of programs must find ways to sustain their own services long term. One way of sustaining services for both *Faith in Action* Programs and Parish Nurse Programs is to establish supportive partnerships in the community. Social policy must be directed toward facilitating and rewarding partnerships that support services and share in the cost of maintaining programs. Questions for policy experts are: How can public/private partnerships be encouraged, and how can business sponsors be solicited to assist with resource development? Program leaders must become comfortable working in partnership with others in order to maintain program services.

Future Directions

Gerontological literature and research have paid scant attention to the role of culture, ethnicity, and race in general or the effect of these variables on family caregiving practices (Dungee-Anderson & Beckett, 1992; Farran et al., 2003). Studies of religiosity among older adults invariably suggest higher levels of religiosity among African-Americans (AA), females, and older persons (Picot, Debanne, Namazi, & Wykle, 1997). With expected growth in the multicultural nature of the aging community, culture, ethnicity, and race will become increasingly important.

Race, Cultural, and Ethnic Considerations

Evidence indicates that religious involvement is central to the lives of AA. Black churches have provided social and psychological support and facilitated linkages to community health resources (Collins, 2004). AAs are frequent church attenders, have a high probability of being church members, and frequently engage in private devotional practices such as prayers and reading religious materials (Collins, Holt, Moore, & Bledsoe, 2003). Levin, Chatters, and Taylor (1995) suggested that the positive association between organizational religiosity and well-being reflects something more than the positive effects of social support and health. Religious traditions with expected public religious behavior represent involvement in distinct communities that provide existential coherence and personal integration; the affirmation of shared beliefs, values, and behaviors; and the development and commitment to special personal and communal social bonds. AA religious traditions are distinctive in continuing to play a principal role whereby religious institutions remain the focus of spiritual and secular life for Blacks. AA caregivers have reported caregiving as being more satisfying, less intrusive, and less straining than Caucasian caregivers in similar situations (Picot et al., 1997). Black caregivers also report lower levels of perceived burden and less depression (Mui, 1992). These findings may be explained by Black caregivers' ability to be more flexible and the tendency to use multiple sources of support because of multiple extended families (Collins, 2004; Dilworth-Anderson, Williams, & Cooper, 1999). Additionally, because of historical backgrounds of discrimination and deprivation, Black caregivers tend to have better coping mechanisms under adverse circumstances. The end result is that African-American's seem to have greater resistance to institutionalizing their elderly than Whites do. Collins et al. (2003) offer first-hand case studies illustrating how values and attitudes of an African-American family may be different than attitudes and values in a Caucasian family.

Future Research

Scholars agree that many dimensions exist related to religion and spirituality that need to be assessed separately. The field lacks consensus on how many and what the dimensions are. To remedy this problem, a panel was convened to identify the conceptual domains and specific measures of religion and spirituality that hold the most promise to understand the links between spirituality and health. The Fetzer Institute, in collaboration with the National Institute on Aging (NIA), has published *Multidimensional Measurement of Religiousness/Spirituality for Use in Health Research* (1997), a list of measurement tools with reliable and valid psychometric properties. Fewer than 10% of the measures reviewed by the panel included any mention of spirituality; rather, items were phrased in terms of religion. Thus, current research tends to omit an important segment of the population: persons who report they are indeed spiritual, but not religious (George et al., 2000). Two measures that assess spirituality and avoid the term religion were identified e.g., Hutch, Burg, Naberhaus, and Hellmich (1998) and Maugans (1996). Criticism about many of the measurement tools were that many were single-item measures with little psychometric assessment, lacking reliability and validity. The panel's report highlighted the need for further development and evaluation of measures (National Institute on Aging/Fetzer Institute Working Group, 1997).

Several priority areas for future research have already been identified in this paper. First, it would be very helpful to the field if a consensus was reached about a conceptual definition of spirituality and religiousness. Second, additional attention is needed in the area of measurement. Empirically distinct measures of spirituality and religiousness must be developed or both concepts must be explicitly incorporated into one instrument. These new instruments will require careful psychometric assessments for reliability and validity. Further research is needed to assess spiritual experience, as well as caregiving conditions that foster that experience. George et al. (2000, p. 113) argue that spiritual experience is the most ignored dimension of spirituality and identifies multiple questions of interest: How many people experience this transcendent state of being in the sacred? How frequently do they achieve this state? Do they experience this state while they are alone or in the presence of others? Do certain conditions facilitate this state? Is religious faith a primary route to this state? What is vitally needed is a closer link between research and practice and vice versa. Researchers need to understand the concerns of practitioners and practitioners need to understand the concerns of researchers

Additionally, we need to know more about non-Western and non-Judeo-Christian traditions. We know very little about Hindu, Buddhist, and Muslim experiences related to religion, spirituality, and caregiving. Another subgroup that merits further study is the role of spirituality among agnostics and atheists. One does not have to believe in God to be spiritual.

Future Practice

Interventions developed to promote self-transcendence in caregivers hold much promise (Teixeira, 2008). Practice experiences related to spirituality and caregiver coping suggest that psychosocial interventions designed to connect spiritual belief systems of caregivers to their caregiving experience and to their relationship with the care recipient might help diminish some of the negative outcomes of caregiving. This literature indicates a future professional role, when helping caregivers might be to gently guide them to search for meaning in life. Caregivers need assistance in transcending their burden by acknowledging that loss is an ever-present part of life (McElligott, 2010). Reed (1994) suggested that self-reflective techniques such as journaling, visualization, life review, and mediation might help the caregiver find meaning within this difficult life situation. Caregivers need time to commune with God, even if they have to escape to the bathroom or sit in the car in the driveway (Hall, 2000).

Interventions designed to use the congregation as a natural helping network to provide increased contacts with caregivers need to be given increased emphasis. Encouraging frequent church-affiliated social support, such as visits from one's faith group, might be interventions that enhance a caregiver's ability to take part in faith group activities and satisfy their spiritual needs. Services provided through faith groups, such as support groups and respite programs, may be more acceptable to caregivers than those offered by no spirituality affiliated groups (Stuckey, 1998). Using clergy, prayer, forgiveness, and spiritual reading materials as resources for caregivers may also be helpful.

Future Education and Training

Caregiver described their spiritual perspective as an important resource in the caregiving situation (Spurlock, 2005). Professionals should partner with faith groups to provide services to caregivers. Church-affiliated support and education may be more acceptable to caregivers than similar services from professionals without affiliation. An example of an outreach program might be to develop respite videos of church/synagogue services (using traditional prayers and hymns from the care recipient's early life). Volunteers could then be trained, matched with a caregiver and person with dementia in order to take the video and provide respite for the caregiver. Volunteers from faith groups might also provide education on the disease process in order to destigmatize dementia. Public education through open discussion might destigmatize dementia in much the same way that cancer has been destigmatized.

In summary, the search for meaning and transcendence in stressful caregiving situations will not be a simple or straightforward process. Potential for significant contribution exists in this area because so much effort is still needed in so many different areas.

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Chapter 7
Family Caregivers as Members of the Alzheimer's Treatment Team

Jeffrey N. Nichols

Introduction

Alzheimer's is a common disease with predictable neuropathology changes and characteristic functional declines. Family members of people with Alzheimer's disease most frequently generate the impetus for workup and diagnosis, since it is a hallmark feature of the disease that patients lack the ability to recognize their own functional decline. Following initial diagnosis, family caregivers find themselves directing a series of multiplying and complex interactions with the health care system on behalf of their afflicted relations as the disease pursues its course through complications to the finality of death. Alzheimer's disease patients are hospitalized more frequently and, when hospitalized, experience significantly longer lengths of stay than matched controls. Sixty-three (63) percent of Medicare expenditures for patients with Alzheimer's disease are for in-patient hospital care (Lyketos, Sheppard, & Rabins, 2000). More than 60% of residents in skilled nursing facilities suffer from dementia (Matthews & Deming, 2002; Rovner et al., 1990). This cognitive dysfunction (not always but primarily Alzheimer's disease) is usually the major reason for institutional care. The role of the family caregiver in this progression is pivotal, the responsibility enormous. This chapter will consider the pivotal role of the family caregiver, the shortcomings inherent in current modes of practice and reimbursement, as well as the direction of promising new approaches, and the need for ongoing research to firmly establish a justification for a major paradigmatic shift.

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Caregiver Responsibilities

Throughout the illness, family caregivers (or their surrogates, hired caretakers) assume responsibility for initiating medical care. Typically they observe new behaviors, identify anatomic or functional problems, and then seek out professional evaluation and advice. Although patients admitted to institutional health settings may have routine observation by health professionals, the vast majority of community-dwelling Alzheimer's Disease patients are not eligible for professional home care services since they are considered to have no "skilled" need (see Medicare Benefit Policy Manual Section 40.1.2 Rev 144,05-06-11). Caregivers thus must often rely on caregiver advice manuals such as the popular *The Thirty Six Hour Day* (Mace & Rabins, 2001) or caregiver support services, such as the Alzheimer's Association hotlines, to decide whether a new concern requires a new encounter with the health care system and professional caregivers.

When an appointment with a health care professional—a physician, nurse or nurse practitioner, psychologist, social worker, or rehabilitation specialist—occurs, the family caregiver is usually the source for the medical history. Due to the memory deficits that characterize Alzheimer's Disease, patients are rarely able to describe the events that preceded the encounter, much less accurately report current medications, coexisting conditions, medication allergies, family history, social history, and more. Thus the family caregiver becomes the repository of all this information, and functions as a kind of portable medical record accompanying the patient.

Besides simply supplying information, family caregivers must navigate the medical system for their loved ones. They are faced with the daunting task of making executive decisions that will result in the best possible care. The caregiver has the responsibility for choosing the sources of care, the form of insurance to pay for care, the decision for brand or generic drugs, and to decide whether a scheduled appointment will suffice or if a situation requires an emergency visit. It is the family caregiver who decides whether a new symptom, such as decreased ability to walk, should be seen by the primary physician, the neurologist, the physical therapist, the podiatrist, the orthopedic surgeon, the ophthalmologist, or perhaps the psychiatrist. The family caregiver must also negotiate with suppliers of durable medical equipment, with insurance companies, with home care agencies, with laboratories, pharmacies, and discharge planners. Sometimes the caregiver must make the decision between hospital admission and home management of a medical complication. Ultimately the family caregiver makes the decision for institutional placement when care at home has become overwhelming or impossible. Obviously, the role of family caregiver for an Alzheimer's patient is stressful. These demands generated by a complex, irrational, user-unfriendly system constitute a significant additional burden (Levine, 1999). Caregivers are frequently called on, de facto, to make medical decisions on behalf of the patient, whether they have been legally designated as health care proxy or not. While issues regarding this problem are discussed in other chapters in this volume (see Chap. 8 in this volume on end of life issues and Chaps. 9 and 10 which address ethical issues), it is important to add this significant category of interactions between the caregiver and the health care providers to the list of caregiver responsibilities.

Finally, family caregivers are generally called on to execute the care plan determined by the health care team. Whether it is timed administration of complex medical regimens, direction of an exercise program, provision of a therapeutic diet, application of topical wound dressings, or prompting voiding, the family caregiver is expected to carry out the plan of care. Often this may include tasks such as tube feeding or suctioning for which the caregiver has no prior skills or experience. Even when paid caregivers or a licensed home care agency will be performing many of these tasks, the family caregiver is still required to provide supervision.

The Traditional Paradigm

It is clear from this description that the role of the family caregiver combines functions usually performed by parents, health care workers, and the patients themselves. Nonetheless, the role of the family caregiver for Alzheimer's disease patients continues to be forced onto the Procrustean bed of the traditional Western medical paradigm. In this construct, an individual patient with a disease interacts with (in traditional medical jargon, "presents to") an individual or team of health care professionals. The patient describes his or her symptoms and the course of the disease. The professionals then examine the patient, develop a differential diagnosis, and propose a course of tests and treatments to the patient. The autonomous medical care consumer then selects among the proposed courses of treatment. Alzheimer's disease is currently understood as a progressive neurological disease characterized by stages of functional and cognitive loss and complicated by physical comorbid conditions and behavioral disturbances. These losses and behaviors are mediated by anatomic and functional changes within the brain. Various health care professionals, trained in specific aspects of diagnosis and treatment, offer their specialized knowledge and experience in the treatment of different aspects of the disease. These professionals work independently of each other within medical institutions that provide the safest and most appropriate locations for care delivery.

Caregivers are most frequently laypersons performing skilled and unskilled tasks on behalf of their family members. In terms of this paradigm it has been difficult to find a rightful place for the family caregiver. Nonetheless, the health care profession has responded to the reality of the role of the caregiver with a number of ad hoc accommodations. Conscientious and concerned professionals intermittently recognize the serious and compelling emotional needs of caregivers and attempt to offer whatever support, reassurance, education, and respite can be cobbled together. Health care teams are often well aware that in order to provide care to the patient they must deal with the needs of the involved caregiver, and attempt, under the best circumstances, to be inclusive. The caregiver is welcomed as an assistant to the team. The structural weakness in this system of unequals relating to each other is exposed when, at inevitable times of stress or disagreement, the caregiver cannot or will not follow instructions, and appears to the health care professionals as a needy obstructionist.

In accordance with this model, advice manuals for caregivers provide instructions for caregivers to communicate more effectively with the treatment team. The National Family Caregivers Association (www.nfcacares.org) has offered a "train the trainer" conference intended to teach an audience primarily composed of social workers to train family caregivers in a curriculum on effective communication techniques. Similarly, the medical literature refers to family caregivers primarily in terms of their needs (Dang, Badiye, & Kelkar, 2008; Parks & Novielli, 2000).

An excellent example of the best in the traditional paradigm is contained in the Clinical Practice Guideline on "Dementia" developed by a committee of the American Medical Directors Association. This generally admirable 25-page compendium of the best of current practice in the diagnosis and management of dementia, prepared for the Medical Directors of nursing homes, home care agencies, and hospices, contains only two references to families. In the first, family caregivers are cited as a potential source of information on the patient's abilities and disabilities (p. 8). In the second, Medical Directors are advised to instruct staff

> about detailed procedures on how to address family concerns and issues, and how to manage problematic family behaviors. Physicians should help reinforce for families the realities of the patient's underlying condition, reassure them …. Other members of the interdisciplinary team also have important roles in providing information and support (p. 18).

Similarly, in 1998, the *American Journal of Geriatric Psychiatry* (the official journal of the American Association for Geriatric Psychiatry) published a special supplement "Alzheimer's Disease Management: *The Emerging Standard of Care*." This 100-page journal was based on an AAGP consensus conference and the proceedings of that year's AAGP Annual Meeting. The discussion of primary care management states that families tend to underreport symptoms. It blames the "normal tendency … to compensate for dysfunction …" as a factor delaying "a physician's ability to diagnose the condition of dementia" (p. S35). The primary care physician is instructed to "train caregivers in effective strategies to manage behavioral disturbances" (p. S38) and to "prescribe" interventions such as caregiver support groups to maintain the health of the family caregiver. Reiterating these points, the section on psychological and behavioral interventions states, "[T]hese guidelines emphasize behavioral management of patients' symptoms and appropriate supportive therapy for families" (p. S42).

Family physicians are generally comfortable caring for Alzheimer's patients but believe that the caregiver support should come from elsewhere (Yaffe, Orzeck, & Barylak, 2008). They frequently refer patients and their families to community support services, but these tend to be formal medical services such as home health agencies and adult day care programs rather than Alzheimer's support groups, respite care, or the Alzheimer's Association (Fortinsky, Zlateva, Delaney, & Kleppinger, 2010). A 2009 Belgian review of the international research literature found that family caregivers were generally dissatisfied with the communication process and were equally unhappy with the level of practitioner involvement in dementia home management problems (Schoenmaker, Buntinx, & Delepeleire, 2009).

Unsurprisingly, the traditional paradigm is reinforced by the reimbursement structures that underlie and define the American health system. In an insurance-based system, health care services are provided to insured individuals (in managed care, referred to as "covered lives"). Even when the same insurer covers multiple members of a family, reimbursable services for Patient A can only be provided to Patient A. None of the services provided to a family caregiver, including those advocated by the expert opinions cited above, can be billed to an insurer since they were not provided to the patient. The patient, defined by the system as the individual diagnosed with the disease rather than the suffering family group, must be physically present to receive a billable service. This has produced the peculiar situation familiar to many primary physicians in which dementia patients are brought to an office visit during which their family caregiver discusses their behavior and receives instructions while "the patient" sits mute. Federal privacy regulations may endanger even these unsatisfactory encounters. Some practitioners are still concerned that the privacy regulations in HIPAA, the 1996 Health Insurance Portability and Accountability Act, preclude these discussions unless the caregiver is a legally designated health care proxy. Multiple studies have pointed to the time demands and inadequate financial rewards as major obstacles to effective collaboration between practitioners and caregivers (Schoenmaker et al., 2009).

It is apparent to all those professionally involved in the diagnosis and care of Alzheimer's patients that the traditional paradigm is inadequate. At the same time that the current care models for Alzheimer's disease are extremely expensive for an aging population and a financially stressed health care system, the current care models are poorly suited to the needs of both patients and caregivers. Hospitalization of elderly patients has been repeatedly associated in studies with functional decline of the patient (Covinsky et al., 2003). The proliferation of instructional materials and programs to train caregivers to communicate with professionals bears witness that the nature of these communications is fraught with difficulty for caregivers. That current care structures increase rather than relieve caregiver burden is borne out by numerous personal accounts and caregiver focus groups.

Where the current model has been objectively tested, it has generally been found lacking. For example, multiple studies have shown the extraordinarily limited ability of Emergency Department staffs to recognize abnormal cognitive ability, whether delirium or dementia. Other studies have extended this failure to the hospital setting itself (Silverstein & Maslow, 2006). Similarly, a study performed on the medical–surgical unit of a major teaching hospital documented the failure of physician and nursing staff to recognize acute worsening of mental status in hospitalized patients with preexisting dementia (Fick & Foreman, 2000). This is particularly significant and worrisome because the worsening often represented delirium, an ominous finding usually caused by infection, electrolyte imbalance, or medication side effect, which is associated with dramatic increases in morbidity and mortality. What is particularly interesting about this study, although not discussed in the section on implications for practice, was that family members, *without exception*, recognized the abrupt change. Professional staff failure to recognize these changes “persisted despite family members indicating they had observed a significant and abrupt change from the usual mental state … (p. 34).” The family members in this study constituted a population that was 92% female, of whom 69% were daughters, and 54% were Black. It is telling that though they came from traditionally under-respected groups, they saw clearly what the medical professionals did not.

Towards a New Paradigm

In response to the manifest inefficacy and inadequacy of existing practice, professionals in dementia care have been reaching towards a new paradigm, based on a different understanding of the nature of the illness and the role of the family caregiver. The new direction is based on a series of assumptions that begin where the old assumptions began, but proceed with a very different strategy based on a realistic assessment of the whole picture—the disease, the patient, the caretaker, and the medical system. In this model, Alzheimer’s disease is still understood as a progressive neurological disease, but concentration is shifted from the patient’s neuropathology to the patient’s functioning. Manifestations of the disease vary tremendously from patient to patient as do successful adaptations to these manifestations. Family members and those close to the patient are usually those best positioned to observe functional changes. Importantly, Alzheimer’s patients’ behaviors are purposeful and based on needs (Kitwood, 1997). Professional health care workers need to observe and evaluate these behaviors in order to respond appropriately. Caregivers who have provided hands-on care have acquired valuable and specific expertise and training in the management of the patient. They have the greatest experience with the particular individual and are often those most knowledgeable about their interpretation. In particular, caregivers have specialized knowledge of how functions, such as the activities of daily living, have been maintained.

The new model locates home as the preferred and safest place for most Alzheimer’s disease patients. Home contains objects that are already known to the patient and is the site of “overlearned” functions that can be performed through repetition of the familiar. It is *prima facie* absurd to ask and expect patients with diagnosed memory deficits to learn new systems. It follows, then, that medical institutions need to adapt to the needs of the patient, attempting to replicate, insofar as is possible, the familiar schedules and structures of a domestic setting so that patients can function at the highest attainable level. Since the caregiver participated in the creation of the home environment and is, in fact, a part of that environment, the caregiver is a pivotal member of the team that attempts to tailor the institutional context to the home setting. In this paradigm, which goes far beyond the biopsychosocial model of disease, the caregiver is a key member of a professional–patient–caregiver team. The doctor–patient relationship has been expanded *from dyad to triad*. Three case examples illustrate this point in human terms.

Case Example 1: Mrs. C.

Mrs. C. was an 80-year-old widow with advanced Alzheimer's disease, cared for at home by her two sons who lived nearby and a 24-h live in attendant. Mrs. C. had a vocabulary of three words, required assistance with all daily activities including transferring from bed to chair. She was fed a pureed diet, always spoon-fed with the same spoon. She developed pneumonia and was admitted to the hospital, where doctors suspected aspiration of food as the cause. In the hospital, she received intravenous feeding. The speech therapist was asked to see Mrs. C. but was able to perform only a limited examination as Mrs. C. refused all trials of food. She recommended a feeding tube and skilled nursing care. The home attendant was asked to demonstrate to the staff how she fed the patient at home. Bringing in the familiar spoon from home, she sang hymns to Mrs. C. during the meal while slowly feeding her. Before each bite, she tapped Mrs. C.'s left cheek with the spoon. Mrs. C. completed an entire meal without difficulty. She was discharged home. In retrospect, the hospital staff concluded that the perceived inability to eat was simply inability to recognize the feeding process and mealtime. Mrs. C. remained at home for another year, until she died quietly in her sleep.

Case Example 2: Mr. R.

Mr. R. was an 88-year-old man who lived with his aged wife. Mr. R. had moderately advanced dementia and was not capable of expressing his needs. He walked brief distances in his house with a rolling walker but was unable to climb stairs and was brought to the doctor's office in a wheelchair. Mrs. R. reported that her husband was sleeping poorly, and calling out for help during the night, which kept her awake and worried her. When asked what help he needed, Mr. R. was unable to answer. The doctor initially suggested consultation with a psychiatrist, but when faced with Mrs. R.'s distress and a 2-week wait before any possible appointment with the consultant, he proposed a trial of a major tranquilizer for a presumed diagnosis of dementia with agitation and possible paranoia. Mrs. R. requested a trial of pain medication because "I noticed that he screws up his face at night the same way he did when his arthritis used to bother him." The physician prescribed a combination analgesic with a small amount of codeine to be given at bedtime. Mr. R.'s sleep problem resolved.

Case Example 3: Mr. F.

Mr. F. was a 68-year-old married man living in a specialized Dementia Assisted Living Facility where his wife visited him daily. Mr. F. had moderate stage Alzheimer's disease, with disorientation to time and place, but was ambulatory and continent. His care needs were increased by severe visual impairment, which made him easily frightened when approached without warning. Mr. F. developed a severe prostate infection, which required intravenous antibiotics. At the time of hospital admission, his wife informed the staff that Mr. F. became extremely agitated when his shoes were removed. At the Assisted Living Facility he was allowed to sleep with his shoes on. The shoes were removed individually once daily to wash his feet and change his socks, but never simultaneously and always with a verbal explanation of the need to remove the shoe and the washing process. The hospital staff, after a brief telephone discussion with the infection control nurse, complied with Mr. F.'s normal regimen and allowed him to sleep with his shoe on in bed. His hospital stay was brief and uncomplicated.

These examples share three elements in common. First, the patients' behaviors are treated as meaningful, rather than random acts of disordered cognition. Second, the treatment team, in all three instances, accepted the caregivers' observations of behavior as valid information. Third, the family caregivers were actively involved in the creation of the treatment plan based on that information. The swallowing expertise of the therapist, the prescribing expertise of the physician, and the infection control knowledge of the nurse were respected, but in each case, the family was a valued member of the care team. As a consequence, patient care and comfort were enhanced. In such a model there is also much less stress generated for the caregiver. The emotional support provided includes better care for the patient and more dignity for both caregiver and patient. The professional team is also strengthened by positive outcomes from their intervention.

Clearly, there is a long road to travel from the current paradigm to this somewhat visionary notion of a true collaboration between professionals and family caregivers. But some advances have already been made, while glimmerings of hope are emerging in many other areas. A significant number of institutional or semi-institutional care providers have already begun to incorporate many of these notions into contemporary practice. These include many dementia programs in Assisted Living and Skilled Nursing Facilities. Professionals in these units have undergone training with Alzheimer's Association local chapters or with consultants trained in the new paradigm. The so-called Pioneer Movement in nursing homes is trying to reshape skilled nursing care around the needs of the patient, encouraging the inclusion of the family into the care team. Many good Alzheimer's Day Programs also work closely with family caregivers, although their efforts are limited by the lack of physician involvement.

Parallels between issues that confront pediatricians and issues that confront geriatricians are unavoidable. In this context, although concentrating on the role of parents as caregivers, several major professional organizations have recently adopted positions supporting or strengthening the role of the family caregiver in the treatment process. In 1997, the American Association of Critical-Care Nurses published protocols on family visitation and "partnership" in the critical care unit. Among other steps, the protocols advocate for an end to visitation policies and movement towards visitation guidelines (www.nacm.org/WD/practicedocs/practicealerts/family-visitation-adult-icu-practicealerts.pdf). The Emergency Nurses Association adopted a resolution supporting family presence during invasive procedures including cardiopulmonary resuscitation (Dougal, Anderson, Reavy, & Shirazi, 2011). The National Association of Emergency Medical Technicians has called for a "mutually beneficial collaboration of health care professionals and family members." In their document titled "Family-Centered Pre-Hospital Care: Partnering with Families to Improve Care" they encourage use of the family as a source of information and family presence during procedures and transport. Although aimed primarily at children this document includes "all other patients" (www.naemt.org/). Unfortunately, these recommendations have rarely been incorporated in hospital policies (Dougal, Anderson, Reavy, & Shirazi, 2011).

Individual hospitals, including (but not limited to) the University of Washington Medical Center in Seattle, Woodwinds Health Campus in Woodbury, Minnesota, Dana-Farber Cancer Center in Boston, and the Milton S. Hershey Medical Center in Hershey, Pennsylvania, have all begun interventions to become more friendly to family caregivers in all or part of the adult inpatient units of the hospital. These changes have included making spaces available for families to prepare food for the patient, to participating in turnover rounds, and/or to sleep over in the hospital. The National Alzheimer's Association in 2000 initiated a national "request for proposals" (RFP) to improve the hospital care of patients with dementia. That RFP led to funding for a hospital-wide program at Providence Milwaukie Hospital in Portland, Oregon. The hospital initiated routine screening, staff training, stimulating activities packets, education focused on the needs of family caregiver, and inclusive discharge planning. The program was expanded prior to implementation to include delirium and depression, ultimately melding into a general institutional process to improve hospital care for seniors. Given these transformations, no outcome evaluations were possible nor are it clear which, if any, of these interventions are still in place.

The United Hospital Fund and New York City Initiatives: Windows to the Heart

In 1998, the United Hospital Fund in New York City began a Family Caregiver Initiative providing $2,000,000 in funding to seven innovative hospital-based programs (Nichols & Heller, 2002). Hospitals were asked to collaborate with a community-based partner to plan and execute projects aimed at responding more effectively to the needs of caregivers for sick or disabled elderly New Yorkers. Three hospitals chose the New York City Chapter of the Alzheimer's Association as a partner. Mount Sinai Hospital created a Caregivers and Professionals Partnership (CAPP). This partnership created a CAPP Caregiver Resource Center with educational materials, a website (www.mssm.edu/capp/), and walk-in, and telephone assistance. Professionals were educated about caregiver needs and urged to refer caregivers to CAPP.

New York University Medical Center developed tools to help family members and staff to communicate more effectively. The project also provided education to hospital staff about Alzheimer's disease and the needs of family caregivers. The Medical Center created a Dementia Care Helpline staffed by trained counselors. Interestingly, the program produced almost no referrals of hospital patients or their caregivers but was extensively used by the staff themselves (M. Mittelman, verbal communication).

Cabrini Medical Center created an eight-bed family-centered acute care unit for patients with dementia (Nichols & Heller, 2002). This unit, called "Windows to the Heart," evolved from a planning process during which an interdisciplinary team of hospital staff met regularly with family caregivers to design a unit that centered on meeting the needs of the patient and caregiver. As the unit developed, staff members themselves grew to recognize the vital role that caregivers could play on the care team and the profound cultural changes that would be required to incorporate them. The two hospital care examples discussed above come from that unit.

As one of the few explicit attempts to develop a partnership of health care professionals and family caregivers of dementia patients, the Windows to the Heart unit merits some specific attention. The unit was decorated to explicitly feel less "institutional," with a living room where patients and families were encouraged to congregate, a table and chairs for joint or family dining, and carpeting on the floor. On admission, names and contact numbers for caregivers were sought out and recorded. Caregivers were asked to supply information regarding the patient's daily routine, activities of daily living (including details of how these were maintained), and ideal communication strategies with the patient. Family members were encouraged to continue to participate in their familiar care roles, such as feeding, dressing, and bathing if they desired to do so. Family members were welcome to stay overnight on foldout beds in the living room or bedside cots if they wished. Indeed, there were no "visiting hours" or "visiting guidelines" since family caregivers were part of the team, not visitors. Attempts were made to schedule tests when the family could be present to assist. On admission, the family was also given the telephone number of the unit nursing station and encouraged to call for progress reports. A portable telephone at the nurses' station also allowed family caregivers who could not be physically present to call and speak directly to their loved one anywhere on the unit. The patient could also request a telephone call to a loved one even when they could not master the hospital telephone system or remember the necessary telephone numbers. Dietitians recognize that printed menus, left at bedside the night before, were ineffective with dementia patients. They met with family members to plan out appropriate meal choices several days in advance. Snacks were always available on the unit for patients whose eating schedule might not match that of the hospital kitchen. Caregivers were welcome to approach any member of the team—from the environmental aide cleaning the room to the floor Attending Physician—for information, although the location of the nursing station in an open area in the middle of the unit made nursing a natural conduit for regular contact and discussion with the caregivers. Transmitter bracelets and alarmed doors allowed patients to walk in the hallways with family or wander on the unit without the need for physical restraints and without danger to the patient. This unit was extremely well regarded by families, had a stable care staff for over 5 years, and appeared to experience lengths of stay comparable to hospital averages. Unfortunately, the financial implosion and ultimate bankruptcy of the entire hospital complex led to closure of the unit before any formal outcome studies could be completed. Nevertheless, it did demonstrate that such a model is feasible (Nichols & Heller, 2002).

Directions for Research

Professionals who have adopted new models of collaborative care have done so largely based on personal experience and beliefs. Family, staff, and (where possible) patient satisfaction with these new models can be easily demonstrated. But assertions that the new paradigm actually improves other key clinical patient outcomes are generally anecdotal. For example, the Pioneer Movement nursing homes have not compared their outcome data with more traditional facilities despite the availability of national computerized databases containing facility-based Minimum Data Set measures on every nursing home resident in the country. Of course, many of these facilities are still in development or transition, but the movement emphasis continues to be on process rather than outcome. Similarly, the Cabrini Windows to the Heart Unit collected only caregiver and staff satisfaction data for its initial evaluation. This is not to undervalue the importance of measuring the satisfaction of those who use the health care system and those who work in it.

It is indubitably the case, however, that advocates of a transformational change in the culture of care would greatly benefit from substantial reinforcement of their arguments with rigorous studies documenting beneficial effects on quality measures and costs for the inclusion of caregivers as full members of the treatment team. One set of necessary outcome measures would be actual disease parameters, such as decline in cognitive and functional performance. Although there is no reason to expect that any change in the culture of care would actually affect the course of a progressive degenerative disease, proponents certainly do assert that preservation of function is enhanced by the new approaches. Secondary outcome measures should include disease complications such as behavioral disturbances, weight loss, skin breakdown, falls with injury, and complicating infections. Secondary outcome measures should also include traditional positive outcomes, such as delayed nursing home placement, as well as negative outcomes, such as hospitalization and unnecessary or inappropriate use of psychotropic medications. Finally, economic research should evaluate whether these innovations are cost effective. Do they shorten or lengthen hospital stays? Are staff hours increased by the demand for increased caregiver involvement or decreased by greater ease of care and the volunteer work of the caregivers? Finally, such research needs to identify whose health care dollars are being saved. Reduced hospital costs may be a powerful argument to hospital administrators but reduced number of hospitalizations is not. Innovations that shift work to family caregivers may save hospitals money at the expense of lost income to caregivers. Delayed institutionalization is a powerful argument to Federal and State officials who must fund Medicaid, but may not necessarily delight providers of long-term care. Answers to these research questions will certainly help to frame debate.

At the same time as these issues are explored, research should also include evaluation of specific programs for best practices. For example, is weight loss best prevented through the preparation of familiar foods or feeding by familiar individuals? Does the combination add significantly more than each individually? Or can we identify subgroups of patients for whom either intervention is key? Many participants in the Pioneer movement have argued for redesign of nursing homes into small "neighborhoods," while others highlight the cultural change components. These proposed architectural changes are inevitably extremely expensive, and many existing facilities are unable to achieve them despite extensive internal renovations. Systematic analysis of their role in the overall changes proposed might help differentiate what is truly necessary from what is simply desirable.

Future Steps

Policy changes on the national level could assist the transformation of the culture of care. The frequently quoted aphorism "form follows financing" recognizes the truth that even minor changes in health care financing can profoundly affect the structure of health care institutions and interactions. Reimbursable services are validated as core services, while non-reimbursed services may be marginalized or ignored. One significant policy advance would be to change the insurance definition of an "encounter" which serves as a minimum requirement for reimbursement. The current definition requiring the physical presence of the insured person should be expanded to include direct interactions between the family caregiver and the health care provider. This would inevitably expand the time made available for such meetings, increase communication, and facilitate training. For patients in hospitals or nursing homes, such encounters should be billable on the same day as the physician, nurse practitioner, or physician's assistant visit to the patient, encouraging joint discussion and care planning. Medicare (technically CMS—the Federal agency which administers Medicare and Medicaid), the primary insurer for most Alzheimer's patients, could initiate such changes. Changes in Medicare coverage automatically spill over to Medicare HMO's, which are required as a minimum to cover all services covered by traditional Medicare.

Regulatory changes could also dramatically encourage a transformative process with minimal budgetary impact. Current Federal policy authorizes the Joint Commission for the Accreditation of Healthcare Organizations (JCAHO) to inspect hospitals, clinics, and many other health care providers to guarantee both quality and compliance with Federal regulations. JCAHO accredited facilities are "deemed" to be federally compliant. JCAHO requirements, which are extremely detailed and complex, cover areas as diverse as fire safety and Hospital Board involvement in ethical decision making; policies on organ donation; the credentialing of physicians; documentation of nursing staff training in age-appropriate care; and food temperatures. JCAHO requires written evidence of the creation of a patient education plan and of discussions with the patient concerning advance directives. Thus, JCAHO could significantly advance the position of family caregivers within health care institutions through new requirements for documentation that family caregivers were included in the care planning process, for altered hospital policies on visiting, and through required hospital policies on the role of the caregiver in the provision of hospital services.

Changing expectations of professional activities could also be reflected in professional education and training. Although professions such as nursing, medicine, social work, and the rehabilitation therapies all include skills in patient education within their standard curricula, these areas reflect the assumptions of the old paradigm and need to be revisited and revised. Professionals must learn both how to educate caregivers and how to be educated by them. Senior personnel may need first to acquire and then to model these skills during the professional's clinical training and early practice experience. Ultimately, these skills should be included in the requirements of the professional licensing organizations and incorporated into the structure of Continuing Medical Education courses.

Many barriers stand between the current unsatisfactory reality and the idealized paradigm proposed. Collaborations between laypersons and professionals in other fields have not proven easy, as witnessed by attempts at parental involvement in schools or lay involvement with the clergy. The two prospective partners are often separated not only by education and training, but also by class and social status, gender, and racial or ethnic background. Transforming the health care system requires a struggle against powerful entrenched institutional forces with their own agendas. Hospitals and nursing homes, though theoretically open to improvement, are often fearful and suspicious of change—more comfortable with inertia than with innovation. Any revisions in health insurance coverage may be looked on suspiciously by the powerful health insurance industry, whose political power continues to be amply demonstrated. Even providing new funding for caregiver encounters through Medicare, in the current political environment with its shrinking pot of available tax levy monies, would mean compensatory funding decreases elsewhere.

Despite obvious obstacles, and perhaps some less obvious, the struggle is well worth undertaking. With regard to the medical care of patients with Alzheimer's disease, the Emperor is parading stark naked. Change is inevitable. We need to identify the path to improved care before those who would simply cut costs impose their own solutions.

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Chapter 8
End-of-Life Issues for Caregivers of Individuals with Alzheimer's Disease and Related Dementias

Donna Cohen

> *As we grow older the world becomes stranger,*
> *The pattern more complicated of dead and living.*
>
> T.S. Elliot "East Cocker"

Values about the meaning of life and caring for others are woven into our society's moral orientations. With an increasing proportion of individuals with Alzheimer's disease and other dementias in our older population, a group believed by many to be a drain on the productivity of our society, the pressure to reassess our ethical responsibilities for our aging population has become an issue of international concern (Cohen & Eisdorfer, 2011). Alzheimer's disease and other serious chronic illnesses have become a metaphor for aging, challenging us to grapple with the meaning of the inalienable dignity of living and dying.

Even if there are dramatic research advances in early detection, treatment, and prevention of Alzheimer's disease, we will still be facing clinical, ethical, and social challenges resulting from the care of millions of affected individuals and family caregivers in the foreseeable future (Blass, 1984; Cohen, Kennedy, & Eisdorfer, 1984). Not only will the numbers of "individuals-turned-patients" escalate because of increasing life expectancy, proportionally more will have mild and severe dementia as a result of improved early detection and better health care over the course of the illness. The result will be more patients who are not only living longer but also taking longer to die.

Developing effective intervention and prevention strategies to assist people diagnosed with dementia as well as family members over the course of what is often a long and dehumanizing illness are necessary to promote mental health, reduce the

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risk of depression, and minimize other negative health, work-family, social, and economic consequences. Caregiving tests the resilience of even the most resourceful family members struggling to cope with the psychological death of the patient long before physical death. One daughter described this experience of "the death of the mind, the worst death imaginable" (Cohen & Eisdorfer, 2002).

Living with Alzheimer's disease also challenges the person with the illness to find personal meaning, maintain social attachments and relationships, and find integrity and dignity in a world that others may find frightening and difficult to embrace. Interventions are essential to rescue individuals-turned-patients from the stigma, isolation, and misunderstandings that others may impose, however well-intentioned their words and actions be. This is as important in the mildest phases of dementia through the later phases, even approaching death.

Depressive symptoms and disorders are the most common health consequence in family caregivers (Schulz & Martire, 2004). Sadness and depression, usually mixed with anxiety and anger, are normal reactions, because so many choices, decisions, and actions throughout the illness are ambiguous, painful, and confusing. However, clinical depression interferes with personal, family, and social functioning, and if undetected and untreated leads to personal pain and suffering; decreased problem solving and overall effectiveness; family disruption; abuse and neglect; death wishes and violence, such as suicide, homicide, and homicide–suicide; and emotional isolation of the dying patient (Cohen & Eisdorfer, 2011).

It is common for family members to have death wishes accompanied by guilt, especially when the advanced or final stages are prolonged. Alzheimer's disease is painful for everyone, and a common reaction is to run away or attempt to eliminate the cause of the pain. As a result, some caregivers distance themselves or think about ways to kill the person rather than see them suffer (Cohen, 2004; Cohen & Eisdorfer, 2002). These thoughts and feelings, coupled with depression and the intense distress of caregiving, can lead to a premature, violent death.

On October 29, 2002, Gary Pearson, age 60, killed his 81-year-old mother in Florida. He taped her face with duct tape, bound her arms and legs, covered her face with a towel, and suffocated her. Mr. Pearson had intended to kill himself, but instead he drove her body to the police station. He confessed to officers that he loved his mother but she was driving him crazy. Ruthie Mae Pearson had Alzheimer's disease, and her son told the judge that the stress of her pain and suffering had overwhelmed him as a full-time caregiver. Mr. Pearson pled guilty to second-degree manslaughter and was sentenced to 2 years of house arrest and 18 years probation.

The judge issued a memorandum indicating that his decision was influenced by several factors, including Mr. Pearson's military service, his service to his community, previous devotion to his mother, his mental illness, and the stress of caring for his mother. Mr. Pearson had a long history of bipolar depression, but he had stopped taking his medication several months before he killed his mother. Mr. Pearson's manic-depressive symptoms returned, and he became more agitated and frustrated with his mother's care, culminating in her murder.

Importance of End-of-Life Caregiving

Although caring for sick and frail relatives exacts a high toll, there are unique circumstances, pressures, and stresses associated with dementia caregiving (Ory, Yee, Tennstedt, & Schultz, 2000). These include, but are not limited to, witnessing the progressive loss of self, dealing with the uncertainties of the rate of progression, managing behavioral problems, maintaining an unrelenting vigilance for safety, sleep deprivation, and coping with the emotional pain of the terminal phase. Additional stressors will likely affect family members in the future, with the introduction of new cognitive-acting drugs, earlier detection and diagnosis, genetic screening, and interventions such as preimplantation screening, the extended care required as people live longer with dementia, and the prolonged process of dying.

Unique challenges arise when people with dementia are dying (Chatterjee, 2008; Cohen & Eisdorfer, 2011; Volicer, 2005). They are clinically and psychosocially vulnerable and dependent on others to make decisions on their behalf. Most individuals and family members have not discussed preferences for end-of-life care options, and family members may disagree about the right time to let go, especially in the late stages. Moving on and letting go are particularly stressful, because the unrelenting slow course to death with dementia differs from trajectories of change associated with other types of conditions. In diseases such as cancer, death occurs after a relatively short period of decline, whereas death associated with organ system failure occurs abruptly during exacerbations in the course of chronic illnesses (Blanchard, McCann, & Lynn, 2002; Field & Cassel, 1997).

Family members are often unsure what end-stage dementia looks like, because the physical signs and symptoms are different from other terminal illnesses and can manifest in different ways among patients (Nuland, 1994). This uncertainty makes decisions about active treatment vs. comfort care difficult. Family members, physicians, and other health professionals usually have different views about intervention in advanced dementia, including the use of cardiopulmonary resuscitation and treatment of other medical conditions, such as infections, artificial feeding, and comfort measures (Blasi, Hurley, & Volicer, 2002; Cohen & Eisdorfer, 2011; Kim, Yeaman, & Keene, 2005; Volicer, 2005).

Relationship of Caregiving and End-of-Life Dementia Care

Discussions about dying and death are uncomfortable for many reasons (Kastenbaum, 1999–2000). Attitudes and beliefs about life and death are grounded in personal, religious, and cultural roots, and they generate intense emotional responses. A pervasive denial of death has been a barrier to accepting the special needs of dying patients and palliative care. Until the early 1960s, death was a taboo subject, end-of-life care was seldom discussed, courses on death education and counseling did not exist, and little research has been done. Hospice programs and professional palliative care organizations in the USA were only first established in the 1970s.

Discussions about death and dying with regard to dementia are especially distressing (Hurley & Volicer, 2002). The fears and emotional responses of patients and family members can increase spiritual and social isolation as well as prohibit important discussions about end-of-life preferences and final arrangements. Psychological distress becomes more intense when patients are deteriorating into the terminal phase, a process family members have described as a “living funeral.” The experience of short-term and long-term bereavement can be an emotional roller coaster, even when families are relieved that the suffering is over.

As the illness progresses and extinguishes the humanity and dignity of the patient, a natural feeling on the part of family members is to wish the person to be dead. However, they are usually ashamed or embarrassed to admit these feelings. Roscoe and Cohen (1999) compared attributional styles, hopelessness, and depressive symptoms as predictors of physician-assisted suicide desirability in persons who cared for relatives with dementia and those who were not caregivers. Caregivers who felt less in control of the stress in their lives or who felt factors causing stress were unchangeable reported significantly more depressive symptoms. The attribution that factors causing stress were unchangeable was significantly associated with caregiver desire for assisted suicide. However, depression and hopelessness were unrelated to the desirability of physician-assisted suicide. More than two-thirds of caregivers and non-caregivers believed assisted suicide could be a rational decision, but almost half of dementia caregivers compared to one-quarter of non-caregivers believed physicians should help patients die.

Current Standards of Practice for Dementia Care

An estimated 1.8 million people in the USA are in the final stages of Alzheimer’s disease and related dementias. Although quality palliative care can be provided, end-of-life issues are uncharted territory for physicians, other health professionals, and family members (Hurley & Volicer, 2002). Most physicians do not learn the personal and family history of their patients, knowledge that could be used to mediate a dignified death as well as comfort families in their grief and bereavement. The usual standard of medical practice is to largely ignore dementia as an illness and continue with invasive procedures for medical comorbidities, instead of finding ways to make patients more comfortable (Morrison & Morrison, 2006). Physicians seldom discuss dying and palliative care, or they communicate these issues poorly, leaving patients and caregivers with little or no support.

Consensus guidelines been developed for the care of people with advanced dementia, recognizing that they and their families have special needs (Hurley, Volicer, & Blasi, 2000; NHPCO, 2007). The U.S. Department of Veteran Affairs and the Alzheimer’s Association convened an advisory group, which drafted recommendations for improving palliative care (see Table 8.1). These recommendations complement and enhance broader recommendations on standards of care at the end of life (Cassel & Foley, 1999; Field & Cassel, 1997).

Table 8.1 Consensus recommendations for improvement of end-of-life care for patients with advanced dementia

Palliative care
Palliative care must be available to persons with advanced dementia earlier than at a point when the person is eligible for inclusion in existing hospice programs
Health maintenance organizations, assisted-living and nursing facilities must support and provide appropriate EOL care for persons with dementia
Programs that provide comprehensive and life-long services, such as Programs of All-inclusive Care for the Elderly (PACE), need to be expanded and made more accessible to persons with dementia, including those who do not have family caregivers
Decision making
Advance care planning must begin at the point of diagnosis, preferably when the person can still make his or her own decisions
Ethical principles important for EOL decisions must be incorporated into heath care policies and caregiving practices to support good EOL care for persons with terminal dementia
Acute care
Hospital and emergency care for persons with advanced or terminal dementia must recognize the specific needs of this population and include presence of a familiar caregiver during the treatment process
Research and education
Dementia EOL cooperatives should be created to engage in rapid cycling improvement studies in an effort to improve EOL care for persons with dementia
Knowledge of EOL care for persons with advanced and terminal dementia must be widely disseminated to professional and lay caregivers

Although a number of studies have documented significant inadequacies in caring for terminally ill individuals (Harris, 2007; Lorenz et al., 2008; Shega et al., 2007), dementia patients are at particularly high risk for poor care across the continuum of care in North America, South America, Europe, and Australia (Goodman et al., 2010). Almost 75% of all people with dementia die in nursing homes and assisted living residences, where most staff members are not trained to deal with terminal care (Hurley & Volicer, 2002). Many die with aggressive medical treatment and non-palliative care, including tube feeding, restraints, and intravenous therapy, and without adequate pain management (Sachs, Shega, & Cox-Hayley, 2004).

The Alzheimer's Association commissioned a study to improve policies and practices for end-of-life dementia care (Volicer, 2005). It included recommendations for research in several areas, including evidence-based palliative care as well as improved physician/caregiver communication and decision making, for palliative care education of health care professionals and family members, and for policy changes in Medicaid and Medicare to eliminate fiscal incentives for hospitalization and tube feeding and changes in Medicare for dementia palliative care.

Very few dementia patients are admitted to hospice, but the care is beneficial when they are admitted (Mitchell et al., 2007). Less than 7% of hospice patients have a primary diagnosis of dementia (Knowlton, 2003). A major problem facing hospice and long-term care providers is the difficulty in predicting 6-month survival, a Medicare and Medicaid requirement for hospice reimbursement (McCarty & Volicer, 2009). With increasing federal regulation and fear of denial of payment, some hospice programs are hesitant to admit more than a few dementia patients. There are medical guidelines for determining prognosis in advanced dementia that successfully target 6-month survival in 85% of patients (NHPCO, 2007; Schonwetter et al., 2003). Specific indicators include the severity of medical comorbid conditions, rate of physical deterioration, and swallowing and feeding difficulties, as well as recurrent infections despite antibiotics.

Few physicians have specialty training in palliative care, and only in the recent past have groups such as the Institute of Medicine, the American College of Physicians, American Society of Internal Medicine, American Geriatric Society, American Psychiatric Association, and others worked internally and collaboratively to improve knowledge and skills (Cohen & Eisdorfer, 2011).

Hospice care is underutilized (Hurley & Volicer, 2002; Volicer & Hurley, 1998), often because physicians are reluctant to make the referral, but this is true for family members as well. Since the end-of-life stage of dementia is so much longer than other disorders and conditions, most existing models of hospice are not equipped to deal with people who have dementia. Pain management, one of the central tenets of hospice care, can be particularly difficult when people cannot communicate how and what they feel.

Current Models of Education and Training

There are many ways to educate and train family members: Alzheimer family self-help groups; community forums; lectures and discussions; psycho-educational skill-building groups; individual and family counseling; community care providers; and telecommunication technology interventions, using telephones and computers, as well as videoconferencing. Unfortunately, there is no outcome research on the impact of educational interventions to prepare family caregivers for end-of-life care decisions.

Few caregivers are exposed to end-of-life education. The Alzheimer's Association and other professional and advocacy organizations provide educational materials, seminars, and other community resources to educate families (www.alz.org; www.eperc.org). Caregivers need to know about many core issues: how people with dementia die; preparation of advance directives, such as a durable power of attorney for health care and a living will; the importance of palliative care and the elements of good care and comfort at the end of life; the availability of hospice care; what to expect from health professionals; and where to reach out for help. At some point after diagnosis, people with dementia and family members need to clarify values and preferences for end-of-life care and be prepared for critical decisions, such as the use of feeding tubes or a respirator, hydration, cardiopulmonary resuscitation, and medications to avoid hospitalization.

Current Research

The rising number of individuals with Alzheimer's disease and related dementias has stimulated important research in many arenas: (a) appropriateness and efficacy of person-centered end-of-life interventions; (b) usefulness of different models of care across the continuum of care; (c) development of criteria to define the end stage(s) of dementia; (d) improving communication and decision making between health professionals and family members; (e) management of bereavement and grief in surviving family members; (f) detection and prevention of abuse and severe violence; (g) detection and prevention of suicide, homicide, and homicide–suicide involving patients and families; and (h) assisted suicide and physician-assisted suicide.

A number of innovative hospice adaptations have been created and evaluated (Volicer, 2005). The Jacob Perlow Hospice, Beth Israel Medical Center in New York City developed a full service hospice program targeting advanced stage dementia patients who met specific end-stage criteria, the most important being eating and swallowing problems, recent weight loss, incontinence, and recurring infections (Brenner, 1998). A total of 124 patients and families were served in the 3-year program, with an average length of stay of 154 days, significantly longer than the average stay of 51 days for hospice programs in the USA. The model program resulted in 70% of patients dying comfortably at home compared to 17% in the hospice inpatient residence and 13% in nursing homes.

Investigators at the University of Chicago and the Hospice of Michigan created a two-pronged approach to improving hospice care known as PEACE—Palliative Excellence in Alzheimer's Care Efforts (Sachs et al., 2004; Shega et al., 2004). The Hospice of Michigan PEACE model was a palliative care consultation program targeting residents with advanced dementia who might not be eligible for hospice and are living in long-term care residences. The University of Chicago PEACE project integrated palliative care, from diagnosis through the course of illness and death, into the primary care of dementia patients in a geriatric outpatient practice. Preliminary results of the Chicago program showed high ratings of quality of care at enrollment, greater satisfaction over time, mean pain ratings averaging little or no pain, but family stress stayed high. More than 60% of PEACE patients died at home and less than 20% died in the hospital; families of patients not enrolled in PEACE reported significantly more problems in the last 2 weeks of life, including patient pain and distress.

Innovative approaches are emerging for physicians to guide the process of making difficult palliative care decisions for those with dementia who lack decision making capacities when families are unsure or disagree. Karlawish, Quill, and Meier (1999) advocated expanding the clinician's role beyond explaining medical circumstances to actively guiding dialogue and facilitating decision making when patients were too cognitively impaired to participate. Narrative theory and principles of negotiation were used to clarify the values of the patient, family caregivers, and professionals mediating terminal care. The meaning of suffering is highly subjective, and understanding the experience of persons with late stage dementia is extraordinarily difficult. Families will benefit from guided support, because they have to live with themselves long after the patient has died.

The latest research findings indicate that stomach tubes, which have been increasingly used over the past 15 years, are not medically or ethically justified to feed patients (Cervo, Bryan, & Farber, 2006; Chernoff, 2006). Feeding tubes not only can cause diarrhea, bloating, infections, and other health problems, but can also increase the risk of pneumonia or choking. The patient's preferences, quality of life, current medical condition, and course of terminal deterioration are important considerations in decisions about withholding the artificial administration of fluids and food in late stage dementia.

Abuse and severe violence by family caregivers places some individuals at risk for increased mortality as well as a violent death (Cohen, 2002a, 2002b; Paveza et al., 1992). The overall prevalence of severe violence, e.g., kicking, hitting, stabbing, and shooting, in families caring for relatives at home is 17%: About 5% were cases in which caregivers were violent towards the patient; 15% were cases in which the patient was violent towards the caregiver; and 4% were situations in which the violence was interactive. The presence of significant caregiver depression tripled the risk of violence, and a depressed caregiver living with a patient at home, but without a spouse, increased the risk ninefold.

Undetected depression in male caregivers can be lethal, resulting in homicide or homicide–suicide (Cohen & Eisdorfer, 2011). Roswell Gilbert, who killed his wife with Alzheimer's Disease in 1995 and was sentenced to 15 years for first-degree murder, raised the issue of "mercy killing" to national attention (Cohen & Grabert, 2001). Homicides are rare in the older population, but about 20% of victims of homicide–suicide are women with dementia who are killed by clinically depressed husbands (Cohen, 2002a, 2002b).

Little is known about the prevalence, causes, and risk factors for suicide and homicide in the dementia population. It is estimated that about 10% of individuals with dementia are at risk for suicide (Cohen, Vergon, & Malphurs, 1998), but the prevalence of completed suicide is only about 3%. Suicidal ideation, depression, and serious physical illness are prominent, and whereas memory and reasoning may be impaired, executive functioning and attention are less impaired. However, the methods of death, e.g., rat poison and other agents, drowning, and hanging, are significantly different than those seen in non-dementia populations, in which guns are most frequently used.

Homicides or homicide–suicides perpetrated by individuals with dementia are rare (Cohen, 2004; Cohen, Malphurs, & Eisdorfer, 1998). The presence of psychotic depression, paranoia, and coexisting vascular dementia may be predisposing factors for homicidal behavior. Random circumstances may escalate into violent deaths at home or in long-term care settings when residents have catastrophic reactions, overreacting or misinterpreting the actions of others.

Current Policy Positions

Existing state and federal policies have emerged from the developing consensus about what constitutes quality dementia palliative care. Medical professional specialty organizations have developed consensus statements (Cassel & Foley, 1999; National End of Life Care Programme, 2010), and several, including the American Medical Association, the American Geriatric Society, and the Veterans Administration/Alzheimer's Association, have developed specific recommendations for principles of dementia care. Another chapter in this volume (Riggs) articulates policy positions by the national Alzheimer's Association and also analyzes current state and federal legislation.

Alzheimer's disease has become a central issue in the debate about physician-assisted suicide, and the policies that emerge will have a dramatic impact on attitudes towards care and the quality of care available for persons at the end of life, especially those who are vulnerable with diseases like dementia. Two countries, the Netherlands and Belgium, have legalized physician-assisted suicide, and both prohibit assisted suicide for cognitively impaired individuals. Oregon, Washington, and Montana are the only states in the USA to have legalized physician-assisted suicide by lethal prescription.

Janet Atkins, who decided to commit suicide the day she was diagnosed with probable Alzheimer's disease, was the first person Jack Kevorkian euthanized. In 1990, after speaking with her husband, Kevorkian agreed that Mrs. Atkins could use his first suicide machine and die by lethal injection. Kevorkian never spoke to Mrs. Atkins, age 54, who had been a college instructor and a member of the Hemlock Society. After this event, the Alzheimer's Association released a statement recognizing that this occurrence underscored the desperation patients and families feel. Although Mrs. Atkins made a personal decision, the association affirmed the right to dignity and life for every Alzheimer patient and urged families to make use of services and professionals to help them cope. In 1998, the Alzheimer's Association issued a policy statement on physician-assisted suicide, emphasizing that the debate had stimulated the organization to improve end-of-life services for patient and families.

Kevorkian, who did not have a medical license, probably assisted in the deaths of at least 130 persons from 1990 to 1998. A review of the records of the 69 persons who died and were investigated by the Oakland County, Michigan Medical Examiner (Roscoe, Malphurs, Dragovic, & Cohen, 2000) showed that only 25% were terminally ill; 71% were women, mostly older; and only 33% were married. Of the 38% who had neurological conditions, mostly multiple sclerosis and ALS, only one other person besides Janet Atkins had dementia. These results underscore the vulnerability of women and those who are not married to euthanasia and assisted suicide, especially when safeguards are lacking.

Future Needs and Directions

Practice

New standards for end-of-life care practices need to be driven by biobehavioral, clinical, psychosocial, and health systems research. However, physicians and other health care professionals can make a difference with small changes, such as talking with patients at an appropriate time after the diagnosis to make plans for advance directives. One health care team increased the documentation of advance directives in charts from 15 to 90% in 3 months (Lynn, Lynch, & Kabcenell, 2000). The National Health Service in the UK has published a comprehensive online resource for improving palliative care practices (National End of Life Care Programme, 2010). The resource identifies end-of-life care tools and discusses a six-step pathway including the following phases: discussions as the end-of-life approaches, assessment care planning and review, care coordination, delivery of quality services in different care settings, care in the last days, and care after death.

Although significant quality improvement will require systems change in the delivery and financing of health care as well as medical education, physicians need to improve their knowledge and skills in several areas, including but not limited to: communication with patients and families; decision making about life-sustaining treatments; relief for pain and other physical symptoms; interactions with patients and families about end-of-life care; evaluation of practical aspects of clinical management, such as handling conflict among family members and staff and clinical and ethical issues in the use of high-dose narcotics; and orchestration of dignity, meaning, and closure for dying patients and family members (National End of Life Care Programme, 2010; Volicer, 2005).

Palliative care is a process of caring from diagnosis through the terminal phases. Programs known to provide comprehensive and integrated services, such as PEACE and PACE (Program of All-Inclusive Care for the Elderly), need to be made more available and accessible to people with dementia and their caregivers. However, for this to happen, palliative care must be seen as a priority in hospital settings, including the emergency room, outpatient offices, HMOs, nursing homes, and assisted living facilities. This involves discussions about the philosophy of end-of-life care, increased opportunities for discussions with patients and caregivers, coordination with other staff members, and promoting humanistic interventions to enhance physical, spiritual, and emotional well-being. Innovative approaches to hospice programs remain a priority.

Education and Training

There are two key priorities for training and education of informal caregivers: (1) information about end-of-life care needs to be widely disseminated to formal and informal caregivers and (2) the experiences from other countries should be examined to improve standards of care in the USA. Solomon, Romer, and Heller (2000) have written an informative and inspirational handbook to guide professionals working with family-centered advance planning and dementia.

There are a number of excellent Internet resources targeting dementia palliative care information for caregivers, including but not limited to (a) the International Association for Hospice and Palliative Care (www.hospicecare.com), (b) On Our Own Terms (www.pbs.org/onourownterms), (c) Robert Wood Johnson Last Acts (www.lastacts.org), (d) the Hospice Foundation (www.hospicefoundation.org), (e) Growth Key (www.growthkey.org), (f) the American Academy of Hospice and Palliative Care (www.aahpm.org), (g) the Palliative Dementia Care Resources (www.pdcronline.org), and (h) the University of South Florida (www.fmhi.usf.edu/amh/homicide-suicide/). The University of California at Los Angeles maintains an extensive virtual library on palliative care (www.bol.ucla.edu/~rdavidon/palliative/hcpwebsites.html). The organization Partnership for Caring (www.PartnershipForCaring.org) has a comprehensive set of links on palliative care.

Palliative care training and education are a high priority for physicians, nurses, psychologists, social workers, and other health professionals across the continuum of care as well as clergy, community care providers, lawyers, and other professionals. Many excellent resources are referenced in the consensus position papers as well as institution-based Internet sources, but most have limited information specific to dementia. Excellent Web sites include but are not limited to (a) the End of Life/Palliative Education Resource Center (EPERC, www.eperc.mcw.edu) maintained by the Medical College of Wisconsin; (b) the Center to Advance Palliative Care (www.capcmssn.org); (c) Edmonton Palliative Care Program (www.palliative.org); and (d) Beth Israel Medical Center's Stop Pain! (www.stoppain.org).

Research

Very little research has been published on dementia care in the major palliative care journals, indexed at http://som.flinder.edu.au/FUSA/PalliativeCare/links/links.htm. There are several priorities for future research, including but not limited to (a) creating cooperative studies within and across the continuum of care; (b) examining ethnic and cultural influences on dying and palliative care; (c) implementing anthropological studies of the process of dying and the subjective experience of patients and family members at home and in long-term care settings; (d) improving measures to predict prognosis; (e) improving outcome measures of program innovation and efficacy; (f) testing the impact of person-centered care on patients with advanced dementia as well as family members; (g) creating long-term studies of bereavement; (h) improving professional, family, and patient communication using narrative theory and techniques; (i) increasing our ability to detect, intervene, and prevent violent deaths of patients and family caregivers; (j) developing strategies to maximize mental health and well-being of long term care staff; and (k) testing the efficacy of different educational and training strategies to improve knowledge and skills of professional and family caregivers.

Policy

There are several productive avenues to guide future policy at the federal and state level. Professional constituency groups, including the Alzheimer's Association, the Alzheimer's Foundation of America, medical associations and academies, palliative care organizations, the Veteran's Administration, and other health organizations, should create a task force to create specific goals and objectives for research, professional awareness, public awareness, and public policy agenda to improve dementia end-of-life care over the next decade. The task force could also identify and forge essential linkages with organizations, such as the American Pain Society, to integrate the special needs of dementia patients into their pain policy agenda.

There are many productive strategies to integrate dementia special needs into existing state policy initiatives in end-of-life care. Alzheimer and aging constituencies could organize a statewide awards program similar to the Policy Heroes program created by the Partnership for Caring (http://partnershipforcaring.org/) to honor those who have shown exceptional leadership in palliative care. Other strategies include creating special public education outreach initiatives, educating state policy-makers and their chief staff members, and advocating state work groups which include the Attorney General's office, the state department on aging, state department of health, and other agencies.

The controversy about physician-assisted suicide will continue, and the challenge is to participate in discussions as informed, thoughtful individuals and professionals. The debate about the right to die and the sacredness of life is over 3,000 years old (Kaplan, 1999–2000), and it continues in the courts, legislative and executive bodies of government, professional organizations, public interest groups, religious institutions, and the general public. As we move into the future, demographic, economic, and sociopolitical forces, as well as medical and scientific advances, will fuel the debate.

Individuals with dementia and family caregivers will continue to be a vulnerable population with the continued rapid aging of society. We need to have a better understanding of vulnerability to develop and implement better strategies to detect, intervene, care for, and protect those who are vulnerable. Most suicides occur in the context of psychiatric problems, alcohol misuse, hopelessness, and anomie. Assisted suicide decisions may occur in the context of unrecognized depression and lack of geriatric or palliative care. Discussions about physician-assisted suicide occur in the context of clinical uncertainty, legal sanctions, and limited manpower with palliative care training. Homicides, sometimes referred to as mercy killings, occur in the context of unrecognized caregiver depression, inadequate health care, and limited community-based services.

Conclusion

The family provides more than 80% of the care for relatives with dementia throughout the course of illness and into the final phases. Quality palliative care from trained, sensitive professionals should be available for families and friends, to help patients die as comfortably as possible. People with dementia and their family caregivers endure and prevail over the cruel vicissitudes of dementia with a power that still defies scientific study—love. I want to end with a personal note about the death of one of my Alzheimer patients. Mr. M. had lingered in a dementia hospice at the Beth Abraham Hospital in the Bronx. The morning he died, his wife walked from his bed to my office down the hall. I listened to her describing the goodbye, and as she left, Mrs. M. gave me her husband's two favorite books. One was the Hebrew Bible and the other was Thornton Wilder's *The Bridge of San Luis Rey* (*1927*). Mrs. M. turned to a page to show me her favorite lines:

> Even memory is not necessary for love.
> There is a land of the living and a land of the dead.
> The bridge is love—the only survival, the only meaning.

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Part III

Cross-Cutting Issues Impacting Caregivers and Caregiving

Chapter 9
Ethical Issues: Perspective 1: Providing the Care for Individuals with Alzheimer's Disease: Practice, Education, Policy, and Research

Peter J. Whitehouse

Providing care for ourselves and our family, as well as our community and the world around us, is a ubiquitous part of life. The act of caring creates a field of human endeavor in which the potential emerges for both confluence and conflict between different values.

This chapter specifically concerns individuals affected by AD and their caregivers. However, the concept of AD may be examined in the broader context of age-related cognitive impairment. The term AD has become salient in the lives of individuals as well as societies (Whitehouse, 2001b) and carries with it a terrorizing connotation (Whitehouse, 2001a, 2002b). Yet, cognitive impairment at the end of life has been with human beings since early in the development of our species, certainly since the time of recorded history. There have been many diverse social responses to what we now call dementia and mild forms of memory impairment. In most cultures around the world, cognitive changes are viewed as a normal part of aging. The politics in Western countries, which are dominated by scientific models and scientism, have been framed in one particular way: AD is not normal aging; it is a disease. 2006, the 100th anniversary of the scientific presentation of what became known as the first case of AD, fostered opportunities to reflect on the value of the current dominant concept of AD as a single entity clearly differentiated from cognitive aging. Now the new National Alzheimer Advisory Panel creates yet another opportunity. In the background, the new "diagnostic" guidelines are

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producing much confusion (George & Whitehouse, 2011; Whitehouse & George, 2011). First, the new proposed neuropathological criteria no longer allow a definite diagnosis to be made at autopsy because the cardinal features, plaques and tangles, occur in people without dementia. Second, a new category, preclinical or asymptomatic Alzheimer's, "diagnosable" only by incompletely standardized and validated, expensive biomarkers, represents the scientific model gone to unsustainable extremes. Even before we begin our discussion of the ethics of caregiving we come face to face with asking the question who benefits from the medicalization of brain aging. Ethics has much to do with power and following the money is one way to follow who has power and influence.

Continuing in this theme of interrogating the labels we use to categorize people consider the word "caregiver" itself. When as a neurologist I diagnose someone with "dementia" do I automatically label and pathologize the partner as a "caregiver" at risk for "caregiver burden." In the moment of diagnosis do I disrupt the normal caring relationships between the two people in front of me? Do I rob the person with dementia from giving care to his or her partner? I prefer the terms "carer" or "care partner" than "caregiver" to avoid the risk of such an affront. However in this chapter we will follow the convention of this book and use the term caregiver.

This chapter will focus on care provisions for human beings whom society has labeled as having Alzheimer's disease (AD) by examining the ethical issues that emerge in caregiving practice, research, and education. We will begin our deliberations by asking what options we have for both the theoretical framework and methods of ethical considerations in caregiving. After considering the different perspectives from which care values can be viewed, we will then turn to the issue of labeling people and the power of language. Further, by considering the ethical issues and "disease" conditions for which we are providing care, we will consider the terminal life course of someone diagnosed with AD and the implications of this course for caregiving. Following a temporal sequence, we will examine ethical issues associated with risk assessment prior to diagnosis, particularly genetics, and conclude with some thoughts about the impact of these on caregivers. Caregiving considerations to enhance the quality of death will be noted. The final section will take a look at the future of caregiving to predict some of the ethical issues that will emerge in the years to come.

Ethical Frameworks and Methods

Throughout the history of ethics in the West, particularly in the last 30 years as bioethics has evolved, the dominant method of thinking about values has been a *philosophical*, *analytical*, *principle-based approach* (Evans, 2000). The traditional approach is based on balancing concerns about autonomy, beneficence, and justice for informed decision making, and each of these plays a role in the ethical dilemmas that arise in the care of dementia patients. Autonomy concerns how much independent action should be granted to someone whose decision-making capacity is impaired. A major issue in autonomy is finding the balance between maintaining independence and promoting safety. The consequences of those decisions will affect not only the person receiving care but also the individuals providing care.

Beneficence directs care providers to act in merciful ways that promote human dignity, while justice refers to the necessity of making fair decisions while caring for a demented individual and his family, specifically in the context of the needs of the caregiver and family members, community, and other affected people. Issues concerning justice have much to do with the political environment surrounding AD. For example, what is considered a fair allocation of community and national resources to cognitively impaired people and their families?

The philosophically oriented framework seems to be able to address some clinical issues (Beauchamp & Childress, 1994); however, competing approaches offer perhaps a more grounded approach to ethics. *Casuistry* is another ethical methodology with a long and somewhat controversial history. By basing the analysis of ethical issues on cases, this approach highlights the chronological development of a particular clinical situation. The casuistry approach offers the advantage of stressing the details of individual situations and contextual material that influences decision making. A third approach, though not so commonly considered in bioethics, is *virtue ethics*. In this approach, the focus is not so much on the principles or the case narrative, but rather who is telling and participating in the story; concerns about honesty, integrity, trust, power, and sincerity are at the fore. The final approach to ethics considered here might be labeled *narrative*, *discourse*, *or communicative ethics*. Lumping these terms together neglects differences amongst these concepts. However, they are all built on the power of story sharing. They allow the life course and the values of the individuals in question to emerge in a fuller and perhaps more authentic way than the formulation of a medically oriented case history. In any story of value conflicts and ethical principles, the virtues of various characters as well as the complex fabric of individual lives can emerge. Thus, attending to self-generated stories offers the most integrative approach to considering ethical issues in caregiving (Goldman, 2002). This general approach is often called narrative ethics, and is embedded in a narrative medicine framework.

Ethical Perspectives

A common concern regardless of the ethical framework and methodology employed is the issue of perspective. From whose view is the deliberation considered? This is particularly evident in the case of narrative approaches where the story is told from the view of an individual with a memory problem, caregivers, or from the perspective of society at large. In general, more global perspectives are frequently omitted for individual ethical deliberations, although this may change as health resources become more restricted. In other words, there are and will be increasing demands on our social and health resources. How much effort and money can we put into caring for older person with dementia?

Ethical Considerations on a Larger Scale

Although the majority of this discussion focuses on individual and caregiver perspectives, broader perspectives remain important. For example, increasing attention is being paid to organizational ethics (Srivastva & Cooperrider, 1998). What are the values that emerge from institutions and communities that participate in the care of persons with dementia? What are the attributes of end-of-life care that may be hidden in the policies of different nursing homes? How do the values of acute hospitals differ from those of chronic care? Moreover, as we increasingly turn our attention to public health and readdress the tremendous inequities in health care services in the USA and other countries, we must recognize the potential consequences and resulting iniquities. For example, Hurricane Katrina demonstrated both the consequences of human impact on the environment through global warming and wetlands destruction, and demonstrated the vulnerability of children and the elderly, especially during times of crisis. The practical and ethical implications of Katrina remain to be fully appreciated by our leaders and our citizens. For example, we cannot rebuild on sites that will be increasingly threatened over the decades to come.

As we increasingly see our health in relation to the overall health of the planet's ecosystems, we should consider returning to the original formulation of bioethics by Van Rensselaer Potter (1971). Potter, who coined the term "bioethics," was inspired by Aldo Leopold, whose land ethic valued maintaining the integrity, stability, and beauty of the planet in all ethical decision making. Thinking of the future of life on our planet will help us to consider how to care for people with severe cognitive impairment without neglecting the care of children and all other living creatures. All life has value and how we value people of different ages and cognitive abilities and people in relation to ecosystems that support our communities will be a challenge.

Overarching Models in the Caregiving Process

Too frequently, conceptions of dementia caregiving are based on deficit considerations alone. Thus, we talk of the terror of AD and the burden of caregiving. Much of this negativity emerges from the medical model, which frequently uses war metaphors to attack disease states such as AD. Also, psychosocial models can adopt a framework of negativity. The principal concern of clinicians is often exclusively the negative consequences, both physical and psychological, for family and professional caregivers. The tremendous stress placed on our health care system by people with cognitive impairment is emphasized in discussions of health care financing and policy, while the opportunities for positive personal and organizational growth are not considered.

Although these deficit perspectives offer a helpful view into the reality of caregiving, there are other ways of envisioning caring and its future. We can create a system of care and organizations that enhances opportunities for positive growth.

For example, a technique called *Appreciative Inquiry* addresses the future of individuals and organizations (Srivastva & Cooperrider, 1998). In this model, one begins not with the problems, but with opportunities. The Appreciative Inquiry technique emphasizes the positive experiences in the lives of people with memory problems and those caring for them. It is highly likely that despite promises of biomedical research, cognitive impairment in old age will be with the human race for time immemorial in one form or another. Thus, it is critically important that we look for the positive as well as try to address the challenges to life that cognitive impairment brings. Moreover, we must continue to struggle with developing integrated biopsychosocial (and spiritual) models of care. Such models should not neglect the importance of medical interventions, but highlight the value of caring relationships.

Labeling and Diagnosis

The evolution of mild cognitive impairment (MCI) (and now Asymptomatic Alzheimer's) is challenging the traditional label of AD as outside the realm of normal aging (Petersen, 2003). Beginning in the 1960s, a variety of labels were applied to people who had some degree of memory or cognitive impairment, but not enough to warrant the diagnosis of a dementia. Benign Senile Forgetfulness, Aging-Associated Memory Impairment (AAMI; Crook et al., 1986), and others have now been supplanted by the term MCI. This term was developed to identify people at risk for AD, with hopes that we could enter them into trials with agents that might prevent the progression of the memory problem and the diagnosis of AD. However, the seeds of deconstruction regarding AD as beyond the normal aging process are found within the term MCI. Whereas MCI as a research term is motivated by the desire to develop better therapies, its clinical usage, which has been recommended by the American Academy of Neurology, is fraught with ethical and practical difficulties (see Petersen, 2003). Does an MCI diagnosis preclude AD or does it indicate its early stages? Further, we now have the genetic label "APOE4 homozygote" (two copies of a gene which codes for a cholesterol related protein), which can indicate a genetic predisposition for AD without any current symptoms. As they age, people with APOE4 alleles are at a somewhat greater risk for cognitive impairment from AD and perhaps in other circumstances as well (such as after head trauma and coronary artery bypass) (Barber & Whitehouse, 2002), but the risks may vary by ethnic group. The vision of medicine as a world of inexpensive genetic screening that permits identification of disease susceptibilities and designer drug treatment completely ignores population genetic issues, such as the risks associated with culturally defined racial categories and the effects of environment. Race is not a biologically well-defined concept, yet it dominates much of our thinking about genetic risk.

The labeling of caregivers is intimately associated with the labeling of the person to whom care is being provided. Prior to any diagnostic label, most people in a family-type relationship are already providing care to one another. However, when someone is labeled as having AD, the other person is labeled the caregiver of someone with dementia, which, to many academics, results in the risk of "caregiver burden." Normal caregiving, in the absence of a cognitively impaired partner, has its own burdens, but for many, it is still a rewarding experience. Yet when we move to a medicalized model, we run the risk of losing track of the positive aspects of caregiving. For example, the spiritual aspects of caregiving may be lost in the world of biomedicine (Stuckey, Post, Ollerton, FallCreek, & Whitehouse, 2002).

The concept of MCI challenges this process of labeling care recipients and caregivers. For instance, we are not clear whether MCI is a diagnosis, a label, a precondition, or a risk factor. Since there are no biological markers or tests, including clinical brain imaging or even autopsy, that permit the diagnosis of AD, the changes that occur with aging occur on a continuum and medical personnel decide the arbitrary cut point on any test in order to label someone with AD rather than describe the individual's changes as normal and associated with aging. Thus, the caregiver is faced with an uncertain role and future. Are they a caregiver of this person with MCI or someone with early AD? In many ways, the label "caregiver" is worse than patient. Persons with dementia may never be aware of their condition or lose insight as the condition progresses. This leaves the caregiver at risk for maintaining the functioning of the dyad.

However, not all diagnostic labels are bad. Some people may gain comfort from having a distinct medical explanation for symptoms. Also, the AD label may permit access to medical and psychosocial services. Often, in order to be eligible for a prescription drug benefit or other reimbursement for medical and social care, one needs a diagnosis. In this way, medical labels do serve a larger purpose.

Ethical Issues in the Care of People with AD

Genetic Testing

One of the current challenges that blood relative caregivers of persons with AD face is caring with the knowledge that they may be at risk for the same condition. Modern genetics has the ability to provide information to individuals about their genetic risks for various dementias (Post & Whitehouse, 1998a). In circumstances where an individual has an autosomal dominant form of AD, his or her child has a 50% chance of inheriting that gene. In these circumstances, testing one member of the family and finding a genetic mutation has direct implications for others. The parent will know that the children are at risk, and the children may know that they not only are at risk but also have the opportunity to find out if they carry the gene or not. Thus, some people live with the knowledge that they will develop AD at an age similar to their affected parent while perhaps caring for that parent.

Autosomal dominant mutations may create challenging ethical problems, but they are not as complex as genetic susceptibility loci. These genes affect an individuals' risk for AD, but are not causative. Such a gene is apolipoprotein E. All humans possess two copies of the APOE 2, 3, or 4 genes. Individuals with one, and especially two copies of E4, are more at risk for AD. They may also be at risk for not being able to recover as well from other insults to the brain, such as stroke or lack of oxygen.

Genetic markers affect one's risk for certain cardiovascular diseases as well, and we have recently evaluated an individual who had apolipoprotein E testing as part of a risk assessment in cardiology. This individual was presented to our clinic with the following story: "I was tested by another health organization without my permission and now know I have two copies of APOE 4. I am a double cancer survivor who has always used my mental faculties to help me through the stresses of life and of cancer, and I am now devastated by the possibility that I will lose those mental faculties." In actuality, the risks associated with apolipoprotein E4 are difficult to quantify, and are clearly not well enough defined to recommend this test for clinical use. Thus, both autosomal dominant and susceptibility testing challenge individuals to understand complex risks. Such information might be beneficial, providing individuals with the foresight to purchase long-term care insurance, or plan families differently. However, this knowledge also has the potential to affect lives in negative ways, and in the absence of specific preventative therapies, many people find the information of little use. Either type of genetic test results in the possibility of being a caregiver of someone at risk for, rather than someone with, symptoms of AD. Caregivers who are married and may produce children are in some sense caregivers of each other's genes, for both good and bad.

Diagnostic Disclosure

The problems of diagnosis previously described are reflected in the ambiguities of labels and the uncertainty of the relationship between AD and normal aging. However, the diagnostic disclosure process is complicated because it is not a simple transmission of information from a doctor to a patient, but a negotiation concerning the appropriateness of a label in a relationship that may be characterized by more or less trust. Thus, when a physician says to an individual that he has AD, the doctor will communicate with varying amounts of explanation and care, presenting information to someone with widely varying knowledge about AD. The resultant conversation may bring clarity and hope, or confusion and despair.

Research Ethics

A diagnostic label is potentially important not only for access to health services but also for research. An ethical foundation of research is the concept of informed consent (Karlawish et al., 2002). A potential research participant must be aware of his condition and its implications in order to make decisions about the potential risks and benefits of a particular research protocol. However, despite decades of effort, we have not achieved a social consensus about appropriate guidelines for conducting research with people who have cognitive impairment. Frequently, this issue has been embroiled in the politics of mental illness in which the challenges to informed consent add even more complexity.

It is still unclear how to determine when someone can no longer decide for himself whether to participate in research (i.e., lose capacity that may lead to a legal determination of incompetence). Moreover, choosing appropriate proxies and determining what degree of risk proxies can be allowed to assume on behalf of others are controversial. Federal regulations are unclear on this matter, and many states have varying and incomplete legislative positions. Family members and professionals vary in their attitudes regarding the degree to which people need protection from research risk. Concern is increasing that clinical scientists are driven to more aggressive behavior, such as in research recruitment, not only by their hopes for developing more effective interventions but also by career ambitions and financial gain. Further, the power of the pharmaceutical industry to drive research and care systems towards valuing medical over social interventions is increasingly evident. Direct consumer advertising and the growth of marketing budgets attest to the influence of profit-making models on our very conceptions of illness.

A variety of other ethical issues emerge in research, such as the use of placebos (Kawas et al., 1999). The question has risen regarding the appropriate use of a so-called inactive substance in a long-term study. Since we have approved medications to treat dementia, even if minimally effective, shouldn't these be considered a standard of care? However, placebos are not inactive; they provide benefit even to people with memory problems. Truthfully, currently available drugs are not of sufficient impact to make short-term placebo controlled studies ethically inappropriate. Moreover, from a social perspective, more information can be derived about the value of new medications from placebo controlled trials than from other designs, and thus benefit others in the long run.

Practical Ethical Issues in the Middle Stages of Dementia

Many practical issues emerge as the memory problem worsens. The major theme is preserving as much independence as possible while at the same time recognizing increasing dependency. For example, the safety of the patient and caregiver become more of an issue. Related to this, and perhaps the greatest problem that affects both the person with the disease and his/her caregivers, is the issue of driving. Patients with cognitive impairment, even those early in disease, are impaired in driving. Yet we know that drivers who are impaired for a variety of other reasons are permitted to drive, including teenagers with fluctuating endocrine levels and emotional growth as well as people who drive under the influence of various substances. The diagnosis of AD itself does not increase the risk of an accident, but the age-related changes in reaction time and cognition do. This is problematic on a case-by-case basis; when should we decide that someone should stop driving, and how forceful should we be in our enforcement of limitations? These decisions have profound implications upon both the AD sufferer and his/her caregiver. To deal with each case individually, it has been suggested that a family member or a professional assess the person's driving. Balancing the needs of the caregiver and the patient becomes more of a concern. Moreover, the caregiver increasingly needs to become the primary decision maker and will likely need to activate a durable power of attorney and advance directives.

End-of-Life Care

Maintaining and enhancing quality of life should be the goal throughout the life of someone labeled with AD, and should continue to be so at the end of life (Post & Whitehouse, 1998b). So much is done in our health care system to impair quality of death rather than to enhance the end of life. For example, patients with AD should not be subjected to overly aggressive care. Increasing evidence shows, for example, that feeding tubes do not enhance nutrition nor prevent aspiration pneumonia. Ethical practice includes awareness of the evidence for or against medical interventions. More fundamentally, we must decide how actively we should keep someone alive. How much time can we spend feeding profoundly demented people? How should we interpret "refusal" to eat? Is such a refusal a clinical problem or a sign the patient is ready to die? As the number of patients with AD and other cognitive impairments increases, and the challenge to our health care system to provide end-of-life care increases, we need to examine our goals for caring in relationship to other health priorities.

Future of Care

The future of care depends fundamentally on the values and resources of particular societies (Whitehouse, 2001b). Both developed and developing countries are aging, yet have very different assets, both financial and cultural, to address the needs of their growing elderly populations. For instance, oil and natural resource-rich countries like Norway can afford to experiment with the latest technologies to enhance care. In addition, social commitments vary across national and cultural boundaries. Japan and Scotland are prime examples of countries that are struggling to honor their political commitments to provide long-term care to the elderly. As women enter the workforce, as in Asia, for example, they do not have the time to provide care for aging parents (or parents-in-law as was the tradition in Japan). The pressures of increasing globalization of the economy of the world, environmental problems, and the potential for more warfare make the social context of providing care for the elderly all the more difficult.

Future Directions in Policy and Advocacy

Those countries with a post-World War II population bubble (the so-called baby boomers) will have a particular problem. This generation is likely to be on average wealthier and healthier than their parents. They are used to expressing their political will successfully. Whether they become greedy geezers or morally enlightened beings (or likely a blend of the two) is yet to be seen. Likely their behaviors will range from demanding some services for themselves while, hopefully, also attending to the needs of future generations. For instance, they will be challenged to find solutions to issues such as social security at a time when the current generations of elders and near elders are receiving more payouts from retirement systems than they contributed. This dilemma represents a huge unsustainable practical problem as well as a great ethical challenge for human beings in general.

To age well, it is critical to maintain a sense of life purpose and remain connected to one's family and community. The label AD can serve as a barrier to further life development and limit community engagement. Recognizing that we all have some degree of cognitive impairment (however mild, as in poorer short-term memory or difficulty multi-tasking), we must not stigmatize those less fortunate with the cognitive aging process than ourselves. In the future, we need to advocate new ways to maintain life quality as we rethink just how terms like Alzheimer's stigmatize people and communities.

We also need to reframe the concept of AD and tell different stories about cognitive aging. One example is to consider AD as a form of learning disability. We know that mental and physical activity is generally healthy and may in fact delay cognitive decline. We believe that older adults need a sense of purpose in community engagement.

In September 2011 the new national Alzheimer's Advisory Panel held its first meeting to contribute to developing a national strategic plan. The Alzheimer Association, which is strongly represented on the panel, is advocating heavily for biology solutions (breakthroughs and cures). The ethics of an approach build on unbridle faith in science (scientism) and fear mongering must be challenged. Spending more money on old solution is not likely to be productive. New ideas such as fostering quality of life in community need to be given more emphasis.

Future Directions in Practice

Improving interdisciplinary care should remain a priority. However, the role of physicians is particularly important in the future of care for persons with dementia. Although much hands-on-care is provided by other health care professionals, particularly nurses and social workers, physicians dominate the system politically and financially. Currently the medical profession is beginning to recognize its relationship to the pharmaceutical industry as the tremendous moral crisis that it is. As long as drug companies can convince doctors (and patients through direct-to-consumer marketing) that the answer to health care is a pill, particularly a newly developed expensive one with unknown long-term side effects, we will never develop the resources to provide better care systems. People need to depend less on professionals and biology and more on themselves and their communities in order to age successfully. Chronic disease self-management and health coaching should continue to emerge as important priorities. Public health attention to the health of communities through urban planning and sustainable practices will provide better long-term answers to aging associated cognitive challenges.

Future Directions in Education and Training

We must come to realize that education in various forms, not drugs, is the major intervention that we have in medicine to enhance the quality of lives of people affected by dementia. The Alzheimer's Association plays a valuable role in providing education to people affected by memory problems while also advocating for their needs. Such groups are increasingly challenged to provide appropriate information to those diagnosed early in the disease. Advocacy and education groups addressing AD, such as the Alzheimer's Association, should be judicious in their support of today's dominant medical model because doing so may, in fact, in many cases disrupt the opportunities for more positive caregiving experiences.

Education is a critical part of the development of professional and family caregivers. New models of health education are needed, such as the recently developed concept of geriatric interdisciplinary learning teams (Whitehouse, 2002a), which creates a more effective caring team by having the members learn together. Emphasizing the critical importance of involving patients and families as team members leads to enhanced outcomes for both care providers and care recipients. Families should be guided to self-help groups that work in both real life and virtual reality. Computer support groups are a wave of the future. Lifelong learning for successful aging should be encouraged even at early ages.

We must not forget that the person with the memory problem is himself/herself someone who could benefit from assistance with learning. AD could be framed as a progressive learning disability, and we could create environments, using various outside tools, in which people with memory problems could remember better. Computers could help them remember their daily events as well as past memories, or could serve as an assistant caregiver providing appropriate reassurance and feedback to an individual to keep him oriented and comfortable. Hand held devices with photographs, songs, and information, and individualized digital videodisks might provide people with the ability to remember past events that gave them pleasure. Pilot studies that include the use of this type of electronic technology have been developing (Whitehouse, Marling, & Harvey, 2002). Also, we have developed a simpler process, the LifeBook, which facilitates families collecting stories, songs, and photos to capture the values of elders and help shape decision making for individuals who are losing the capacity to make decisions for themselves.

Contributing to the education of younger children could serve as an activity for preserving cognitive well-being. The development of schools where people with memory problems could interact with younger people, creating a meaningful sense of contribution to the community for all, should be pursued. One example of this is the world's first intergenerational public school, The Intergenerational School (TIS), which is based on lifelong, developmentally appropriate, experiential service learning. In this environment, older adults with labels such as MCI and AD contribute to the education of children between kindergarten and sixth grade. TIS is the top-rated charter school in Ohio and is recognized for its excellent scores in reading and math, as well as attention to community values and service (Whitehouse, Bendezu, FallCreek, & Whitehouse, 2000). Moreover quantitative and qualitative research has demonstrated the value of volunteering and learning in the school for persons with mild to moderate dementia (George & Whitehouse, 2010).

Future Directions in Research

The essential aspect of research in the ethics of care for the future will be to break away from old categories of thinking. Understanding how labels such as Asymptomatic Alzheimer's disease, MCI, and AD affect people with cognitive challenges and their caregivers will be key. Recognizing and studying the positive aspects of caregiving will continue to be important. The development of medical and social programs that foster positive attitudes towards cognitive aging should be pursued. Further, we need to investigate how people of various cognitive abilities can be integrated into social programs without stigmatization. Studying how the culture of communities and institutions affect quality of life is essential. Culture change movements in long-term care, such as the Pioneer Movement, Eden Alternative, and Green House efforts, should be further evaluated. Quality of life should be further incorporated into trials of interventions. Comparisons of drug interventions and psychosocial programs should be made. Programs that are environmentally friendly and create opportunities for intergenerational work and play should be developed and evaluated, with particular attentionbeing paid to developing and evaluating effective programs for end-of-life care. The use of information technology to support elders in their homes and other residential areas should be encouraged and evaluated. The pervasive influence of the pharmaceutical industry on our conceptions of disease and the behavior of physicians should be scrutinized. The impact of direct-to-consumer marketing should be evaluated, in the process of likely limiting it. Cross-cultural studies of long-term care systems will be valuable to understand how different social, cultural, and ethical belief systems affect care. Qualitative, particularly narrative methods, should be encouraged as we open our minds to new possibilities for ethical caring.

Concluding Comments

As we approach the future of care, we should return to a lesson known to eighteenth-century physicians. Physicians then referred to their patients as "cures." Although perhaps reflective of therapeutic optimism or the arrogance of physicians, this terminology was more likely based on the identical Latin derivation of the words "care" and "cure." Physicians provided care and/or cure for everyone to the point of recovery, plateau, or death. The lesson here is that biological treatments are just one of the many approaches that we can provide patients with cognitive impairment. Rather than caring being in the shadow of cure-seeking molecular biology and genetics, we must insist that caring comes first.

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Chapter 10
Ethical Issues: Perspective 2: The Fundamental Role of Personhood

Stephen G. Post

Person-Centered Perspectives on Ethics in Alzheimer's Disease

The syndrome of dementia is an irreversible decline in cognitive abilities that causes significant dysfunction. It is distinguished from "normal age-related memory loss," which affects most people by about age 70 in the form of some slowing of cognitive skills and a deterioration in various aspects of memory. Since 1997, a degree of cognitive impairment that is greater than normal age-related decline but not yet diagnosable as dementia has been labeled "mild cognitive impairment," or MCI, with about a third of those in this category "converting" to dementia each year.

Although dementia can have many causes, the primary cause of dementia in our aging societies is Alzheimer's disease (AD). Approximately 60% of dementia in the elderly in the USA is secondary to AD (USA General Accounting Office, 1998). Without delaying or preventive interventions, the number of people with AD, in the U.S. alone, will increase to 14.3 million by 2050 (Evans et al., 1989).

This discussion will focus on the so-called Alzheimer's dementia in order to illustrate ethical issues that pertain to all progressive dementias. One epidemiological study in the USA estimated that 47% of persons 85 years and older (the "old–old") had probable AD (Evans et al., 1989), although this is widely considered an inflated statistic. According to a Swiss study, 10% of nondemented persons between the ages of 85 and 88 become demented each year (Aevarsson & Skoog, 1996). Some argue that those who live into their 90s without being affected by AD will usually never be affected by it, but this is still speculative.

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The Fundamental Moral Question: Do People with Dementia "Count?"

Despite the seriousness of dementia and the responsibilities it creates for caregivers, it is ethically important that the person with dementia not be judged by "hypercognitive" values (Post, 2000a). As Steven Sabat wrote, the self is not cognition alone, but is rather a complex entity with emotional and relational aspects that should be deemed morally significant and worthy of affirmation (2001). However, in an earlier discussion of the disparities in bioethical thinking about what constitutes a person, Stanley Rudman concludes, "It is clear that the emphasis on rationality easily leads to diminished concern for certain human beings such as infants,…and the senile, groups of people who have, under the influence of both Christian and humanistic considerations, been given special considerations" (1997, p. 47).

A bias against the deeply forgetful is especially pronounced in philosophical theories of "personhood" in which the moral status or considerability of "persons" is based on an intact set of cognitive abilities, while "nonpersons" have no status other than to be euthanized painlessly (Kitwood, 1997). Often, the personhood theorists couple their exclusionary rationalistic views with utilitarian ethical theories that are deeply incoherent with regard to life and death. As Rudman summarizes the concern, rationality is too severe a ground for moral standing, "allowing if not requiring the deaths of many individuals who may, in fact, continue to enjoy simple pleasures despite their lack of rationality…" (1997, p. 57).

The fitting moral response to people with dementia, according to classical western ethical thought and related conceptions of common human decency, is to enlarge our sense of human worth to counter an exclusionary emphasis on rationality, efficient use of time and energy, ability to control distracting impulses, thrift, economic success, self-reliance, self-control, "language advantage," and the like. As Alasdair MacIntyre argues, we have made too much of the significance of language, for instance, obscuring the moral significance of species that lack linguistic abilities, or human beings who have lost such abilities (MacIntyre, 1999).

It is possible to distinguish two fundamental views of persons with dementia. Those in the tradition of the Platonic-Stoic and Enlightenment rationalism have achieved much for universal human moral standing by emphasizing the spark of reason (*logos*) in us all; yet according to this tradition, when this rationality dissipates, so does moral status. Those who take an alternative position see the Platonic-Stoic heritage as an arrogant view in the sense that it makes the worth of a human being entirely dependent on rationality, and then gives too much power to the reasonable. This alternative view is generally associated with most Jewish and Christian thought, as well as that of other religious traditions in which the individual retains equal value regardless of cognitive decline. As the Protestant ethicist Reinhold Niebuhr wrote, "In Stoicism, life beyond the narrow bonds of class, community, and race is affirmed because all life reveals a unifying divine principle. Since the principle is reason, the logic of Stoicism tends to include only the intelligent in the divine community. An aristocratic condescension, therefore, corrupts Stoic universalism" (1956, p. 53). This rationalistic inclusiveness lacks the deep universalism of other-regarding or unlimited love (Post, 2000a).

The perils of forgetfulness are especially evident in today's western culture of independence and economic productivity, in which intellect, memory, and self-control are highly valued. AD is a quantifiable neurological atrophy that objectively assaults normal human functioning. However, as medical anthropologists highlight, AD is also viewed within the context of socially constructed images of the human self and its fulfillment. A longitudinal study carried out in urban China by Ikels, for example, indicates that dementia does not evoke the same level of dread for Chinese as it does among Americans (1998). Thus, the stigma associated with the mental incapacitation of dementia varies according to culture.

This stigma is pronounced in the work of the eminent philosopher Peter Singer, for example, as part of a "preference utilitarian" philosophical culture that believes that those who do not project preferences into the future and implement them are not people. Those with memory impairment must then ultimately be devalued (Singer, 1993). For people with dementia, who in different instances maintain human capacities (cognitive, emotional, rational, or aesthetic) and can still experience many forms of gratification, this is not plausible. The challenge is to work with remaining capacities.

Quality of Life

Emotional, relational, aesthetic, and symbolic well-being are possible to varying degrees in people with progressive dementia (Kitwood, 1997). Quality of life can be much enhanced by working with these aspects of the person. The first principle of care for persons with dementia is to reveal to the one suffering from dementia their value by providing attention and tenderness in love (Kitwood).

Kitwood and Bredin (1992) developed a description of the "culture of dementia" that is useful in appreciating emotional and relational aspects of quality of life. They provide indicators of well-being in people with severe dementia: the assertion of will or desire, usually in the form of dissent despite various coaxings; the ability to express a range of emotions; initiation of social contact (for instance, a person with dementia has a small toy dog that he treasures and places it before another person to attract attention); and affectional warmth (for instance, a woman wanders aimlessly in the facility without much socializing, but when people say hello she stops to give them a kiss on the cheek).

In enhancing quality of life, it is crucial to accept the reality of the person with dementia rather than try to impose one's own reality. In the mild stage of AD, there is good reason to try to orient a person to reality. The aesthetic well-being available to people with AD is similar to that achieved from an art or music therapy session. In some cases, a person with even advanced AD may still draw a valued symbol from earlier in life, as though through art a sense of self is retained (Firlik, 1991). The abstract expressionist de Kooning painted his way through much of his 14-year struggle with AD until his death in 1996. In contrast, at some point in moderate AD it becomes oppressive to impose reality upon them. Good caregivers know how to work with remaining capacities in a person with dementia, rather than against them.

A sense of purpose or meaning on the part of caregivers can enhance quality of life for the person with dementia. In an important study by Rabins, Fitting, Eastham, and Fetting (1990) 32 family caregivers of persons with AD and 30 caregivers of persons with cancer were compared cross-sectionally to determine whether the type of illness affected the emotional state of the caregiver and to identify correlates of both undesirable and desirable emotional outcomes. While no prominent differences in negative or positive states were found between the two groups, correlates of negative and positive emotional status were identified. These include caregiver personality variables, number of social supports, and the emotional support from religious faith. Specifically, it was stated: "emotional distress was predicted by self-reported low or absent religious faith" (Rabins et al.). Moreover, spirituality predicted positive emotional states in caregiving. Interestingly, the study suggests that it was "belief, rather than social contact, that was important." Spirituality and religion are especially important to the quality of life of African-American caregivers, for whom it is shown to protect against depression (Picot, Debanne, Namazi, & Wykle, 1997). Spirituality is also a means of coping with the diagnosis of AD for many affected individuals (Elliot, 1997).

In general, quality of life can be a self-fulfilling prophecy. If those around the person with dementia see the glass as half empty and make no efforts to relate to the person in ways that enhance his or her experience, then quality of life is minimal. Steven R. Sabat, who has produced the definitive observer study of the experience of dementia, underscores the extent to which the dignity and value of the person with dementia can be maintained through affirmation and an existential perspective (Sabat, 2001).

Specific Clinical Ethical Issues

Nearly every major issue in clinical ethics pertains to AD (Post, 2000b). The Alzheimer's Association issued a definitive 2001 publication on ethics that covers truth in diagnosis, therapeutic goals, genetic testing, research ethics, respect for autonomy, driving and dementia, end-of-life care, assisted oral feeding and tube feeding, and suicide and assisted suicide (Alzheimer's Disease Association, 2001).

Truth telling in diagnosis is generally recommended because this allows the affected individual, while still competent, to make plans for the future with regard to finances, health care, and activities. Most clinicians in the USA and Canada now do disclose the probable diagnosis of AD, even though it is only about 90% accurate and must be verified upon autopsy. This transition has been encouraged by the emergence of new treatments (Alzheimer's Association, 2001).

AD is a genetically heterogeneous disorder—i.e., to date, it is associated with three determinative or causal gene mutations (i.e., someone who has the mutation will definitely get the disease) and one susceptibility or risk gene. These are autosomal-dominant genes and pertain to early-onset familial forms of AD (usually manifesting between the early 40s and mid-50s), which, according to one estimate, account for possibly fewer than 3% of all cases. These families are usually well aware of their unique histories. Only in these relatively few unfortunate families is genetic prediction actually possible, for those who carry the mutation clearly know that the disease is an eventuality. Many people in these families do not wish to know their genetic status, although some do get tested. Except in the early-onset familial cases where a single gene mutation causes the disease, genetic testing is generally frowned on by the Association, for several reasons.

Currently, there is no clearly predictive test for ordinary late-onset AD that is associated with old age. There is one well-defined susceptibility gene, an apolipoprotein E ε4 allele on chromosome 19 [apoE=protein; APOE=gene], which was discovered in 1993 and found to be associated with susceptibility to late-onset AD. A single ε4 gene (found in about one-third of the general population) is not predictive of AD in asymptomatic individuals—i.e., it does not come close to foretelling disease, and many people with the gene will never have AD. Among those 2% of people with two of the ε4 genes, AD does not necessarily occur either (Post et al., 1997). Such susceptibility testing can be condoned in a research setting, but is not encouraged in clinical practice because it provides no reliable predictive information upon which to base decisions, it has no medical use, and it may result in discrimination in obtaining disability or long-term care insurance (Alzheimer's Association, 2001; Post et al., 1997).

Despite its lack of encouragement in testing for susceptibility, the Association does support candor in early diagnosis when possible. The Association's statement (2001) includes the important argument that disclosing the diagnosis early in the disease process allows the person to "be involved in communicating and planning for end-of-life decisions." Diagnostic truth telling is the necessary beginning point for an ethics of "precedent autonomy" for those who wish to implement control over their future through advance directives such as durable power of attorney for health care, which allows a trusted loved one to make any and all treatment decisions once the agent becomes incompetent. This can effectively be coupled with a living will or some other specific indication of the agent's material wishes with regard to end-of-life care. Unless the person knows the probable diagnosis while still competent to file such legal instruments, the risk of burdensome medical technologies is increased. Even in the absence of such legal forms, however, many technologically advanced countries will allow next of kin to decide against efforts to extend life in severe dysfunction. This is important because many patients suffer incapacitating cognitive decline long before having a diagnostic workup; those who are diagnosed early enough to exercise their autonomy can often quickly become incapacitated.

The Alzheimer's Association (2001) does not support mandatory reporting of a probable diagnosis of AD to the Department of Motor Vehicles, although this does occur in California. There are a number of reasons for this caution, one of which is patient confidentiality. Reporting requirements might discourage some persons from coming into the clinic for early diagnosis at a time early in the course of disease when drug treatments are most clearly indicated. Eventually all people with AD must stop driving when they are a serious risk to self or others. Family members must know that if a loved one drives too long and injures others, they may be held financially liable and insurers may not be obliged to cover this liability.

Ideally, any privilege would never be limited without some offering of viable alternatives to fill in the gaps and diminish any sense of loss. Compromise and adjustments can be successfully implemented by those who are informed and willing, especially when the person with AD has insight into diminishing mental abilities and loss of competence. The affected person should retain a sense of freedom and self-control if possible.

AD is on the leading edge of the debate over physician-assisted suicide (PAS) and euthanasia. The policies that emerge from this debate will have monumental significance for people with dementia and for social attitudes toward the task of providing care when preemptive death is cheaper and, to some, more desirable. Currently, the Alzheimer Association affirms the right to dignity and life for every Alzheimer patient and does not condone suicide (Alzheimer's Association, 2001). However, the Association asserts that the refusal or withdrawal of any and all medical treatment is a moral and legal right for all competent Americans of age, and this right can be asserted by a family surrogate acting on the basis of either "substituted judgment" (what the patient when competent would have wanted) or "best interests" (what seems the least burdensome option in the present).

The Association concludes that AD *in its advanced stage should be defined as a terminal disease*, as roughly delineated by such features as the inability to recognize loved ones, to communicate by speech, to ambulate, or to maintain bowel and/or bladder control. When AD progresses to this stage, weight loss and swallowing difficulties will inevitably emerge. Death can be expected for most patients within a year or two, or even sooner, regardless of medical efforts. One useful consequence of viewing the advanced stage of AD as terminal is that family members may better comprehend palliative (pain medication) care as an alternative to medical treatments intended to extend the dying process. Some argue that efforts at life extension in this advanced stage create burdens and avoidable suffering for patients who could otherwise live out the remainder of their lives in greater comfort and peace. Cardiopulmonary resuscitation, dialysis, tube feeding, and other such invasive technologies may not be considered desirable by many in AD's most advanced stages. The use of antibiotics usually does not prolong survival, and comfort can be maintained without antibiotic use in patients experiencing infections. Physicians and other health care professionals have the option to recommend this less burdensome approach to family members and to persons with dementia who are competent, ideally soon after initial diagnosis. Early discussions of a natural and less invasive, if earlier, death should occur between persons with dementia and their families, guided by information from health care professionals on the palliative care approach (Alzheimer's Association, 2001).

In closing this section, attention will be directed in greater depth to three representative areas of special concern to family and professional caregivers: cognitive enhancing compounds, research risk, and tube feeding.

Cognitive Enhancing Compounds

New compounds that mitigate the symptoms of dementia have emerged in the market. These compounds, known as cholinesterase inhibitors, slightly elevate the amount of acetylcholine in the brain and boost communication between brain cells. In the earlier stages of the disease, while enough brain cells are still functional, these drugs can improve word finding, attentiveness to tasks, and recognition of others for a brief period in the range of 6 months to 2 years. Thus, some symptoms can be mitigated for a while, but these drugs have no impact on the underlying course of the disease, and neither reverse nor cure dementia. Some affected individuals, after taking a new compound, whether artificial or natural, may exude a burst of renewed self-confidence in their cognitive capacities. But how much of this is due to the compound itself remains unclear. Presumably each person with AD is a part of some relational network that inevitably plays a role in the self-perception of cognitive improvement—indeed, self-perception is dependent on the perceptions of others. Realistically, a medication may add to the self-perception a renewed sense of mental clarity, as though "a fog has lifted," yet none of the available cognitive enhancing compounds actually slow the progression of disease.

It is hard for professionals to know how to respond to the passion for the possible. Questions such as indulging unrealistic hopes for emotional reasons (Post, 1998, 2000b), or the appropriate expenditure of money on marginally effective compounds in comparison with other environmental and relational opportunities, pose problems. Some fear that the efficacy of the compound is exaggerated by exploitative by pharmaceutical companies. Many clinicians caution both persons with AD and their family caregivers against thinking that the new compound is a miracle cure. Many still remain somewhat skeptical of studies of cognitive testing indicating significant but always minor benefit; no such studies take into account confounding factors such as the quality of relationships, environment, and emotional well-being. Medication needs to be placed within a full program of dementia care (including emotional, relational, and environmental interventions) so as not to be excessively relied upon; family members should be respected when the person with AD desires to stop medication. Conversely, even when medication is desired, families need to appreciate the limits of current compounds.

It is possible as well that the antidementia compounds can be double-edged swords, especially in those cases where they may have some capacity to give what is always at best a modest and fleeting cognitive boost—fleeting because the underlying cognitive decline is intractable. While some slight cognitive improvements may occur, these may come at the cost of renewed insight into the disease process on the part of the affected individual, and of relational difficulties in the context of affected individuals and their caregivers. If the kindest point in the progression of AD is when the person with dementia forgets that he or she forgets and is therefore able to get free of "insight" and related anxiety, then a little cognitive enhancement might detract from, rather than add to, quality of life. It is possible then to speak of "detrimental benefits."

Decisions about these compounds are ethically and financially complex because their efficacy is quite limited, the affected individual remains on the inevitable downward trajectory of irreversible progressive dementia, and there may be non-chemical interventions focusing on emotional, relational, and spiritual well-being that are both cheaper and more effective. In the future, as compounds emerge that can actually alter the underlying progression of AD, affected individuals and caregivers will be faced with difficult trade-offs between length of life and quality of life (Post, 1997, 2001a).

Research Risks

The *crucial* unanswered question in AD research is this: What should be the maximal or upper limit for permissible potential risks in any AD research, regardless of whether the research is characterized as potentially therapeutic for the subject or not? A secondary unanswered question is this: Should proxy consent be permitted in higher risk research, even when there is no potential therapeutic benefit for the participant, just as it is permitted when the research is considered potentially therapeutic? Without agreement on these fundamental questions, the upcoming treatments, promising both greater benefit and greater risk, will not expeditiously reach those in most need.

The Alzheimer Association's statement (2001) on this issue is as follows:

(A) For minimal risk research all individuals should be allowed to enroll, even if there is no potential benefit to the individual. In the absence of an advance directive, proxy consent is acceptable.

(B) For greater than minimal risk research *and* if there is a reasonable potential for benefit to the individual, the enrollment of all individuals with Alzheimer's disease is allowable based on proxy consent. The proxy's consent can be based on either a research-specific advance directive *or* the proxy's judgment of the individual's best interests.

(C) For greater than minimal risk research *and* if there is no reasonable potential for benefit to the individual only those individuals who (1) are capable of giving their own informed consent or (2) have executed a research-specific advance directive are allowed to participate. In either case, a proxy must be available to monitor the individual's involvement in the research. (*Note*: this provision means that individuals who are not capable of making their own decisions about research participation and have not executed an advance directive or do not have a proxy to monitor their participation cannot participate in this category of research).

The Association's statement endorses surrogate consent in all research of potential benefit to the subject, even if there is potentially a greater than minimal risk. Surrogate consent should always be based on accurate facts about the risks and potential benefits of the clinical research or trial, rather than on understatement of risks or burdens and exaggerated claims of benefit. Participants in all research should be protected from significant pain or discomfort. It is the responsibility of all investigators and surrogates to monitor the well-being of participants.

The Alzheimer Association indicates that surrogates must not allow their hopes for effective therapies to overtake their critical assessment of the facts or to diminish the significance of participant expressions of dissent. Subject dissent or other expressions of agitation should be respected, although a surrogate can attempt reasonable levels of persuasion or assistance. People with dementia, for example, may initially refuse to have blood drawn or to take medication; once a family member helps calm the situation and explain things, they may change their minds. This kind of assistance is acceptable. Continued dissent, however, requires withdrawal of the participant from the study, even if surrogates would prefer to see the research participation continue.

At this point in time, the most important unresolved issue in dementia research is how much potential risk society should allow to those affected by AD. Research in AD is becoming increasingly physically invasive and biologically complex. In general, research ethics has not addressed such issues as maximum thresholds of potential risk, how discomfort can best be monitored, or to what degree discomfort should be allowed, focusing instead on matters of subject and proxy consent.

End of Life and PEG Tubes

Gastrostomy tube feeding became common in the context of advanced dementia and, more generally in elderly patients, after 1981, secondary to the development of the percutaneous endoscopic gastrostomy (PEG) procedure. The PEG procedure was developed by Dr. Michael Gauderer and his colleagues at Rainbow Babies and Children's Hospital in Cleveland (1979–1980) for use in young children with swallowing difficulties. The procedure required only local anesthesia, thus eliminating the significant surgical risk associated with general anesthesia and infection (Gauderer & Ponsly, 1981). Gauderer wrote two decades later that while PEG use has benefited countless patients, "in part because of its simplicity and low complication rate, this minimally invasive procedure also lends itself to over-utilization" (Gauderer, 1999). Expressing moral concerns about the proliferation of the procedure, Gauderer indicates that as the third decade of PEG use begins to unfold, "much of our effort in the future needs to be directed toward ethical aspects…" (p. 882). PEG is being used more frequently even in those patients for whom these procedures were deemed too risky in the past.

For over a decade, researchers have underscored the burdens and risks of PEG tube feeding in persons with advanced dementia. The mounting literature was well summarized by Finucane et al., who found no published evidence that tube feeding prevents aspiration pneumonia, prolongs survival, reduces risks of pressure sores or infections, improves function, or provides palliation in this population (Finucane, Christmas, & Travis, 1999; Gillick, 2000; Post, 2001b).

Families often perceive tube feeding as preventing pneumonia or skin breakdown, and many assume that it extends survival. These perceptions are erroneous. The main benefit of PEG is that it makes life easier for the informal family caregiver who, for reason of competing duties or perhaps physical limitation, cannot find the time or energy to engage in assisted oral feedings. Yet PEG use is not really “easy,” because it has its technological complexities, and the recipient will usually have diarrhea. In some cases, physical restraints are used to keep a person from pulling on the several inches of tube that extend out of the abdomen. Due to these difficulties, for some, assisted oral feeding might be a better option. In practice, there will be some cases in which the limited capacities of an informal family caregiver justify tube feeding as the ethically imperative alternative to starvation when the ability to swallow has begun to diminish. Ideally, home health aides would make assisted oral feeding possible even in these cases, but this is not a priority in the current health care system. Institutions, however, should uniformly provide assisted oral feeding as a viable alternative to tube feeding, a measure that would profoundly obviate the overuse of this technology.

There will be many family caregivers who have no interest in PEG, or any other “intrusive” medical technologies, and who feel that they are being loyal to their loved one’s prior wishes. A physician should expect this response. A study included in-person interviews of 84 cognitively normal men and women aged 65 years and older from a variety of urban and suburban settings (including private homes, assisted-living apartments, transitional care facilities, and nursing homes). Three-fourths of the subjects would not want cardiopulmonary resuscitation, use of a respirator, or parenteral or enteral tube nutrition with the milder forms of dementia; 95% or more would not want any of these procedures with severe dementia (Gjerdingen, Neff, Wang, & Chaloner, 1999). These subjects were adequately informed of the burdens and benefits of such interventions. With adequate information, these people were able to make informed decisions that best suited their individual needs and desires.

Conclusions

AD poses a host of ethical challenges that family caregivers, professionals, and the Alzheimer’s Association are taking seriously. Considerable empirical and conceptual work is being pursued on the various topics considered herein. In the future, the economic realities of an aging society will require the aging societies around the world to consider how the needs of persons with dementia can be ethically balanced with the needs of older adults more generally, and with other strains on the healthcare system. It will require a significant commitment to human dignity and the well-being of persons with dementia to avoid neglecting them in the calculus of distributive justice. Moreover, with no magic biochemical bullet to cure AD on the horizon, the fundamental questions of human respect and dignity will challenge many families. Thus, hope still should be placed for the most part in the possibilities for enhanced caregiver support and insight into continuing selfhood in those with dementia, and in the potential for a cultural recognition of the value of the deeply forgetful (Post, 2011).

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Chapter 11
Legal Issues for Caregivers of Individuals with Alzheimer's Disease

Jack Schwartz and Leslie B. Fried

When a family member or friend is diagnosed with Alzheimer's disease, the initial reaction is often sadness and distress at what the future may hold. Over the course of the disease progression, families and caregivers are faced with an array of health and legal issues. As our society ages and our life expectancy steadily increases, the number of people directly touched by this disease expands. This will have significant ramifications for health care and legal policy. Questions of the use and limitations of advance care plans, and their implication for participation in research, continue to arise. The influence of Medicare coverage policy on access to health care and the implications of Alzheimer's disease and behavioral complications for our health and legal systems must be further explored. In this chapter, we examine these multifaceted issues and identify policy challenges for the future that should seek to balance the interests of the various stakeholders with the need to protect individuals with Alzheimer's disease.

Advance Care Planning

The overall goal of advance care planning is that the last portion of a person's life ought to reflect the person's values, ideas, and hopes. Advance care plans and directives increase the chances that the medical response to urgent situations will

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conform to the individual's own priorities. Effective advance care planning can also make caregiving less difficult, for it provides family members and friends some assurance that difficult end-of-life decisions are made within a framework of the patient's own choice.

Advance care planning is especially important for someone diagnosed with probable Alzheimer's disease. The typical course of the disease, involving slow deterioration and inevitable loss of capacity, both permits advance care planning and heightens the importance of doing so before the disease makes it impossible.

The process of advance care planning for someone with Alzheimer's disease should begin with reflection and conversation, not the signing of legal documents. Nevertheless, the decisions that emerge from kitchen-table discussions are best documented in a legally recognized manner. That is the role of advance directives.

Over the last three decades, beginning with the enactment of California's Natural Death Act in 1976, every state has enacted some kind of advance directive statute. In addition, health care facilities are subject to federal and sometimes state requirements intended to promote the use of advance directives. The federal Patient Self-Determination Act requires hospitals, nursing homes, home health agencies, hospice programs, and health maintenance organizations that receive Medicare or Medicaid reimbursement to provide patients with information about advance directives.

Advance directive laws provide a means by which an individual can plan for end-of-life care when the individual is no longer able to direct that care personally. Advance directives fall into two general categories: *instructional directives*, like a living will, and *proxy directives*, like a durable power of attorney for health care.

The typical instructional directive says that, when medical deterioration has reached a certain point, the person no longer wants medical interventions aimed at prolonging life. In most states, decisions of this kind may be implemented when the individual has been determined to be in terminal condition or a persistent vegetative state. In some states, instructions in an advance medical directive are allowed by statute to extend to advanced disease that is not yet terminal. Moreover, whatever a particular state's advance directive statute may provide, individuals are free to express their wishes about care in the event of Alzheimer's or other irreversible disease, and such expressions are likely to be given effect. Consequently, someone with mild Alzheimer's disease may use an advance directive to make decisions about end-of-life care for the time when the disease will get far worse.

A proxy directive, such as a durable power of attorney for health care, expresses the individual's choice about who should decide health care matters if the individual cannot. The individual may describe the proxy's authority over end-of-life decisions broadly, or as narrowly as the individual wishes. Often, individuals execute both instructional and proxy advance directives. Although there remains doubt about reliance on instructional advance directives as an effective means of conforming proxies' decisions to patient preferences (Ditto et al., 2001), proxies who forgo life-sustaining medical treatments experience heightened stress if they bear sole responsibility for the decision, compared with proxies who feel that they have shared responsibility with the patient, based on prior guidance (Tilden, Tolle, Nelson, & Fields, 2001).

A major issue concerning advance directives is their limited use. Although estimates vary, most studies show that only around 25% of the adult population has executed an advance directive (Assistant Secretary for Planning and Evaluation, 2008). Even among nursing home residents, probably fewer than half have completed advance directives. Perhaps the main effect of laws like the Patient Self-Determination Act is merely to improve documentation of existing advance directives rather than to motivate people who have not done so (Bradley, Wetle, & Horowitz, 1998).

Part of the reason for this relatively low prevalence is the difficulty of making prospective decisions about life-sustaining medical treatments. Few people are keen to engage in a detailed medical description of their own demise, especially if, as with Alzheimer's disease, the description is of an inexorable loss of the capacities that people value most highly.

A second problem with instructional advance directives is the disjunction between what people say about life-sustaining treatment in the abstract and what they might want, or what might be best for them, once the actual situation arrives—what one prominent geriatrician calls the concern "that well people will make glib pronouncements about refusing treatment in hypothetical futures" (Finucane, 2001, p. 696).

A third problem is that state advance directive laws typically contain highly legalistic and treatment-oriented model forms. Some state laws require an advance directive to be "substantially" in the form of the statutory model, an ambiguous phrase at best. Even in states with more permissive laws, a statutory model becomes the de facto standard. If the model contains confusing or overly complex language, it undermines the presumed goal of promoting advance directive use. Such a form does not encourage conversations between an individual and family members or with doctors.

Those assisting with advance care planning should consider giving less emphasis to hard-and-fast treatment instructions and more to a combination of proxy designations and personalized descriptions of preferences and values. For many people, the decision about *who* should decide is much easier to grasp and make than the decision of exactly *what* treatments should be used or declined as future health problems mount. Indeed, many people with Alzheimer's disease might have the capacity to designate a health care agent even after they have lost the capacity to give specific health care instructions.

Caregivers who become health care proxies also need help in understanding that role and the tools to carry it out. They must be advocates for the patient, seeking to establish a plan of care that promotes the patient's own preferences and goals (not those of the proxy) and the patient's best medical interest. Because the health care system may not be responsive to that priority, proxies need a range of advocacy knowledge and skills, including the ability to hold firm under pressure to the patient's goals and interest. In this often lonely and demanding role, they need support and assistance.

Case Study: The Impact of Regulation on Use of Feeding Tubes in Patients with Advanced Alzheimer's Disease

The failure of some nursing homes to provide their residents with wholesome food has rightly been seen as scandalous. An investigatory report by a congressional subcommittee noted complaints, for example, that uneaten food left by one resident was not infrequently served to another (United States Senate Special Committee on Aging, 1994).

A logical solution to the problem of inadequate nutrition is a legal mandate that adequate nutrition be provided. This is the gist of the regulations governing nursing homes that participate in the Medicare and Medicaid programs, and of comparable state licensing regulations. For example, a federal regulation instructs nursing homes to "provide each resident with a nourishing, palatable, well-balanced diet that meets the daily nutritional and special dietary needs of each resident" (Department of Health and Human Services [HHS], 2002a). Another federal regulation requires each nursing facility to ensure that a resident maintains "acceptable parameters of nutritional status, such as body weight and protein levels, unless the resident's clinical condition demonstrates that this is not possible" (HHS, 2002b). Still another regulation states that a nursing facility "must provide each resident with sufficient fluid intake to maintain proper hydration and health" (HHS, 2002c).

These regulatory requirements are entirely understandable. They respond to a genuine problem, and they contain an acknowledgment that clinical situations will exist in which conventional markers of deficient nutrition are inapposite. In their enforcement, however, the regulations have taken on the character of rigid mandates. Surveyors from state licensing and regulatory agencies frequently have been unwilling to exercise judgment and discretion in differentiating weight loss that signifies neglect from weight loss that signifies an inexorable disease process. Consequently, nursing home administrators take the "safe course" of insisting on tube feeding, even for residents with advanced dementia, so as avoid regulatory sanctions (Gillick, 2003).

Yet, for patients with advanced Alzheimer's disease, artificially administered nutrition and hydration may be inconsistent with their preferences and best medical interest. Commentators have concluded that tube feeding does not improve either the functional status or the comfort of demented patients, does not prolong survival, and indeed, owing to its many serious adverse effects, may cause suffering (Finucane, Christmas, & Travis, 1999; Gillick, 2000).

The response to this problem requires action at several levels: greater knowledge on the part of physicians about the actual efficacy of tube feeding (or lack of it), and professional courage in advocating for their patients' appropriate care no matter the pressure to the contrary, to avoid what is, for some patients, a useless and burdensome intervention; better training of regulatory officials, to abate overly rigid application of the regulations; and a greater willingness on the part of caregivers to insist that the use of medical technology be clearly linked to agreed-upon goals of care, to escape the fallacy that the availability of technology implies the need to use it.

Research Participation

Research into the etiology, prevention, and treatment of Alzheimer's disease is active and promising. For example, more than 250 open studies related to Alzheimer's disease are listed in an online government compendium (National Institutes of Health, n.d.). For some of these research efforts and, no doubt, many more in the future, people with Alzheimer's disease will be the research subjects (Sutton, 2003).

Some research can be carried out with subjects who, despite mild Alzheimer's disease, retain capacity to give informed consent to their research participation. Even if they are able to do so at the outset, however, they might lose capacity during the course of the research. What happens then? Other clinical trials might be aimed at the symptoms of advanced Alzheimer's disease, in which case presumably none of the subjects will have capacity to give informed consent. Who, if anyone, may give consent on their behalf?

The diagnosis of Alzheimer's disease alone ought not to be a bar to an individual's consent to research participation. Rather, the ethical principle of respect for persons means that researchers must assess whether the individual is "capable of deliberation about personal goals and acting under the direction of such deliberation" (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1979, p. 4). If so, the individual's informed consent should be accepted; if not, the individual may not be enrolled in the research unless another's consent is legally and ethically acceptable.

Even if a reasonable capacity assessment process concludes that an individual with Alzheimer's disease may give consent, future loss of capacity can be anticipated. One device that can address this problem is the research-related advance directive. Such a document, created by the individual prior to loss of capacity, could indicate the individual's desire to remain in an ongoing study even after loss of capacity, describe the types of future research in which he or she might want to participate, and name a proxy for future decision making (National Bioethics Advisory Commission, 1998).

As a practical matter, however, it is unlikely that research-related advance directives will be widely used, given that health care advance directives, which have been promoted for more than a decade, have not been. Moreover, there are significant questions about the extent to which an individual can successfully imagine, and reflect in an advance directive, preferences about future research (Dresser, 2001a). Consequently, research participation after loss of capacity will most often depend on permission from a proxy who was not named or given guidance by the individual.

Under the regulations that govern federally conducted or funded research, a researcher ordinarily may not enroll a human subject in research without the informed consent of the subject or the subject's legally authorized representative (HHS, 2002d). Neither the regulations nor any other federal law identifies the circumstances under which someone (other than the parent or guardian of a child) is a "legally authorized representative" (Hoffmann, Schwartz, & DeRenzo, 2000). The regulations merely define "legally authorized representative" as "an individual or judicial or other body authorized under applicable law to consent on behalf of a prospective subject to the subject's participation in the procedure(s) involved in the research" (HHS, 2002e). This definition is of no help in resolving the question of what "applicable" law grants this authority to proxies.

Although a few states (most recently, California and Virginia) have enacted statutes expressly authorizing family members and other surrogates to give consent for a decisionally incapacitated individual to participate in research, most have not. In the latter, more numerous groups of states, some contend that those who have authority to make health care decisions ought to be recognized as research decision makers as well, at least when research participation holds out a reasonable prospect of direct medical benefit (Bonnie, 1997). Others worry that proxies have conflicts of interest that cast doubt on the appropriateness of decisions to enroll an individual with dementia in research. For example, they may place undue weight on the scientific knowledge to be gained, thinking of the ultimate benefit to themselves and their children, and so downplay the risks to the subjects (Dresser, 2001b). Indeed, an assessment of risk is especially difficult when the subject's experience of the research procedures cannot be confidently predicted or known. Yet, if the alternative to recognition of family proxies is guardianship, few researchers would be likely to pursue that expensive and often time-consuming alternative. There is, in short, no consensus about the best policy outcome, one that is both sufficiently protective of vulnerable subjects and supportive of crucially important research.

Medicare: The Influence of Local Coverage Policy on Access to Care

Medicare is the primary health insurance program for individuals with Alzheimer's disease. In 2009, 95% of Medicare beneficiaries with dementia have additional chronic conditions, including coronary heart disease (30%), diabetes (29%), and congestive heart failure (22%).[1] Sixty to eighty percent of Alzheimer's individuals suffer from neuropsychiatric symptoms.[2] This vulnerable population has higher use of Medicare hospital and physician services, higher Medicare costs for hospital,

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[1] Alzheimer's Association, 2012 Alzheimer's Disease Facts and Figures, Alzheimer's & Dementia, Volume 8, Issue 2.

[2] Lyketsos, C., Lopez, O., Jones, B., Fitzpatrick, A., Breitner, J., & DeKosky, S. (2002). Prevalence of neuropsychiatric symptoms in dementia and mild cognitive impairment: Results from the Cardiovascular Health Study. *Journal of the American Medical Association, 288*(12), 1475.

skilled nursing facility services and home health services, and higher total Medicare costs compared with all other Medicare beneficiaries.[3]

Medicare Overview

When the Medicare program was created in 1965, it was Congress' intention to establish a comprehensive health care insurance program to ensure that aged (and subsequently disabled) persons have access to adequate medical services at a nominal cost. From its inception, Medicare has primarily covered acute care treatment in a traditional medical environment. Medicare coverage of long-term care has been extremely limited.

The Original Medicare fee-for-service program is divided into two distinct parts: hospital insurance (known as Part A) and supplemental health insurance (known as Part B). Medicare Part A covers acute care services, such as hospital, skilled nursing home, home health, and hospice care. Part B covers physicians' services, outpatient hospital services, physical, occupational, and speech therapy, diagnostic X-rays, laboratory tests, durable medical equipment, blood, home health care, and mental health services. These two Medicare parts are significantly different in benefits, deductibles, and coinsurance payments. When Medicare covers a particular service, it usually only pays for a portion of what Medicare has determined to be the reasonable charge for the covered service.

In January 2006, Medicare began to cover outpatient prescription drugs under the new Part D program. Unlike Parts A and B, these benefits are provided only through prescription drug plans developed by private insurance companies or through managed care plans. Medicare beneficiaries who are also on Medicaid are required to receive their outpatient prescription drugs through the Medicare Part D program.

Influence of Local Coverage Policies

The Centers for Medicare and Medicaid Services (CMS) has primary responsibility for the management of the Medicare Program. CMS contracts with private insurance companies (Medicare administrative contractors) to process claims for services in various states and regions of the country. These Medicare contractors are given considerable latitude in determining when covered services are medically

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[3] Bynum et al. Also, Alzheimer's Association (2011) Alzheimer's disease facts and figures. *Alzheimer's & Dementia, 7*(2).

necessary. They develop local coverage rules that specify for which diagnosis a medical procedure is appropriate or necessary.

These local coverage policies, called local coverage determinations (LCD), are guidelines that describe when and under what circumstances Medicare will pay for a medical service, item, or procedure. Currently, there are more than 9,000 LCDs in existence. Every Medicare contractor has the authority to develop and adopt its own local coverage policy, which is applied in the respective geographic jurisdiction. Consequently, a Medicare beneficiary's access to services is dependent on where the beneficiary lives, where the beneficiary obtains the services, and what local policies are in effect. Not surprisingly, LCDs have significant impact on access to Medicare-covered services.

The principal restriction on contractors' use of LCDs is that they cannot conflict with controlling statutes, regulations, or national coverage policies. There are no published regulations that establish standards and procedures for the contractors as they develop their LCDs. Initially, the development of LCDs was a closed process, with limited opportunity for public comment. In November 2000, CMS (then HCFA) issued a program memorandum instructing contractors to establish an open and public LMRP development process. Contractors are now required to solicit and accept comments from providers and members of the general public. In addition, contractors must allow interested parties, including beneficiaries, to make presentations at the Carrier Advisory Committee (CAC) hearings on a proposed LCD.[4] However, some CACs have created barriers to active participation in their hearings. For example, they may require an individual to submit written testimony before the hearing and only upon its review of the testimony will the individual be considered or approved to testify.

The Medicare program manuals require that local coverage policies be supported by published authoritative evidence derived from definitive trials or studies, general acceptance in the medical community, consensus of expert medical opinion, or medical opinion derived from consultations with medical associations or other health care experts. Yet, few of these policies have identified any medical or clinical basis to substantiate the restrictions on coverage. CMS does not have the staff or financial resources to review the policies to assure adherence to or consistency with CMS manuals or federal regulations and laws. This results in divergent local coverage policies across the country. However, administrative law judges, the Medicare Appeals Council, and the federal courts are not bound by these local coverage decisions or policies. Beneficiaries can challenge the validity of the LCDs through, albeit lengthy, administrative or claims appeals processes.

The impact of LCDs cannot be overemphasized. In 1999, after an extensive analysis of Medicare contractors' local coverage policies, the Alzheimer's

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[4] The Carrier Advisory Committee is an advisory committee that provides an opportunity for physicians (and a beneficiary representative) to discuss development of local coverage policies and administrative policies and to discuss other relevant issues that are within the carrier's discretion. See CMS Medicare Program Integrity Manual 13.8.1.1.

Association presented CMS (then HCFA) with evidence that its contractors were systematically discriminating against Medicare beneficiaries with Alzheimer's disease. These beneficiaries were automatically denied payment of claims for medically necessary services solely because of their Alzheimer's diagnosis. CMS issued several program memorandums and transmittals to prohibit these barriers to payment of claims. But for the research and analysis of this advocacy organization, and, ultimately, cooperation by CMS, these discriminatory practices would still be operational today.

Although the issuance of these program memorandums and transmittals is significant, it is only the first step to removing the barriers to medically necessary care for Alzheimer's beneficiaries. Beneficiaries, caregivers, providers, and advocates must be vigilant to ensure the proper implementation of nondiscriminatory policies by the Medicare contractors. Successful advocacy that results in important changes in policy is only meaningful if the changes are implemented and enforced. Education and monitoring is necessary to ensure access to medical care for this vulnerable population.

Lessons Learned and the Medicare Prescription Drug Benefit

In January 2006, Medicare beneficiaries became eligible to receive coverage for outpatient prescription drugs for the first time. Given that this Medicare drug benefit (Part D) is provided only by private entities, it is imperative that CMS, advocates, beneficiaries, and caregivers closely monitor the various plans' benefit structures and formularies (list of covered drugs) to ensure access to medications for Alzheimer's beneficiaries.

The Medicare statute prohibits discriminatory practices by plans that would substantially discourage enrollment by Medicare beneficiaries on the basis of health status, including medical condition.[5] As previously noted, individuals with Alzheimer's disease often have additional chronic conditions and take a combination of medications. It is a delicate balance that requires access to specific medications to enhance the care of these beneficiaries. Cost-saving strategies, formulary lists, and benefit management tools employed by some plans may adversely impact individuals with Alzheimer's disease. Lessons learned from previous monitoring of the impact of LCDs on the Alzheimer's populations should be applied with regard to this drug benefit. There must be vigorous review and evaluation of all plans for anti-discrimination behavior that may affect beneficiaries' access to prescription drugs.

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[5] Section 1860D-11(e)(2)(D)(i) of the Medicare Prescription Drug Benefit of the Medicare Prescription, Drug, Improvement and Modernization Act of 2003.

The Failure to Care for Individuals with Alzheimer's Disease and Behavioral Complications: Impact on the Health, Legal, and Judicial System

An increasing number of individuals with Alzheimer's disease, or other dementia-related diseases, have had encounters with the legal system due to uncontrolled aggressive behaviors. While there is scant national or state data on the prevalence of violent offenses caused by individuals with dementia, such incidences are increasing in our communities and in long-term care facilities, challenging our mental health and legal systems.[6] These individuals often become subject to guardianship, incarceration, or involuntary commitment due to the failure of our health care system to adequately address the needs of individuals who are at risk of violent behavior. Frustrated family members and caregivers, often the victims of unintended acts of violence, feel "lost in the woods with nowhere to turn," seeking a pathway to prevention of aggressive and violent behavior.

In recent years, there has been a growing body of research that supports the need for psychiatric and psychological care for individuals with Alzheimer's disease. In one study, Johns Hopkins University researchers found a high prevalence (60–80%) of neuropsychiatric symptoms in participants with dementia.[7] These symptoms include agitation, depression, apathy, anxiety, delusions, hallucinations, and sleep impairment and have serious adverse consequences on the patients. Physically aggressive and verbally disruptive behavior also occurs and is difficult to address. Appropriate treatment of these symptoms by therapeutic interventions, including psychotherapy, behavior management, and medication, will likely provide substantial benefits to these individuals. Other studies have shown that therapeutic interventions can improve function, reduce disruptive behavior, and mitigate excess disability for individuals with Alzheimer's disease. Despite the recognition of this growing demand for care, few health care providers have the expertise, willingness, or funding to meet the needs of this suffering population. Rather, health care and mental health providers close their doors and terminate their services, leaving the afflicted individual and family members with little recourse. Consequently, the legal system often is called upon to respond to these detrimental circumstances for which it is often ill equipped to appropriately respond.

Case Study

A situation in a New England state is a prime example of the failure of health care and mental health providers to provide the necessary services to an elderly, retired banker who has Alzheimer's disease. "Mr. Banker" lived with his daughter for

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[6] Testimony of Donna Cohen, PhD (2004, March 22). *Hearing on crimes without criminals? Seniors, dementia and the aftermath.* Senate Special Committee on Aging.

[7] Prevalence of Neuropsychiatric Symptoms in Dementia and Mild Cognitive Impairment; Results from the Cardiovascular Study, *JAMA*, September 25, 2002-Vol. 288(12), 1475.

several years until she could no longer provide the care he needed, in addition to caring for her own family needs. In addition, Mr. Banker began to exhibit aggressiveness and his daughter feared he would injure her or her family. Mr. Banker was admitted to a nursing facility but his combative behavior persisted. The nursing facility staff lacked expertise to address the aggressiveness and called the daughter continuously, threatening to discharge her father because the staff could not control him. Due to fear that Mr. Banker would injure another resident or a staff member, the nursing facility sought to have him committed to a psychiatric unit at the community hospital. After a short stay in the psychiatric unit, where they concluded that injections of long-acting Haldol were the appropriate treatment, Mr. Banker was discharged back to the nursing facility. Within 1 week, he was back at the same community hospital, where he spent 24 hours in their emergency room awaiting admission to the medical unit.

Mr. Banker's behavior stabilized but he remained in the hospital, for more than 2 weeks after stabilization, because there was no facility that would accept responsibility for his care. The nursing facility insisted that it cannot handle him and refused to allow him to return to its facility due to his severe aggressive behavior. No other facility in the state would accept him as a resident and the hospital discharge planners sought placement outside of the state. Specialty hospitals and psychiatric units that specialize in mental health and behavior issues would not accept him as a patient because his primary diagnosis is Alzheimer's disease, not a mental health diagnosis. Mr. Banker's daughter was his health care agent but was overwhelmed and frustrated. The family was torn apart by Mr. Banker's crisis. She would no longer act as her father's health care agent and advised hospital staff that they would have to find someone else to handle her father's decisions.

The hospital attorney filed a petition for appointment of a guardian of Mr. Banker's person to assist with discharge plans from the hospital. However, there were several layers to the problem that resulted in Mr. Banker languishing in a hospital for several weeks. It was a domino effect of the unwillingness to properly treat Mr. Banker's behavioral complications due to his Alzheimer's disease. What is Mr. Banker's guardian going to be confronted with when the court makes the appointment?

Breakdown in the community. Mr. Banker may have been able to continue to live in the community with his daughter's family but he could not access mental health services in the community. Due to significant state budget cuts, the state mental health agency would not provide services to Mr. Banker because Alzheimer's disease is not considered a "mental illness." Given these fiscal realities in many states, mental health programs have been forced to absorb budget cuts by severely restricting eligibility and access to their services.

In addition, detection rates for behavioral problems, before they escalate and are out of control, are often quite low. This is a missed opportunity of our health care system to intervene early to prevent severe behavior problems among Alzheimer sufferers. While there are sufficient guidelines and information for preventing and managing these symptoms, this knowledge has not been transferred to the vast majority of care settings. Most primary care doctors have very little background or training on how to treat these symptoms. The same is true for staff at nursing and assisted living homes that are confronted with these symptoms many times a day.

A significant element of the problem is that the costs associated with treating these symptoms are high, and Medicare fee and reimbursement structures are not conducive to clinicians getting paid for managing these symptoms. Payments to physicians, as well as most outpatient providers, are based on a fixed Medicare fee schedule, which does not adjust payment based to the frailty, complexity, or needs of the patient's condition. The fees are sufficiently low that some doctors may not spend the time necessary to appropriately care for these symptoms. In addition, although Medicare covers mental health services, the Medicare payment is currently limited to 65% of the Medicare approved amount, but will gradually increase to 80% by 2013.[8] Some mental health providers refuse to treat Medicare beneficiaries because of the meager reimbursement amount.

When the Alzheimer's individual's condition becomes so problematic, the family member or caregiver usually has few options but to take his/her to the hospital to be stabilized and treated. Hospitals are often not well equipped with specialty units and end up managing these patients on medical or surgical wards or emergency departments often through restraint or sedation. Staff are not usually trained on how to approach and manage the symptoms.

Breakdown in the facilities. Nursing and assisted living facilities are unable or unwilling to care for the more seriously ill and behaviorally complex individuals for several reasons. The level of expertise or training of assisted living and nursing home staff in managing these symptoms must be raised. In some areas of the country, specialty units accept patients with some of the more violent behaviors but are faced with reimbursement pressures due to the long lengths of stay and complexities of caring for some of these very ill Alzheimer's patients. Section 6121 of the Affordable Care Act of 2010 mandates enhanced nurse aid training for nurse aides working in nursing homes on care for residents with dementia. CMS is charged with implementing this new requirement and is developing regulation and training materials that nursing homes may use to train their staff.[9]

When Mr. Banker was admitted to the nursing facility, federal law required that a multidisciplinary team within the nursing facility complete a comprehensive assessment of his functional capacity. Once the assessment was completed, the team must develop a plan of care to meet Mr. Banker's medical, nursing, mental, and psychosocial needs identified in the assessment.[10] The nursing facility is required to provide the necessary care and services so that Mr. Banker will "attain or maintain the highest practicable physical, mental, and psychosocial well-being in accordance

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[8] 42 C.F.R. §410.155. Congress enacted a law that will gradually phase in Medicare payment to 80% by 2014.

[9] Patient Protection and Affordable Care Act (P.L. 111-148, as amended), §6121.

[10] Nursing Home Reform Law, 42 U.S.C. §1395i-3 et seq and 42 U.S.C. §1396r et seq.

with the assessment and care plan."[11] The purpose of the assessment and care plan is to identify with specificity the services the nursing facility must provide to address Mr. Banker's needs. The nursing facility must provide specialized mental health services to Mr. Banker, which may include individual and group therapy, behavior management, and drug therapy. Mr. Banker's aggressiveness required significant interventions by nursing facility staff and providers.

Stranded in the hospital. Frustrated with their inability to stabilize Mr. Banker, the nursing facility staff took Mr. Banker to the community hospital emergency room. Some hospitals refuse to admit individuals with Alzheimer's disease and behavioral disturbances because of difficulties in finding an appropriate placement upon discharge. Federal regulations require that hospitals provide a discharge evaluation and plan for patients who would likely suffer adverse health consequences upon discharge from the hospital.[12] In Mr. Banker's situation, his previous nursing facility refused to readmit him and the hospital is prohibited from discharging him until an appropriate facility agrees to accept him as a resident.

Need for a Coordinated Approach

Frustration abounds and Mr. Banker languishes in a hospital bed. Many individuals with Alzheimer's disease have experienced Mr. Banker's predicament. The health care and mental health systems are fragmented and fail to accept responsibility for providing care to this fragile population. There is limited access to specialized mental health units when the primary diagnosis is Alzheimer's disease, yet there are few specialized Alzheimer's units willing to accept patients with severe behavioral problems.

While these systems crumple, the judicial system, under the guise of a guardianship proceeding, a commitment hearing or even a criminal action, is left to pick up the pieces.

The challenge facing the presiding judge is to ascertain the appropriate agencies and providers of mental health services in their communities. It would be beneficial to bring together representatives from the area office on aging, the long-term care ombudsperson, the mental health agency, the community hospitals, the legal and judicial community, the Alzheimer's Association and other advocacy groups to develop a coordinated approach to address the complex needs of this growing population in each community. It will take a coordinated community approach to establish a path out of these woods.

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[11] 42 C.F.R. §483.25.

[12] 42 C.F.R. §482.43.

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Chapter 12

Advances in Alzheimer's Disease Research: Implications for Family Caregiving

Jiska Cohen-Mansfield

Three areas of research hold interest for family members of persons with dementia. These pertain to research concerning the person with dementia, the process of caregiving, and the impact of caregiving on the caregivers. Whereas a complete discussion of these issues is beyond the scope of this chapter, some of the highlights of this research are described below.

The Person with Alzheimer's Disease

A host of research questions involves the person with dementia. Basic dementia research involves questions such as: symptoms, diagnosis, and progression of dementia, risk factors, and available treatments. The hallmark of dementia is memory impairment and cognitive disturbances, such as aphasia (language disturbance), apraxia (disturbance of motor function), or agnosia (difficulty identifying objects despite adequate sensory functioning). These deficits are gradual and progressive (American Psychiatric Association [APA], 1994; Spinnler & Della Sala, 1999), and result in a decline in daily functioning. These main features of dementia are frequently accompanied by other symptoms, including personality changes, depression, and behavioral disturbances.

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Assessment methodologies in dementia include self-report measures, informant reports by family or professional caregivers, which often substitute self-report when self-report may no longer be viable or reliable, and performance-based or observational assessments. A multitude of assessment instruments has been developed for cognitive impairment (MacNeill & Lichtenberg, 1999), functional status (Desai, Grossberg, & Sheth, 2004; Doble, Fisk, & Rockwood, 1999), and behavior disturbances in dementia (Cohen-Mansfield & Martin, 2010). There are fewer assessments of depressed affect, with the Geriatric Depression Scale (Yesvage et al., 1983) often used as a self-report measure at earlier stages of dementia; informant-based assessments, such as the Cornell Scale for Depression in Dementia (Alexopoulos, Abrams, Young, & Shamoian, 1988) and the Raskin Depression Scale (Raskin, 1988) are used at later stages of the disease (Abrams & Alexopoulos, 1994). Several methodologies have been proposed to document the progression of dementia, such as the Clinical Dementia Rating Scale (Heyman et al., 1987; Hughes, Berg, Danziger, Coben, & Martin, 1982) and the Global Deterioration Scale (Cohen-Mansfield et al., 1996; Reisberg, Ferris, de Leon, & Crook, 1988). Screening instruments have also been used for the detection of undiagnosed dementia. Early screening for dementia has been recommended for persons who have mild cognitive impairment, but not dementia, because they are at higher risk for developing dementia. Such early detection is supposed to help caregivers educate and prepare themselves for the role; plan for upcoming problems, including financial, legal, and decision-making issues; and protect the person with dementia from risks, such as driving or falling. However, there is a lingering debate concerning the benefits and costs of early detection (Boustani, Peterson, Hanson, Harris, & Lohr, 2003; Petersen et al., 2001).

Frequently, it is the behavioral disturbances that are most difficult for caregivers to handle (Lim, Sahadevan, Choo, & Anthony, 1999; Victoroff, Mack, & Nielson, 1998). Behavioral disturbances are related to multiple patient and environmental factors. The prevalence of behavioral disturbances changes with the person's cognitive level (Cohen-Mansfield, Culpepper, & Werner, 1995). Specifically, physically nonaggressive behaviors, such as wandering and general restlessness, tend to increase in frequency with the severity of the dementia; verbal/vocal behaviors such as repetitive questions and requests tend to peak at a moderate–severe stage of dementia; and aggressive behaviors tend to be manifested at the very latest stages of the disease. Verbal manifestation of behavior problems are related to depressed affect and pain (Cohen-Mansfield & Libin, 2005; Cohen-Mansfield & Werner, 1998, 1999), indicating that some types of behavioral disturbances may be a manifestation of discomfort. Environmental factors are also related to the occurrence of behavioral problems. The availability of activities and the presence of other people are related to lower levels of behavior problems, whereas use of physical restraints is related to increased levels of these behaviors (Cohen-Mansfield & Werner, 1995), indicating that loneliness, boredom, and discomfort are associated with behavioral disturbances.

Whereas much of the existing research assessed the losses that occur in dementia, some research has investigated what is left. An analysis of conversations with nursing home residents with Alzheimer's disease revealed that the awareness of self persists into the middle and late stages of the disease (Tappen, Williams, Fishman, & Touhy, 1999). Similarly, interviews concerning role identity in dementia showed that many persons suffering from the disease maintain certain role identities from their past, and sometimes develop new identities (Cohen-Mansfield, Golander, & Arnheim, 2000; Cohen-Mansfield, Parpura-Gill, & Golander, 2006a, 2006b). Understanding such identities can facilitate the engagement of persons with dementia in meaningful activities, thereby enhancing their quality of life. Similarly, research has shown that although many persons with dementia manifest sadness, many can show interest, pleasure, or contentment (Cohen-Mansfield et al., 2012; Lawton, Van Haitsma, & Klapper, 1996).

The results of clinical research clarify factors that influence manifestations of the disease and investigate interventions for changing the disease progression with regard to specific symptoms and well-being in general. The current treatment of memory and cognitive problems in dementia is primarily pharmacological, and results in small, statistically significant improvements in cognitive function (Evans, Wilcock, & Birks, 2004; van Dyck, 2004), yet various cognitive interventions are being tried as well, though much of that work is conducted with persons without dementia (Ball et al., 2002; Daffner, 2010; Loewenstein et al., 2004; Smith et al., 2009; Willis et al., 2006; Wolinsky et al., 2006). Behavior and mood problems associated with dementia have been shown to benefit from a wide range of nonpharmacological approaches (Cohen-Mansfield, 2001; Cohen-Mansfield, Libin, & Marx, 2007; Opie, Rosewarne, & O'Connor, 1999). Pharmacological approaches are widely used, but have come under much criticism (Information for Healthcare Professionals, 2008; Schneider, Dagerman, & Insel, 2006; Sultzer et al., 2008). The nonpharmacological approaches to treating these behaviors are aimed at alleviating the discomfort, boredom, or loneliness that has been found to be associated with such behaviors. Because nonpharmacological treatments address environmental and care problems that cause discomfort, an analysis of these issues and a trial of nonpharmacological treatments should precede pharmacological interventions.

Understanding the person with dementia. Previous research highlights the complexity of the person who has dementia. Functioning on the cognitive, behavioral, and affective domains is influenced by a combination of initial, lifelong, and current factors in the biological, psychological, and environmental domains. For example, Table 12.1 illustrates the factors that influence cognitive functioning. These range from genetic predisposition, which is an initial biologic product through lifelong education and habits, through current medical, psychosocial, and environmental factors, such as type of dementia, sleep, and current level of stimulation, respectively (Cohen-Mansfield, 2000). For example, initial socioeconomic level can affect dietary and physical activity habits, which can then affect cardiovascular status, which in turn affects cognitive function. Current social support affects the level of verbal stimulation and verbal communication which would affect present verbal functioning.

Treating and caring for the person with dementia. Whereas no cure is available for the person with dementia, this does not imply that nothing can be done to help that

Table 12.1 Framework for factors affecting heterogeneity in the expression of dementia: example of factors affecting level of cognitive functioning

	Initial	Lifelong	Current
Biologic/genetic/medical	Genetic predisposition	Physical health, trauma	Dementia type and stage, neurologic damage, comorbid illness, medication
Psychosocial	Gender, race	Education, life habits (alcohol, smoking), stress	Affect, motivation, pain, sleep, social support
Environmental	Socioeconomic status	Home, work, community	Stimulation type and level, access to support network

Note: From Cohen-Mansfield (2000)

person. On the contrary, the quality of life of the person with dementia is highly dependent and responsive to the environment. Indeed, some researchers postulate that persons with dementia undergo a process of environmental press, where their reactivity to the environment increases as their abilities decrease (Lawton, Van Haitsma, & Klapper, 1994).

Successful dementia (Cohen-Mansfield, 1996) is the benchmark toward which family caregivers would want to aim. Its premise is that (1) care aims to maximize quality of life for persons with dementia and (2) the concept of quality of life changes throughout the dementia process. This involves shifting baselines of quality (Cohen-Mansfield, 2011), similar to the concept of the treadmill effect (Kahneman, 2000), which postulates that external circumstances make only small contributions to the variance in happiness. More specifically, in the case of dementia, the most important aspects of care are to minimize pain and discomfort and to maximize contentment or pleasure.

The circumstances that promote successful dementia change over the course of the disease may include (a) preservation or deceleration of decline in function, especially at the early stages of disease; (b) preservation of control over some functions, which may include care of a plant (Langer & Rodin, 1976) or choice of clothes; and (c) a sense of purpose, meaning, or spirituality (Cohen-Mansfield, Thein, Dakheel-Ali, & Marx, 2010), or enjoyment of basic stimuli such as the sunshine outside and a favorite melody (Cohen-Mansfield & Werner, 1997; Gerdner, 2000).

In order to approach this goal of successful dementia, the caregiver needs to understand the factors that affect function and well-being (see Fig. 12.1). The person's current sensory, cognitive, physical, and mental abilities and disabilities interact with lifelong habits, preferences, and personality, and with the current environment and its provision of stimuli, comfort, and social contact. This interaction determines the level of unmet needs, which then affects the person's well-being. Unmet needs lead to a poor quality of life, which may be manifested as depressed affect or behavioral problems.

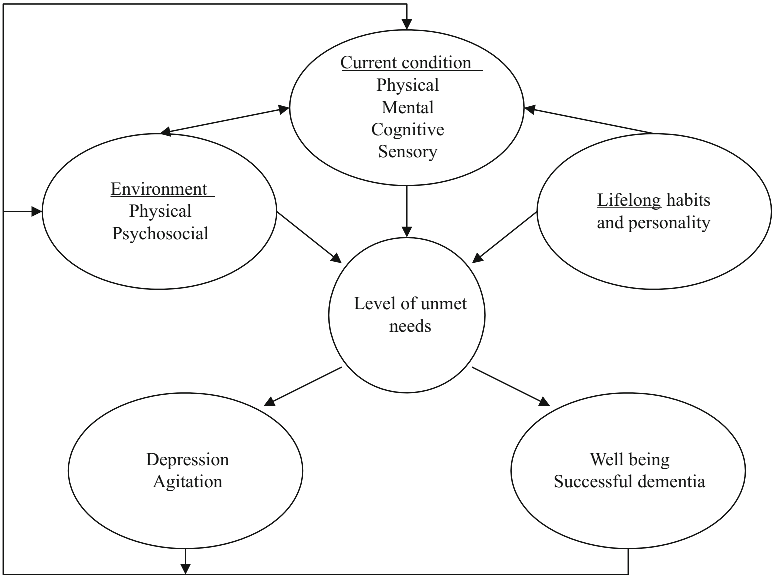

Fig. 12.1 Implications: factors affecting function and well-being. © From Cohen-Mansfield (2004)

It, therefore, follows that the treatment model for persons with dementia who manifest affective or behavioral problems needs to not only initiate an exploration of the etiology of the unmet needs but also understand the interaction between physical environment, caregiver behavior, and the person's unmet needs, which are based on lifelong and current preferences and abilities. When evaluating unmet needs, caregivers need to recognize that even in advanced dementia, higher-level human needs exist. For example, persons with advanced dementia may manifest behavior problems that relate to boredom or loneliness (Cohen-Mansfield & Werner, 1995). In all stages of dementia, past function and identity play a role (Cohen-Mansfield et al., 2012).

This approach places caregivers in a delicate position where they need to balance acceptance of loss due to dementia and recognition of what is maintained. Without the former, the caregiver may resent or misinterpret the patient's behavior, believing it to be motivated by negative intent. Without the caregiver's recognition of remaining faculties, the patient will miss opportunities for engagement and pleasure.

Caregiving Activities

Caregiving is the main activity of caregivers, and is frequently their main interest. For instance, in comparison to reducing their stress level, caregivers are more interested in how to best care for their relatives.

Caregiving activities span a wide range and include (a) listening and communicating with the person who is losing communication skills; (b) direct caregiving by assisting in the performance of activities of daily living (ADLs); (c) provision of leisure, social, and meaningful activities; (d) protecting from harm; and (e) supervising. In addition, most caregivers also coordinate care, such as accessing medical and other care, and make medical, financial, organizational, and other decisions.

Communicating with the person with dementia is essential for understanding the person and minimizing unmet needs. Sensory-assisted communication utilizing verbal and nonverbal methods of communication, and sometimes written communication, which allows persons with dementia to utilize word recognition rather than the more difficult word retrieval, may be needed. The method by which one approaches the person with dementia is crucial to prevent a reaction of fear, which many patients manifest when they are startled by an unexpected advance. Attending to hearing and vision problems is also essential to effective communication. Simplification of communication, such as limiting the length and number of ideas in sentences, is helpful. Finally, caregivers need to understand that the person with dementia sometimes experiences reality differently due to limitations. It is usually more productive to understand the individual's perception of an experience and respond from within that reality than it is to negate that reality by trying to impose the caregiver's perception of reality. Several caregiver training programs in communication have been developed (McCallion, Toseland, Lacey, & Banks, 1999; Ripich, 1994; Ripich, Wykle, & Niles, 1995). Some of these have been associated with improved patient outcomes (e.g., McCallion et al., 1999; Vasse, Vernooij-Dassen, Spijker, Rikkert, & Koopmans, 2010).

Several principles are essential for optimizing all caregiving activities, and ADLs in particular. First, caregivers need to become aware of the many options and types of procedures that are available. For example, in bathing, a person may have a shower, a bath, a bed bath, or at times, nothing. Second, flexibility is essential to making the experience pleasant rather than painful, and this pertains to all aspects of the ADL experience, such as timing, type, and details of the procedure. These include factors such as who is involved and the environment in which it takes place. It is helpful to learn about the person's preexisting habits and trying to emulate them as much as possible. Appropriate communication with the person with dementia throughout the ADLs needs to be used to announce tasks, provide control through choices, provide information, and, most importantly, provide a sense of safety. Finally, attention to the comfort of the person with dementia and of the caregiver is essential. If the task is physically too difficult for the caregiver, it is not likely to be comfortable to the person with dementia, and vice versa: if the person with dementia is uncomfortable, that will make the work of the caregiver much more difficult. Specific instructions on how to make the process more comfortable or enjoyable are available in several publications (e.g., for bathing, Austrom, 1996; Barrick, Rader, Hoeffer, & Sloane, 2002; Cohen-Mansfield & Parpura-Gill, 2007; Kovach & Meyer-Arnold, 1997).

In addition to the general principles outlined above, a combination of assessment, problem-solving, treatment, and evaluation is useful for many domains, including ADL, behavior, and affect. Specifically, it is useful to employ a systematic observation of the process, including antecedents, behaviors, and consequences, as well as brainstorming of options for varying ADL procedures (e.g., using finger food instead of utensils) or other activities. Caregiving may use trial and feedback loops for testing different options. At times, finding the intervention that matches the person's needs and abilities can be time consuming and may require several iteration trials.

Provision of leisure-time social activities that are meaningful to the person with advanced dementia may seem superfluous because the person with dementia may be noncommunicative or not responsive, yet these are at least as important and necessary as ADLs for optimizing quality of life. Even people in advanced stages of dementia have needs for social contact and for stimulation. Some have needs for cognitive stimulation despite their cognitive decline. Similar to the provision of ADLs, there is a myriad of options by which such activities can be provided (Cohen-Mansfield, 2001; Cohen-Mansfield, Marx, Dakheel-Ali, Regier, & Thein, 2010). These involve active participation by the person with dementia, which may allow the person to access stimulation from the environment (as in providing hearing aids or glasses) or involve passive participation, such as in massage therapy. When the person is already engaged in a behavior, such as wandering, it is frequently best to accommodate that behavior. Such accommodation may involve minimizing concerns about risks associated with the behavior or channeling the behavior in routes that will make it acceptable rather than disturbing or disruptive. If a person is inappropriately tearing his diaper as a method of stimulation, other more appropriate materials could be provided to him to handle. An understanding of the large range of options is crucial because the specific intervention needs to be tailored to the person's abilities (cognitive, sensory, etc.), to the past and present identity and preferences, to the caregiver, and to the environment. Use of individually tailored pleasant activities for persons with Alzheimer's disease resulted in improvement in depressive symptoms both for the persons with dementia and for their caregivers (Teri, Logsdon, Uomoto, & McCurry, 1997). Individualized stimuli that are matched to the person's past preferences are more effective than nonindividualized stimuli (Gerdner, 2000).

While most of the intervention studies with persons with dementia were conducted by research personnel and/or in institutional settings, some have trained family caregivers to understand and treat behavior problems. In a review of five such controlled trials, Teri (1999) concludes that the majority found caregiver training to be effective in reducing either behavior problems or psychiatric or depressive symptoms, or in increasing time to institutionalization. More modest results were reported in a more recent review (Smits et al., 2007). Caregivers' health and mental health have also been shown to relate to patient outcome such as survival and institutionalization (Torti, Gwyther, Reed, Friedman, & Schulman, 2004).

As seen above, a variety of interventions have been developed to enhance the cognitive, functional, affective, and behavioral functioning of persons with dementia. These interventions, which are outlined in Table 12.2), are in varying

Table 12.2 Nonpharmacologic interventions: examples

Goal/type	Treatment modalities	Environmental
Enhance cognitive/ communication performance	Cognitive remediation (Butti, Buzzelli, Fiori, & Giaquinto, 1998; Quayhagen & Quayhagen, 2001)	Memory books (Bourgeois, Dijkstra, Burgio, & Allen-Burge, 2001; Hoerster, Hickey, & Bourgeois, 2001)
	Memory training (Butti et al., 1998)	Use of signs and pictures to enhance orientation (Brawley, 1997)
	Spaced retrieval (Camp, Foss, O'Hanlon, & Stevens, 1996)	
	Reality orientation (Bates, Boote, & Beverley, 2004; Metitieri et al., 2001; Spector, Davies, Woods, & Orrell, 2000; Zanetti et al., 2002)	
	Cognitive tasks, such as reading group activities and sorting activities	
Enhance functional performance	Independence promoting strategies (Beck et al., 1997; Namazi & Johnson, 1992a)	Change lighting levels (Beck & Heacock, 1988; Koss & Gilmore, 1998)
	Scheduled or timed voiding (Sogbein & Awad, 1982)	Increase toilet visibility (Namazi & Johnson, 1991), raise toilet seat
	Prompted voiding (Schnelle, 1990)	
Enhance self-perception/ well-being enhance pleasure/reduce depression	Reminiscence therapy (Baines et al., 1987; Brooker & Duce, 2000; Gagnon, 1996)	Provide objects (e.g., furniture, piano, pictures, photographs) which were meaningful/liked in the past
	Validation therapy (Toseland et al., 1997)	Allow access to a secure outdoor garden (Namazi & Johnson, 1992b)

	Self-identity-based interventions (Cohen-Mansfield et al., 2006a, 2006b)	Have smaller units (Sloane et al., 1998)
	Interventions based on past or present pleasant activities	
	Fostering choice, opportunity, support and independence (Skea & Lindesay, 1996)	
	Sensory interventions	
	Structured activities	
Decrease behavior problems	Sensory interventions, such as music or massage	
	Behavioral interventions, such as differential reinforcement	
	Social contact interventions, such as one on one conversation or videotape of a family member talking to person	
	Structured activities, such as group activities, sorting activities or manipulating activities	
	Staff training often includes education about dementia, communication training, and examples of nonpharmacological interventions	
	Environmental interventions, such as access to a sheltered garden, or camouflaging of triggering stimuli	
	Medical/nursing care interventions, such as removal of physical restraints and addressing pain as a cause of behavior problems	
	Combination therapies (see Cohen-Mansfield, 2001, for a review)	Camouflage door knobs (Namazi, Rosner, & Calkins, 1989)

© Cohen-Mansfield (2004), in Cohen-Mansfield, J. (2004). Cognitive and behavioral interventions for persons with dementia. Encyclopedia of Applied Psychology (Vol. 1, pp. 377–385). Oxford: Elsevier levels of development and testing. While some have been studied extensively, others are only anecdotal reports. Similarly, while research shows some interventions (e.g., one-on-one social interaction; Cohen-Mansfield & Werner, 1997) to be effective, others, such as use of reality orientation with people with moderate or advance dementia, are not recommended (Deitch, Hewett, & Jones, 1989). On the whole, however, there is insufficient research about the efficacy and effectiveness of non-pharmacologic interventions in dementia. The reasons for that are complex and include the multitude of difficulties in conducting such research. Many of the difficulties are common to all dementia research. These include (a) difficulties in obtaining consent for persons with dementia (Cohen-Mansfield, 2003); (b) caregiver reluctance to add research demands when feeling overburdened; (c) caregivers' distrust that a new approach could help; (d) high attrition or unavailability of subjects due to comorbidity, decline, and mortality; and (e) the need for time-consuming observational assessments when self-report is not available or is questionable. Other problems, such as difficulties in using a double-blind design and the need for a more complex intervention that accommodates individual differences in habits and preferences, require innovative approaches to research methodologies. Finally, clinical research with persons with dementia is very expensive. Despite some funding from organizations, such as the Alzheimer's Association and governmental agencies, funds are more available to pharmacological studies than to non-pharmacological ones.

Caregivers

Upon review of the above caregiving issues, it is clear that the process of caregiving for the person with dementia is an extremely difficult and burdening process for caregivers. This difficulty is augmented by the fact that in most cases, one caregiver, usually a spouse, a daughter, or a daughter-in-law, provides most of the care (Schulz & Martire, 2004). Several studies have shown that caregiving for a person with dementia is hazardous to one's physical and mental health (Etters, Goodall, & Harrison, 2008; O'Rourke & Tuokko, 2000; Schulz & Williamson, 1994). A large proportion of caregivers experience stress and burden, and caregivers are at greater risk than noncaregivers for experiencing depression, anxiety, health problems, and higher mortality rates (Schulz & Beach, 1999; Schulz & Martire, 2004; Schulz, O'Brien, Bookwala, & Fleissner, 1995). Caregiving to persons with dementia is more demanding and more stressful than caring for persons with physical impairments (Ory, Hoffman, Yee, Tennstedt, & Schulz, 1999). In addition, caregiving places a significant financial burden on caregivers, which includes both direct costs of care and indirect costs, such as lost income, value of caregiving time, and caregivers' excessive health care costs. Costs increase with disease progression and behavior problems, especially with the loss of the ability to perform ADLs (Andersen, Lauridsen, Andersen, & Kragh-Sorensen, 2003; Moore, Zhu, & Clipp, 2001; Small, McDonnell, Brooks, & Papadopoulos, 2002). However, there is a large variability in the estimation of cost due to variation in methodology (Bloom, de Pouvourville, & Straus, 2003; Ernst & Hay, 1997) and to geographic variation in cost, which may reflect different caregiving patterns (Harrow et al., 2004).

The level of burden tends to be higher in females than in males (Gallicchio, Siddiqi, Langenberg, & Baumgarten, 2002). It is also higher among those who live with the care recipient compared to those who do not (Torti et al., 2004). Some studies suggest that caregiver burden is higher in Caucasians than in African-Americans (Haley et al., 2004), but other studies do not support this (Torti et al., 2004). Burden was higher in daughter caregivers than in spouse caregivers and in persons with less education and fewer resources to access assistance compared to individuals with education and resources, when the person with dementia required more personal care, and when dementia was accompanied by behavior problems (Torti et al.).

Caregivers' responses to the caregiving experience vary greatly. Some are overwhelmed with taking care of their relative, others learn to cope effectively, and others hire help for the activities they find too difficult. Some people find inspiration, comfort, meaning, or satisfaction in the caregiving process. Satisfaction with caregiving was linked with encouragement of autonomy (Albert & Brody, 1996) and with altruism (Midlarsky, 1994). Similarly, meaning in caregiving was found to explain a significant portion of differences in depression and self-esteem among caregivers of frail elderly (Noonan & Tennstedt, 1997). African-American caregivers reported more perceived benefits of caregiving than did Caucasian caregivers (Haley et al., 2004; Roff et al., 2004). Alternatively, caregiving can result in patient abuse (Coyne, Reichman, & Berbig, 1993; Wolf, 1998) and depression, or hastened mortality of the caregiver (Schulz & Beach, 1999).

Because of the high toll of caregiving, caregivers face a challenge of balancing caring for a loved one with caring for self. Caring for self is essential for maintaining one's own physical and mental health, which is a prerequisite for continuing to care for the person with dementia. Caring for oneself includes addressing their own needs for social, health, and meaningful life activities, as well as handling their sense of loss or grief at the decline of their relative.

Caregivers frequently need help with many aspects of care and with the impact of care on their lives. Given the growing body of information about caregiving, and caregivers' lack of prior experience, it is evident that there is a need for more channels for caregivers to access information about care alternatives and a need for more support to caregivers so that they can effectively utilize alternatives. Care activities with which they may need help include monitoring and support with ADL care, handling behavior problems, and addressing communication difficulties with the patient due to disease symptoms. Additionally, caregivers may need assistance in responding to the relative's disease (Mittelman, Zeiss, Davies, & Guy, 2003). The caregiver may have an unrealistic view of the disease, deny it, or experience negative feelings, including anger or grief. Finally, caregivers frequently need help with handling the impact of caregiving, including social isolation, handling the new role, balancing the demands of multiple roles, financial insecurity, and self-neglect (Mittelman et al.).

Reflecting the diversity of needs, a range of caregiver interventions is needed. Generally, these can be divided into the following categories: (1) psychosocial and support interventions, (2) formal care alternatives, and (3) environmental modifications.

Psychosocial and support interventions. Caregivers often receive psychosocial and support interventions that are designed to either reduce stress by affecting secondary stressors, such as insufficient support from other family members, or address distress associated with mishandling of behavior problems. The interventions reduce these stresses by (a) providing information, (b) enhancing coping, and (c) resolving or reducing sources of secondary stresses. The interventions frequently combine educational and psychosocial modalities, and include information about the disease, problem-solving interventions, information and support in accessing alternative care options, family therapy, and other treatments. Brodaty (1992) divides the elements of intervention programs into psychological, educational, and those developing support systems. Psychological treatments include support (sharing, ventilation); counseling, including insight therapy; cognitive therapy and stress management techniques; and handling of reactions to the role (such as anger, grief, guilt), self-care, and interpersonal relations interventions. Educational interventions provide information; home care skills; therapeutic and problem-solving skills; emergency planning; and legal and financial assistance that are needed because of the disease. The development of different support systems includes the family system, the community, and the professional system (Brodaty).

The format in which these interventions are delivered can also vary widely. These include individual treatment sessions; support groups; telephone or video conference support systems (Wright, Bennet, & Gramling, 1998); Internet-based support groups (Steffen, Mahoney, & Kelly, 2003); and home-based interventions (Gitlin & Gwyther, 2003). Additional interventions include organization-based support for employees of a company; visitor-friendly policies for family members of residents of a nursing home; and community-level interventions addressing education for the entire community, such as media-based or policy interventions in government agencies, national organizations, and private foundations, which often determine funding for reimbursement, research, and demonstration projects (Coon, Ory, & Schulz, 2003).

In choosing interventions, the format of the intervention can be crucial. The intervention itself (e.g., leaving the home where the care recipient lives) can be perceived as an additional burden or as a respite. For many caregivers, interventions that can be utilized while staying at home (e.g., home visits, telephone, videoconferencing, home videos, media-based educational programs and internet-based interventions) have advantages, such as not having to arrange alternative support for the care recipient. Home visits may facilitate the explanation of the situation and the difficulties. These allow the therapist to better assess the environmental issues that effect care, and the interactions between caregiver and patient.

Formal care alternatives. Formal care alternatives offer care for the person with dementia that is provided by paid caregivers on a temporary or long-term basis.

These span from home care and adult day care to respite care, assisted living, skilled nursing care, and hospice care.

Environmental modifications. Both the care recipient and caregiver are helped by environmental modifications. In addition to the more formal interventions mentioned above, other sources of support or lack thereof will impact level of burden. One major source is caregivers' interactions with a larger service system. Services pertaining to physical health, mental health, dental care, vision care, hearing care, nutrition, and transportation are all needed, as are access to them, coordination among services, and support from professional caregivers, the service providers themselves; all these factors influence burden. Other, nonsystem sources of support are equally important. The extent to which caregivers have a supportive informal network that they can maintain during the caregiving years also will affect their well-being.

Different types of support to caregivers have been shown to be helpful. For example, an intervention that included individual and family counseling sessions, weekly support group participation, and the availability of counselors to help caregivers handle problems as they arise resulted in decreased levels of depressed affect among caregivers in the intervention group as compared to those in the control group (Mittelman et al., 2003). A preliminary study investigating the efficacy of an anger management video series viewed at home or viewed in a class vs. a wait list control condition found that both treatment conditions had lower posttreatment levels of anger and depression in comparison to the control group (Steffen, 2000). Goal setting and critical thinking training for fulfillment of personal goals have been helpful to caregivers (Cotter, Stevens, Vance, & Burgio, 2000). A caregiving psychoeducational program focusing on learning of adaptive cognitive and behavioral skills was superior to a support group focusing on empathic listening in reducing depressive symptoms of caregivers in both Anglo and Latino ethnic groups (Gallagher-Thompson et al., 2003). Use of formal services has also been shown to benefit caregivers. Use of health care service, personal care service, household service, institutional respite care, and adult day care services was found to be related to improvements in caregiver depression, health deterioration, and social isolation (Adler, Ott, Jelinski, Mortimer, & Christensen, 1993; Bass, Noelker, & Rechlin, 1996; Zarit, Stephens, Townsend, & Greene, 1998).

These successes notwithstanding, the documented efficacy of support groups and other treatment modalities has been variable, with some studies showing no effects on burden, well-being, or quality of life of caregivers (e.g., Coen, O'Boyle, Coakley, & Lawlor, 1999), and others showing no difference from control conditions (e.g., Brodaty, Roberts, & Peters, 1994; Flint, 1995). Yet, several reviews of interventions for caregivers conclude that these have positive effects. Knight, Lutzky, and Macofsky-Urban (1993) concluded that individual psychosocial interventions and respite care programs result in moderately strong positive effects, and that group psychosocial interventions result in a small positive effect on caregiver distress. Schulz et al. (2002) maintained that although many of the studies achieved statistical significance, only a few achieved clinically meaningful results. Similarly, Sorensen, Pinquart, and Duberstein (2002) found that intervention effects for dementia caregivers were lower than those for other caregivers. However, more recent trials of combined interventions targeting both patient and caregiver with multiple types of interventions and services and with individualized interventions seem to produce a greater effect than single interventions alone (Parker, Mills, & Abbey, 2008).

A number of avenues have been suggested which could possibly strengthen the impact of interventions for caregivers. These include matching the intervention strategies to caregivers' coping styles (Brodaty, 1992), increasing the length or intensity (frequency) of the intervention (Brodaty, 1992; Schulz & Martire, 2004), and addressing the specific needs of caregivers when issues arise (Gitlin & Gwyther, 2003). Sorensen et al. (2002) identified a number of process variables that moderated intervention effects, including number of sessions, setting, care receiver age, caregiver age, gender, type of caregiver–care receiver relationship, and initial burden. In seeking help, caregivers need to find an intervention that fits their needs in terms of the target of the intervention (caregiver, care recipient, the environment), the domain targeted (e.g., knowledge, behavior, affect), the intensity of intervention (amount and frequency of contact), and the extent to which the intervention is individualized to those receiving it (Czaja, Schulz, Lee, & Belle, 2003; Schulz, Gallagher-Thompson, Haley, & Czaja, 2000). Intervention type and level of use may need to change over the course of the disease as different interventions are needed at different stages of the caregiving process. Informational support changes as dementia progresses, as does the need for formal services, and the reactions of the caregivers. Based on the results of the REACH study, Schulz and Martire (2004) suggest that interventions should address the following risk areas: safety of caregiver and care recipient; self-care; preventive health behavior of caregiver; support of caregiver (informational, physical, and emotional); depression of caregiver; and problem behaviors of the care recipient. The specifics of the intervention need to be matched to the particular profiles of the caregiver and the care recipient.

Future Needs

Family caregivers' most obvious wish is to find a cure for Alzheimer's disease and other dementias. Yet, given the complexity of dementia, it is not likely that a simple cure is an imminent reality. Given this perspective, research needs to focus on the most important goals: successful dementia for the care recipient and successful caregiving for the caregiver.

The very basic understanding of these concepts of success within the difficult process of caregiving is still lacking. To what extent can persons with dementia be comfortable and content at each stage of the dementia process? What are the resources needed to enable them to experience this sense of well-being? What are the specific methodologies needed to individualize environments and care practices to match the heterogeneity among persons with dementia so that their needs will be met? Despite progress in learning about caregiving activities, this topic still has not generated many of the answers caregivers need for optimizing daily activities and care.

Research on optimizing the caregiving experience is needed. What enables some caregivers to provide the best care and feel at peace, or satisfied, or elevated by the experience? Are specific cognitive, spiritual, or coping processes of formal or informal support essential for such reconciliation with the experience of caregiving?

The research on supporting caregivers is similarly lacking, as manifested by the variable results of prior studies. Research is also needed on how to improve this support process by (a) utilizing information, tools, and systems; (b) improving the product of the interventions; (c) better understanding the impact of process variables (in home vs. in office, telephone vs. face to face, length of intervention, etc.); and (d) learning how to tailor the intervention to meet the critical attributes of caregiver, care recipient, and environment/situation.

In this chapter, we focused on family caregivers. Professional caregivers, such as nursing staff members in nursing homes, also suffer burdens related to caregiving for persons with dementia (Cohen-Mansfield & Noelker, 2000). The interaction between professional and family caregivers and how they can support each other is another topic that needs further research.

Research involving systems that support caregivers is also needed. Such systems would help coordinate care as well as address the educational, psychological, financial, and physical aspects of caregiving in a coordinated manner that responds to the life changes in the care receiver and the care recipient.

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