

Controversy and Caring:

An Update on Current Issues in Dementia

Over the past decade, Americans have become increasingly familiar with the terms *Alzheimer's disease* and *dementia*. Although not fully understanding them, most Americans are aware and fearful of such conditions and frustrated by the slow progress in, or lack of, treatment for them. The public is overwhelmed by marketing and media efforts to portray scientists as close to a cure and able to manage the disease with current medications—despite almost no evidence to support this assertion. Furthermore, being diagnosed with Alzheimer's disease brings messages of hopelessness associated with the progressive nature of the disease. As the pendulum swings from promises of “miracle cures” to abject hopelessness, we miss the treatment forest for the trees, neglecting a critical integrated-care approach that must emphasize both nonpharmacological as well as pharmacological treatment approaches.

This special issue is intended to provide a balanced exploration of new trends and challenges in age-related dementia, including medical and nonmedical approaches to this disorder. In this introduction, I will review the information behind the fears about Alzheimer's disease and the increasing frustration about the messages surrounding dementia and will lay out the contents of this issue of *Generations*.

Fears of Aging and Alzheimer's Disease

The fears related to growing older, and the growth of ageism in our country, go hand in hand with the fears about getting dementia—most particularly, Alzheimer's disease. Emphasizing the growing numbers and frequent health challenges facing the older segment of our population, the American Psychological Association (APA, 2002) included age as an aspect of diversity and multiculturalism. This document

utilizes Gordon Allport's Social Categorization Theory in understanding how older adults may become an “out group,” facing significant discrimination. Allport used his social categorization theory to describe the basic tenets of discrimination through the creation of an “in group” and an “out group” (Allport, 1954). In this framework, then, people make sense of their world by creating categories and separate these categories into people like themselves or unlike themselves. The relevance for multicultural diversity issues includes the following common outcomes of categorizing: an exaggeration of the differences between groups, an exaggeration of the similarities within groups, the favoring of one's own group, and the unconscious process of discrimination toward the out group.

Allport's categorization theory lends itself to understanding older individuals as an out group. Essentially, the nondominant out group (older

adults in this case) is viewed as homogeneous and portrayed as having a variety of negative characteristics. Older adults are viewed stereotypically as alike: alone and lonely, sick, frail and dependent, depressed, rigid, and unable to cope (Hinrichsen, 2006). This pervasive view portrays all older adults in a negative light and ignores the incredible heterogeneity of the aging experience and the strengths and positive attributes of older adults. Palmore (1990) estimated that 58 percent to 80 percent of older adults experience ageism, whether as the butt of the joke or as one assumed to be mentally or physically incapable. Ageism becomes most prominent when visible signs of disability or deterioration are evident. Within the medical community, this phenomenon frequently plays itself out as healthcare professionals speak to family members, often ignoring the older adult seeking treatment. Indeed, once diagnosed with Alzheimer's disease, people with dementia are often excluded from all aspects of active decision-making about their own treatment and personal care.

In his book, *The Myth of Alzheimer's*, Whitehouse (2008) described the sensationalism surrounding the course of Alzheimer's disease, with the medical community, dementia groups like the Alzheimer's Association, and the lay community emphasizing the total destruction of the "personhood" of the individual with dementia. These strong messages of deterioration and hopelessness have pervaded the public view of Alzheimer's disease. Indeed, strategic public awareness strategies that call maximum attention to the disease, along with growing impacts of ageism, undoubtedly play a major role in the growing fears older adults have about Alzheimer's disease. In 2006, the MetLife Foundation, an advocate for Alzheimer's disease research for more than twenty years, revealed some startling results from its survey of more than 1,000 adults, age 18 and older. When asked to name the illness they feared most, Alzheimer's disease trailed only cancer (20 percent versus 38 percent) and was ahead of heart disease (14 percent), stroke (13

percent), and diabetes (9 percent). Among those in the survey over the age of 55 years, Alzheimer's disease was the single most feared illness. As the one in three in the survey who has had a family member or friend with Alzheimer's disease knows, the disease is a slow, progressive deteriorating disease that can rob individuals of their faculties, awareness, and control of surroundings. It is, very simply, frightening. Whenever there are great fears, there are also strong expectations for a cure, and without the desired cure, frustration begins to grow.

Frustrations About Dementia: Prevalence, Diagnosis, and Treatment

Over the past decade, older adults themselves have expressed increasing frustration concerning the messages science sends out about aging and dementia. Inconsistencies in the research findings related to Alzheimer's disease are definite bedrock for the frustration tied to the disease, for healthcare professionals as well as older adults. Study results are often inconsistent and confusing. It is estimated that there are already over 5 million Americans with Alzheimer's disease. Is Alzheimer's disease increasing or decreasing? Are the numbers of people with cognitive impairment growing or shrinking? To highlight research inconsistencies, two studies published in 2008, with many of the same authors, using some of the same participants but different data sets, offered differing conclusions.

In February 2008, the National Institute on Aging (NIA) heralded release of the large population-based Health and Retirement Study (Langa et al., 2008), which had found that older adults had less cognitive impairment in 2002 (8.7 percent) than they'd had in 1993 (12 percent). This study found a relative decrease of cognitive impairment by 30 percent in just one decade. The publication was used for major press release material by the NIA and is still one of the lead stories on the NIA website related to news stories about Alzheimer's disease.

A short time later, however, using some of the

same participants from the study above, a very different picture emerged in a separate publication. Based on findings from a substudy of the same data set, alarming news was reported: We were grossly underestimating cognitive impairment in our nation's older adults, according to Plassman and colleagues (2008). This group of researchers estimated that in addition to the 3.4 million adults over age 71 who already suffer from Alzheimer's disease, an estimated 5 million more adults over 71 have cognitive impairment without dementia, or a prevalence rate of 22 percent—almost three times the estimate of the previously cited Langa article above. Interestingly, the National Institute on Aging, the funder of the study, decided not to issue a major press release about that finding.

What is perhaps most frustrating about these articles is the lack of integration between the two and the NIA's touting of one and neglect of the other. The differences in the findings are extreme, yet there was no attempt to bring the differing results together even though several authors participated in both projects. It is likely that measurement issues affected findings of both articles. The Langa study uses a single cognitive screening measure to determine cognitive status. There are significant problems with using single cognitive screening measure scores for dementia estimates, with notoriously increased high false-negative rates for highly educated samples and high false-positive rates for lower-educated samples (see Lichtenberg, 1999). Furthermore, cognition is highly variable and can be influenced by acute illness, medications, and other changeable events and thus does not necessarily reflect stable cognitive states. In the Langa study, the number of years of education was highly related to cognitive test score, consistent with what is known about the false-positive and false-negative rates with screening tests. The authors, however, simply concluded that since our population is more educated in

2002, education is related to less dementia. Most of the effect of change could simply be an artifact of the false-negative rate related to higher levels of education.

There were several advantages in the design and data in the Plassman study. The study was longitudinal, included clinical evaluations in addition to a number of cognitive test scores, and participants were categorized into groups (normal, cognitively impaired with no dementia, and dementia) based on an expert panel. In addition, a more robust set of cognitive measures was used. The weaknesses of this study

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included the small sample size and the large attrition rate over time. The study conclusions that the rates of cognitive impairment were higher than previously thought received no attention or fanfare from the study's main funder, the NIA.

The conflicting messages about cognitive impairment and aging add to the confusion that older adults experience about Alzheimer's disease. On the one hand are messages about the growing problem of Alzheimer's, and on the other hand, the federal government's scientific institute responsible for Alzheimer's disease reports that rates of cognitive impairment are on the decline (even when their own studies provide contradictory evidence).

Early Diagnosis

Viewing Alzheimer's disease as a chronic condition like cancer, diabetes, and hypertension makes early detection and treatment a critical objective. During the past decade, there have been several attempts to create new early detection markers. The focus on mild cognitive impairment (MCI) is one of the most successful of these strategies.

MCI was first characterized nearly a decade ago (Petersen et al., 1999). The new category was applied to people who had significantly reduced memory abilities while retaining strengths in other cognitive and functional areas. Early studies indicated that nearly 60 percent to 90 percent of people suffering from MCI progressed to Alzheimer's disease within five years. Morris and colleagues (2001) concluded that MCI represented early Alzheimer's disease. Morris's study, in which longitudinal data and postmortem examinations were conducted, generated great enthusiasm. Despite these early high hopes, people meeting MCI criteria have not uniformly moved along the continuum to dementia. Indeed, a significant number of older adults meeting the criteria for MCI actually demonstrated improved cognition over time (Brooks et al., 2008).

Some more recent concerns are related to the way cognition is measured in determining MCI. Brooks, Iverson, and White (2007) found that when large numbers of cognitive measures are given, high base rates of "impaired" scores were found in healthy older adults. Over half of the lower intellectual abilities sample had at least one memory score in the MCI range, whereas the same occurred in 21 percent of the high intellectual abilities sample. These authors underscored the importance of understanding base rates (false positives) before making diagnoses of MCI.

The difficulties arising from finding that the MCI label is significantly flawed are numerous. The field has created a new clinical category for which there is unreliable classification and no known treatments. MCI may add to ageism by including in an "impaired" category a great many older individuals whose daily function is not impaired at all. MCI further confuses the lay public about cognitive disorders and, specifically, Alzheimer's disease.

Treating Alzheimer's Disease

A third area of frustration in the past decade relates to the available treatments for Alzheimer's disease and their effectiveness. This has

been a time of great promises from prominent scientists and clinicians alike as they hailed great breakthroughs and the expectation of an imminent cure. In reality, as Whitehouse (2008) has documented, this past decade has been disappointing in terms of medical treatments for the underlying cause(s) of Alzheimer's.

The most widely used treatments are for dementia-related symptoms. The first validity studies of Aricept, a remedy that inspired high hopes, were published over a decade ago (Rogers and Friedhoff, 1996), with other compounds approved and numerous other studies conducted since then. All of the medications target symptoms of the disease, and none is treating the disease itself. A decade of more research and more medications has brought frustration about how poorly the Alzheimer's disease drugs work. Qaseem and colleagues (2008) published a new pharmacological treatment guideline for family physicians. This group of investigators viewed the evidence from the perspective of clinical versus statistical significance with results that suggest that many older adults with Alzheimer's disease are prescribed (and continue to be prescribed) drugs that do not benefit them.

Homes and colleagues (2008) followed up on the long-term effects of the first attempt at an immunization for Alzheimer's disease. This study reviewed the postmortem results for deaths of participants from 2000 to 2006. Eight immunized participants had their brains examined postmortem. While seven of the eight participants had virtually complete removal of the neuritic plaque suspected of causing Alzheimer's, all progressed to severe end-stage dementia. The removal was not associated with either increased survival or reduced dementia symptoms. The results of this study and others indicate the great and continuing challenge to the treatment of Alzheimer's disease. There is no overwhelming evidence that Alzheimer's has a single cause, nor is it likely that any treatments in the near

future will cure Alzheimer's disease. Indeed, borrowing from the cancer model of care, early detection coupled with multiple methods of treatments may provide a high quality of life for many with the disease. Drawing even more from the history of cancer, the talk of imminent cures over two decades ago is not unlike the recent decade's focus on imminent cures for Alzheimer's disease. The current promises range from doing specific mental exercises to prevent Alzheimer's to wearing helmets that deliver infrared light that help strengthen neurons (and cure Alzheimer's disease).

Too little focus on the people

The focus on early detection and new treatments for Alzheimer's disease has overshadowed the focus on people living with dementia and how they and their families can be assisted. By placing most of our resources on early diagnosis and treatment by medications (which are modestly helpful when they work, but do not help a significant portion of those with dementia), the lived experience of people with dementia has been neglected. How can such individuals maintain their identity, participate as partners in their own care with their family and their doctor, and maximize their quality of life? These questions are often ignored in journal issues about dementia, where articles focus only on issues related to prevention, early detection, medical treatments, and cure.


In This Issue

There is a great need for a balanced biopsychosocial approach to dementia and to the caring needed in relating meaningfully to people with dementia and their families. The excessive focus on biomedical cure, along with the social marketing of Alzheimer's disease that promotes fear and taps into the increasing ageism of society, must be replaced by a more heterogeneous description of aging and of brain aging

in particular. While the fear of Alzheimer's disease is very real, and there is a great need to focus on dementia and its growth in an aging population, and while the rising financial costs to society are significant, the form that increased attention to Alzheimer's and other age-related dementias takes often produces paralysis.

A major aim of this issue of *Generations* is to make the information about Alzheimer's and other related dementias accessible and useful to policy planners, practitioners, and researchers alike. The topics chosen represent an attempt at presenting an integrated approach to dementia. Articles include major aspects of biological, social, and psychological knowledge relative to older people with dementia and their informal caregivers.

There are articles related to prevention and latest medical and biological information, and there are articles related to the psychological experiences of persons with dementia, and the experiences of their families and those who care for them.

There are also articles examining the major societal trends. The intersection of health disparities and Alzheimer's disease raises questions about social justice in addition to questions about medicine. Caregiving highlights the great extent to which our nation's healthcare system is built upon unpaid workers—family and other informal care providers. There is also an exploration of the balancing act the United States faces in trying to provide a response to Alzheimer's disease that is caring while also addressing concerns about cost. Highlighting an integrated approach to facing Alzheimer's disease is our most important goal in putting together this issue. 

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Creating Aging-Friendly Communities

Andrew Scharlach, **Guest Editor**

Why America's cities and towns must be more aging-friendly—and how they can be. The issue includes a look at the range of concerns that must be addressed and the components that make communities good places to grow old, along with innovative community initiatives.

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