The Coming Crisis: Aging, Dementia, and Society

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ALZHEIMER'S DISEASE

HOSPICE FOUNDATION OF AMERICA

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INTRODUCTION

"Senator," "Senior," "Senile": these three words have very different meanings. The first is a sign of respect designating a member of a high and wise deliberative body. "Senior" is a more neutral term simply designating a person as older or an elder. Then there is "senile," a now generally discarded term that literally means "pertaining to old age" but generally is used to describe declining mental abilities in older persons.

Ironically all of these terms share the same etymological root *sene*, a Latin word designating "old man." The first two terms have obvious reference. A senior is an elder and the original Roman senators were men of age and substance, hardened by experience, chosen for their abilities to offer wise counsel. The word senile is an unfortunate connotation—a perspective of aging as inevitably leading to mental decline.

Understandings of dementia have evolved in past decades. Dementia is no longer viewed as an inevitable aspect of aging; rather it is viewed as secondary to the aging process. It is the result of a number of diseases and conditions that impair mental functioning. Clearly the incidences of these diseases are more prevalent as people age. While prevalence rates vary over a range, most estimates indicate that about four percent of persons over 65 years of age experience severe dementia and that 10-20 percent of older
persons (65+) have milder forms of dementia (Geller & Reichel, 1999). Prevalence rates rise as the population ages. Current estimates suggest that only one percent of the population 65 and older exhibits dementia. However, 10 percent of those over 75 years old and 25-30 percent of those over 85 years showed signs of dementia (Geller & Reichel, 1999). One study in East Boston found a prevalence of 47 percent of those over 85 years (Evens, Funken-Staun, Albert, et al, 1989). Since the population over 85 years is the fastest growing segment of the older population, the prevalence of dementia seems destined to grow.

Alzheimer's disease is the most common cause of dementia but it is not the only one. Pick's disease, Diffuse Lewy Body disease and Supranuclear Palsy are irreversible disorders of unknown causes. In all of these cases, etiology is unknown or disputed. Other irreversible dementias may be due to vascular conditions (eg. Multi-infarct dementia), genetic disorders (eg. Huntington's disease), infections (eg. Huntington's disease or AIDS-related dementia), or trauma (eg. dementia pogilistica). In other cases, symptoms of dementia may arise from reversible conditions caused by medications or vitamin deficiency. The diagnostic and statistical manual (DSM-IV) uses the diagnosis of "delirium" to distinguish these reversible conditions from progressive dementias.

**DEMENTIA AS A DREADED DISEASE**

Whatever the diagnosis, whatever the cause, dementia is a dreaded disease. In an earlier work (Doka, 1977), I explored the concept of "dreaded diseases." Dreaded diseases are diseases that carry a collective opprobrium. These diseases are feared. Historically diseases have been feared for two reasons. The first types were the great epidemics such as Bubonic Plague, Influenza or diseases such as yellow fever, typhus and cholera. These diseases inspired dread by the huge number of victims left in their wake. The massive death toll radically changed their societies, overturning social structures and creating new patterns of interaction.

The other types of dreaded disease are the ones with shameful stigmas: feared not so much for their collective devastation but by the individual nature of the death. That is the horrific way that individuals die. Cancer, tuberculosis, syphilis and leprosy would, at various points in history, be
included in this category. In that earlier work (Doka, 1997), I suggested that AIDS is especially dreaded since it shows characteristics of both.

So do the dementias. As the population continues to age both in North America and the world, the prevalence of dementia is likely to rise exponentially. It will be epidemic. As the baby boom generation (those people born between 1943 and 1960) ages the prevalence of the disease is expected to rise from a current 4.5 million persons to somewhere between 11.3 to 16 million by 2050 (Hebert, Scherr, et al, 2003). The disease will affect many more million such as spouses and family members.

It is a fearful way to die. One of the more frightful horror movies was "The Invasion of the Body Snatchers." Its premise is chilling. A person goes to sleep one night only to have his body taken over by an alien plant-like creature—a spore. The person looks the same, remains in the same environment yet has been altered by its invader.

In a sense, this is a cinematic metaphor for dementia. The person looks the same, even remains in the family, and yet is now different. The continuing metamorphosis wrought by the disease slowly yet inescapably removes the victim from connections to family and society.

It is the very insidious nature of the disease that adds to the sense of dread. Every lapse of memory to an older person such as the inability to recall a name or face can be a frightening reminder of personal vulnerability. It sustains a fear that one may be in the world though not of it—failing to acknowledge significant others or even self, losing the memories of not only how to do things but what the things are. It suggests the possibility that one may live to the end of life fading into the shadows unaware of the world, relationships, or even self.

The course of dementia also is unpredictable. The image of dementia with later learning peeled away before earlier learning is an inadequate model. In fact, one of the difficulties in treating dementia is that the biology of memory is not well understood. In fact, the models of how memory itself works are insufficient. Therefore, patterns of decline in dementia are not so readily predictable.

As with other dreaded diseases, the very name connotates fear. The term "dementia" not only insinuates a decline in mental facilities, but also strange and aberrant behavior. A person after all, who does unspeakable
acts, is described as “demented.” All of these factors contribute to the sense of dread engendered by Alzheimer’s disease and the other dementias.

It is highly likely then that Alzheimer’s disease, which is identified in the popular mind as the cause of dementia (and in fact, a major cause), is to be the first dreaded disease of the twenty-first century. Alzheimer’s disease challenges the core fears of the baby boom generation.

The baby boom generation has been resistant to the idea of aging. As they file through middle age, the boomer generation has spawned the rise of health clubs and vitamin stores—all partially attempts to stave off the ravages of aging. The ravages of dementia then are incontestable proof that one has succumbed to aging. That alone makes it fearful.

Beyond simply a sign of the loss of valued youth, dementia is an onslaught against so many of the boomer’s cherished values: autonomy, independence, and control. Alzheimer’s disease means the lack of control. The victim loses everything in the loss of mind. That creates a loss of autonomy and independence that the baby boom generation always has resisted.

Alzheimer’s disease clearly will be the dreaded disease.

DEMENTIA AS A SOCIAL ISSUE

Because it will be their dreaded disease, Alzheimer’s disease will be a public social issue for the baby boom generation. C.W. Mills, an American sociologist, distinguished between “private” troubles and “private” issues (1993). To Mills, private troubles are an individual problem, an aspect of a person’s circumstances and character. For example, the fact that mom, now old, was becoming forgetful and confused was a private problem for a small number of individuals, because they had to resolve the issue perhaps by institutionalizing mother or accommodating work or home schedules so they could provide adequate supervision and support.

“Public” issues, on the other hand, merit social action. These problems transcend individual difficulties. There is an awareness that the problem does not just affect one person, but many: it is not one mother who is confused and forgetful, but millions. The problem now begs for social intervention.
Alzheimer’s disease and related dementias are likely to be the social problem of the next quarter of a century. It may very well be a social issue as commanding of public attention as the Civil Rights movement was of the last half of the twentieth century. As baby boomers see their future in caring for their own parents, they are likely to agitate for increased attention to dementia. Much like the draft of an earlier era, the conquest of Alzheimer’s disease has the potential to be their next generational issue.

One reason is sheer scope. The boomer generation, baring a major discontinuity as a major war, new epidemic or environmental catastrophe, is likely to live in large numbers to very old ages. For most dementias, the causes are either unknown or genetic, so they are not, with the exception of vascular dementias, preventable. Even vascular dementias are not easily preventable. Unless there are unforeseen and dramatic breakthroughs in prevention of treatment, the rate of persons affected by dementia can be expected to dramatically increase as the baby boom generation ages. Estimates suggest that well over 11 million, perhaps as many as 16 million, may have the disease (Hebert, Scherr, et al, 2003). Incremental advances in lifespan may even increase these estimates.

There also is the expense. Alzheimer’s disease costs approximately a $100 billion a year (Ernst & Hay, 1994). These expenses include not only direct costs to businesses, families, and individuals, but indirect costs as well. These indirect costs may include increased costs of insurance as well as other indirect costs such as the loss of productivity and absenteeism of those shouldered with caregiving responsibilities.

Moreover, there is increased awareness of dementia. In most American subcultures, it is not a shameful stigma largely hidden from public view. Awareness generates increased awareness. The identified action of dementia in public personalities such as President Reagan or Charlton Heston focus attention on Alzheimer’s disease and the problems caused by dementia. Such public identification is critical for a number of reasons. It lessens the stigma of the disease, allowing other families and individuals to come forward. The publicity personalizes the disease, placing a human face on an otherwise anonymous victim. Finally, awareness increases motivation to act.
Not that the boomer generation needs much motivation. This generation has shown considerable public savvy in dominating political debate. From their youth, their sheer numbers have instigated political debate. Their concerns have become social concerns. Their private troubles—from overcrowded schools to the draft—have transformed into social issues. As Dychwald and Flower (1988) note, the baby boom has been a tsunami wave overwhelming every social institution encountered in their life course.

They have already experienced dementia indirectly as they have cared for aging parents. These experiences have moved caregiving very much to the center of the public arena. As the boomers age and enter later life in large numbers, their experiences with friends and mates, as well as their personal fears will force public attention on Alzheimer’s disease and related dementias.

They are likely to encounter a receptive society. The aging of America, as well as that of most developed societies, is likely to lead to the increased prevalence of Alzheimer’s disease and related dementias. This trend will leave little untouched.

For example, schools, colleges, and other employers, in the absence of mandatory retirement, may need to develop policies regarding screening or testing. As persons stay within the work force, there are likely to be cases where employees experience early stage dementia. This in turn will raise issues once reserved for other illnesses. How far must employers accommodate such illnesses? When does dementia compromise the safety of the work place? How can one mandate that persons are tested or otherwise screened? What are the rights of employees in such situations? When can an employee be terminated?

These debates are likely to spill over into other areas. Driving licenses are a sign of both independence and adulthood. The loss of a driver's license is a symbol of declining capacity, long dreaded by older drivers. Many states already have provisions for periodic testing of older drivers. Yet, the increased prevalence of dementia suggests that states may have to reexamine this issue, perhaps by developing more sophisticated testing procedures and possibly even developing research and tracking. It very well may be that certain types of accidents or violations may be seen as early screening devices for the cognitive losses evident in early stage dementia.
These issues are likely to generate further debates about the rights of individuals versus the needs of the larger society. How early can individuals be tested and on what basis? What are the rights of individuals with cognitive declines? How will their privacy be respected and their independence nurtured? Boomers, after all, have had an historical aversion to the notion of a paternalistic government.

Health and long term care are likely to be affected as well. Research continues on early detection and treatment. Alzheimer’s and perhaps other dementias are likely to be diagnosed earlier. This can exacerbate a range of ethical issues. Can a person in the early stages of the disease terminate medication even for a readily treatable infection? Are they competent to make the decision? Would earlier advance directives hold? Can Alzheimer’s disease especially in the early stages be considered an untreatable disease?

The presence of a great number of persons living in the community with early stage dementia will lead to the redesign of programs and facilities. The treatment of Alzheimer’s disease as well as the other dementias is likely to be a combination of medication, environmental and mental stimulation, and physical stimulation and exercise. There may be a surge of day programs that can offer such services while providing respite for the caregiver. Other respite services such as night sitters may be in demand. The provision of these services may delay more expensive alternatives such as institutionalization within a nursing home. Yet, the funding stream for such vital services is still unclear. There may be increased pressures for insurance programs, including Medicare, to cover these services.

Assisted-living facilities and nursing homes also may need to redesign policies and programs to accommodate a future population with dementia. Assisted-living facilities may need to develop services that offer more supportive care, allowing individuals with early stage dementia to stay longer. All types of facilities may need to reexamine programs to assure that these programs offer the varied stimulation that seems so critical to persons with dementia.

The policies governing hospice will need reevaluation as well. The hospice benefit that limits care to the last six months of life will be further challenged. Under the Medicare Hospice Benefit provision, persons can elect hospice care if a physician certifies that they have less than six months life expectancy. With Alzheimer’s disease however, such prognostication is
difficult. Furthermore, governmental efforts to investigate Medicare fraud have seemed to target patients with dementia. The result is that hospices that have provided care for Alzheimer’s patients have been investigated. In some cases, care for such patients has been excluded, leaving hospices financially liable. Some hospices, then, have been reluctant to admit patients with Alzheimer’s disease. This, in turn, has left individuals with the disease and their families bereft of good palliative care. The growing population with dementia should cause review of such policies that inhibit valued hospice care to dementia.

This, too, will create new challenges for hospices. Hospices were originally designed to treat late-stage cancer patients. How can one assess pain and symptom control in persons with dementia? What new services may be necessary to support patients with dementia and their families? How will staff be supported since caring with patients with dementia is not likely to bring the same satisfaction of working with persons who are aware of death? What ethical issues will arise as hospices encounter the problems of denying life-sustaining treatment to patients of perceived marginal social value—often exacerbated by the fact that these decisions may be made by family or other surrogates without the explicit wishes of the patient fully known?

There is likely to be increased pressure for funding for research and treatment. Yet, such increases carry costs. Increases in funding for research and treatment as well as for healthcare in a society already supporting a large cohort of retired persons, will either need to generate increased tax revenues or reductions in other spending. As agendas are likely to be very different for people at different stages of life, possibilities exist for provoking sharpened generational conflicts. Healthcare and other entitlements for older persons assume much of current governmental revenues. How will new services be provided? Will generational conflict develop over spending priorities?

New positions and new markets will be created for the range of services, products, and programs necessitated by an increased numbers of individuals, and their families, struggling with dementia. Day programs, medications, assisted living, and supportive care will likely grow. As legitimate opportunities increase, so do illegitimate ones. These may range from electoral fraud to miracle cures to elder abuse.
CONCLUSION: THE COMING CRISIS

Alzheimer's disease and related dementias are likely to become the crisis of the first half of the twenty-first century. The rising rates and increased prevalence of dementia will affect every aspect of the social order.

There is one saving grace. There is still time: perhaps twenty-five years before a serious problem becomes an unmanageable one.

The coming crisis of dementia merits debate, discussion, and consideration. Perhaps the most significant marker of a society is how well it treats its most fragile and vulnerable members.

REFERENCES


