

## The Public Health Impact of Alzheimer's Disease

Dementia is emerging as a major public health concern. There are few diseases which have such a profound impact on society, patients, and their circle of families and friends as does dementia. While dementia is a common disorder, our knowledge of its etiology, natural history, treatment, and impact is still incomplete. Although we do know that such deterioration of cognitive functioning is distinct from that attributable to the normal aging process and usually develops insidiously, all too often it is dismissed as simply being due to old age. It also has only been within the last decade or two that dementia has emerged from the shadows into the limelight. With this increased attention has come a better understanding of the magnitude of the public health impact of the disease.

Because dementia is largely a disease of older age, the demographic changes in the United States have resulted in increasing numbers of people at risk of developing the disease. Never before in our history have so many people lived to be so old. Today more than 50 per cent of the entire US population reaches age 75 and 25 per cent live to age 85. The segment 85 years of age and older is growing fastest and expected to increase by over 80 per cent by the year 2000.<sup>1</sup> An increasing number of elderly with significant intellectual and functional impairment will accompany this large increase in the "at-risk" population. Although good epidemiologic data from this country are lacking, the prevalence of severe dementia in the over age 65 population ranges from 1.3 to 6.2 per cent with the medium prevalence of 4.15 per cent. The prevalence of dementia in the age group over 85 years may be as high as 20 per cent.<sup>2</sup> In the United States today, approximately three million persons are moderately affected. Over 56 per cent of the elderly in nursing homes have a diagnosis of chronic mental condition or senility<sup>3</sup> which is a significant factor in the admission to nursing homes in over 50 per cent of the cases. These data represent a tenfold increase in the number of people affected since the turn of the century and the number of people with severe dementia is expected to increase 60 per cent by the year 2000.<sup>4</sup>

It is currently estimated that the most common cause of severe intellectual impairment in the elderly is Alzheimer's Disease, accounting for about 50–60 per cent of all cases; multi-infarct or mixed dementia accounts for approximately 20–40 per cent; and the remaining 10 per cent or so includes a variety of rarer types.<sup>5</sup> Alzheimer's Disease may lead to death in five to 10 years, decreasing life expectancies by one-half to one-third that of healthy persons of the same age.<sup>6</sup> Based on these data, some have suggested that dementia is probably the third or fourth leading cause of mortality in the United States, accounting for at least 120,000 adult deaths annually, although it is rarely reported on death certificates.<sup>7</sup> The number of cases of Alzheimer's Disease is expected to grow significantly in the current decade due to the increasing numbers of the elderly at risk in the population. However, the number of cases could also be increasing due to a changing incidence of the disease and to the changing duration of illness due to improved medical care. If the incidence and duration of the disease change significantly in the coming years, the total number of cases may increase even more dramatically than currently expected.<sup>4</sup>

Another reason for the growing concern for Alzheimer's Disease is the profound effect of the disease on family and friends of its victims. It is estimated that for every American presently suffering some degree of dementia, there may be up to three times that number of close family members whose lives are deeply affected by the emotional, physical, social, and financial burdens of caring for Alzheimer's victims.<sup>8</sup> Approximately two-thirds of those afflicted with Alzheimer's Disease are cared for at home by family caregivers who are thus confronted by the prospect of witnessing the gradual deterioration of a loved one's intellect, memory, and personal relationships over a five to 10-year period. Alzheimer's victims suffer insidious and unrelenting brain failure, progressing from simple forgetfulness to the need for total care in carrying out the simplest routine activities of daily living. The need for total care may span several years and even when Alzheimer's patients are institutionalized, many families continue to play a vital role in the care until their death. Middle-aged caregivers are especially at high risk of becoming secondary victims of Alzheimer's Disease. They may experience conflicts between competing obligations and goals. The needs of an ill or frail parent with Alzheimer's Disease may create or exacerbate a condition of multiple demands for their children's time, energy, money, and emotional support resulting in increased health problems for caregivers.

Aggravating the problem is the fact that the health, social, and personal care services in the community tend to be fragmented and often unresponsive or unavailable to Alzheimer's patients and their families. Institutional care of Alzheimer's patients is often characterized by a lack of thorough assessment, heavy reliance on convenient drug therapies for behavioral problems, and little attention to non-pharmaceutical interventions that may help the patients and the families to cope. These problems are often confounded by lack of staff, at all levels, who are trained in dealing with the symptoms and behavioral conditions associated with Alzheimer's Disease. In many states, few long-term care facilities will take patients with a diagnosis of Alzheimer's Disease who present with any type of behavioral problem.

Another measure of the magnitude of the problem is the economic impact of the disease. Hay and Ernst in this issue of the Journal<sup>9</sup> have demonstrated clearly the tremendous monetary costs of caring for chronically demented patients with Alzheimer's Disease. Their estimates, if anything, are on the conservative side and clearly highlight the impact of the disease. For example, the study assumes mean survival time of the disease from the date of diagnosis of 2.7 years for men and 4.2 years for women. If disease durations are increased to 3.5 years for men and 5.0 years for women, the present discounted value (1983) of total net costs to society for all patients first diagnosed during and after 1983 rises by over \$100 billion. They estimated that the total cost of the disease per patient in 1983 was \$48,544 to \$493,277, depending on the patients age at disease onset. They also estimated the overall cost of the disease to society for all patients diagnosed with Alzheimer's Disease in 1983 to be anywhere from \$27.9 to \$31.2 billion. This can be put into perspective by comparing it to the cost of care (1980) for the other major

causes of death such as heart disease, \$14.5 billion; cancer \$13.1 billion; stroke \$5.1 billion; and accidents \$19.2 billion.<sup>8</sup> The costs for care of Alzheimer's Disease are particularly worrisome, as pointed out by Hay and Ernst,<sup>9</sup> because there are no private or public mechanisms for fully insuring against the economic catastrophe of Alzheimer's Disease.

In spite of these statistics, public policy has been very slow to respond to the need. For example, the total federal obligations by all federal agencies for research on Alzheimer's Disease and related disorders has gone from \$3.9 million in 1976 to only \$53.92 million in 1986.<sup>8</sup> This compares to \$624 million appropriated to the National Heart, Lung, and Blood Institute in 1983 and approximately \$1 billion appropriated to the National Cancer Institute in 1983.<sup>10</sup> It has been estimated by the National Institute on Aging that for every \$1.00 spent on Alzheimer's Disease, only \$0.01 is spent on research. It is apparent that a much greater research effort is needed to bring research on Alzheimer's Disease in line with efforts in other comparable areas.

Another problem is long-term care policy. Individuals with dementia constitute perhaps the largest definable population group of those needing long-term care services for extended periods of time. Because of this, they account for large expenditures under the Medicaid program, which in turn accounts for up to 10 per cent of some states' budgets. One approach mentioned by Hay and Ernst is for insurance programs to cover the devastating costs of the disease.<sup>9</sup> Although the authors propose a disease specific health insurance program, I think the problem needs to be viewed in a much broader context in relation to long-term care financing problems in general in the United States. For example, in addition to policies covering insurance and payments for a full continuum of long-term care services for any chronic illness or infirmity, efforts need to be made to develop appropriate services where they do not currently exist and the trained personnel to staff these services. There is a serious short fall of trained physicians, nurses, nurse practitioners, and other health professionals who have formal training in geriatrics or in dealing with dementing illnesses. The estimated need for academic geriatricians alone is 2,100<sup>1</sup> by the year 2000, and for the other health professionals, the need is even greater.

Public policy needs to address how to reduce the magnitude of the problem in the future as well as how to ameliorate problems already facing patients and their families. A recent report by the Congressional Office of Technology Assessment clearly outlines the federal policy priorities that are needed in Alzheimer's Disease. These include more support for biomedical research and health services research, increased education, improvement in financing of long-term care, development of necessary services for patient assessment and follow-up, and assuring the quality of care.<sup>8</sup> These policies will necessarily need to be based upon a broad perspective since the issues of aging and long-term care are closely tied into the problems of Alzheimer's Disease.

Because federal initiatives alone are not and probably cannot be sufficient in this area, state governments have also shown interest in the problems of dementia. At least 21 states have major legislative initiatives concerning Alzheimer's Disease.<sup>8</sup> A few states—such as California, Maryland, Kansas, Texas, Minnesota, Rhode Island, and Illinois—have

developed statewide approaches to the problems of dementia. These initiatives address the need for public education, treatment for patients and their families, training and research, and long-term care and financing. California, for example, established in 1985 six regional Alzheimer's Disease Diagnostic and Treatment Centers. The purpose of the centers is threefold:

- to provide comprehensive, multidisciplinary diagnostic assessments,
- to provide education and training for both caregivers and professionals, and
- to serve as coordinating units for collecting epidemiologic data and for conducting a wide range of research activities into the causes, treatment, and impact of the disease.

Furthermore, the process of public hearings and debate in the states, such as in California, has helped to better define the problem, raise political interest and sensitivity to the issue, and implement legislation that builds a model system of care for the patient and the family.

Alzheimer's Disease is not likely to be a disease eliminated by a quick "technical fix". Yet, it is a disease for which tremendous strides can be made in alleviating the terrible physical, emotional, and financial costs to families, caregivers, and government. A far more concerted and long-term public health effort is required if the relentless onslaught of Alzheimer's Disease is to be modified.

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