Change in the Prevalence of Severe Dementia

among Older Americans: 1982 to 1999

Elizabeth H. Corder[1]

Kenneth G. Manton[1]

[1]Duke University, Center for Demographic Studies

Abstract

The aging of the U.S. population and age-related increases in dementia prevalence suggest an impending epidemic of dementia. We estimated the prevalence of *severe* dementia for the U.S. age 65 and older population in 1982, 1994, and 1999, overall, and in relation to age and level of disability. Subjects were participants in the respective National Long Term Care Surveys. There was a decrease of 380,000 cases from 1.3 million (4.7%) in 1982 to 0.9 (2.5%) in 1999 (p < 0.0001). Age-standardized estimates demonstrated a larger decline from 5.3% to 2.5%. A million fewer cases were found in 1999 than predicted by the 1982 rate. We conclude that more recent cohorts are less likely to be severely demented in old age despite longer life expectancy.

1. Introduction

The well-known age-related increases in the prevalence of disability and dementia with age are problematic for the U.S. health care system given the aging of the population (Evans et al. 1992). Fortunately, evidence from a series of National Long Term Care Surveys (NLTCS) indicates that there has been a large, and accelerating, decline in the prevalence of chronic disability for the U.S. elderly population (Manton et al. 1997, Singer and Manton 1998, Manton and XiLiang 2001). These rates declined 1.0% per annum from 1982 to 1989, by 1.6% per annum from 1989 to 1994, and by 2.6% per annum from 1994 to 1999.

In this article we explore a potentially major factor in the accelerating decline of disability, namely, the role of severe dementia. The prevalence of dementia as measured by the NLTCS was estimated in 1982, 1994, and 1999, overall, and according to age and level of disability.

2. Data and Methods

2.1 The study sample.

There have been five NLTCS carried out in 1982, 1984, 1989, 1994, and 1999. The 1982, 1994, and 1999 surveys are used in this analysis. The surveys were conducted to describe the level of disability and medical care utilization among the elderly. Sample design and instrumentation of each survey were held constant to minimize the potential biasing effects of changes in methodology (Singer and Manton 1998).

NLTCS subjects are drawn from Medicare enrollments lists to ensure that the entire U.S. population aged 65+ was represented, both the community and institutional populations. Virtually 100% of persons in each survey year could be tracked. Once selected, surviving subjects were included in subsequent surveys. Each survey after 1982 included an age-in sample

of persons 65 to 69 drawn from Medicare enrollment lists. Supplementary samples of persons aged 95+ were drawn in both 1994 and 1999 to increase the precision of estimates for this very elderly population group which, heretofore, had not been well studied.

Each survey was conducted in two stages. A brief screening interview was administered to all participants to detect cases of chronic disability. Here, chronic disability was defined as one or more limitations in Activities of Daily Living (ADL) (Katz et al. 1983) or Instrumental Activities of Daily Living (Lawton and Brody 1969, Katz and Akpom 1976) lasting, or expected to last, 90+ days. In the second stage all cases were given either a detailed community, or institutional, interview. In addition, all cases in any prior survey year received a detailed interview so that improvements, as well as decrements, in function could be detected. Note that 1,762 'Healthy' persons who did not screen-in in the 1994 NLTCS, were given a detailed community interview to increase the precision of estimates for the non-disabled population in 1994. This 'Healthy' over-sample was continued in 1999 after being augmented by 284 persons to replace deaths over the interval.

2.2 Severe dementia criteria

Subjects in the community were defined to be severely demented if three criteria were met: First, the subject did not attempt a brief cognitive screening battery placed toward the end of an hour-long interview. The Short Portable Mental Status Questionnaire (Pfeiffer 1975) was administered in 1982 and 1994. The Mini-Mental State Examination (Folstein et al. 1975) was administered in 1999. Second, the interviewer determined the need for a proxy respondent to assist in answering the survey questions. The proxy was most often the caregiver or a relative of the subject. Third, the proxy respondent indicated that the subject had previously been diagnosed as senile or as having Alzheimer's disease.

For nursing home residents, we took estimates of the prevalence of the diagnosis of severe cognitive impairment/dementia from the 1985 or 1995 National Nursing Home surveys (as appropriate) and applied them to our independent NLTCS estimates of the size of the nursing home population in 1982, 1994 and 1999. These estimates were 31.6%, 24.8% and 22.8% respectively.

2.3 Disability subgroups

The subjects were divided into three disability groups. The 'No ADL limitations' group was composed of persons living in the community who had no ADL limitations. They were able eat, dress, get in and out of bed, get around inside, use the toilet, and bathe without the assistance of another person. They may have had limitations in Instrumental Activities of Daily Living such as shopping for groceries. The 'ADL limitations' group had one or more ADL limitations. The third group was comprised of nursing home residents regardless of disability level. This group had a mean of 4.8 ADL limitations.

2.4 Methods

First, the absolute number of older persons who were severely demented was calculated for each survey year by summing the sample weights for severely demented subjects and dividing by the population size for that year, overall and for each disability group. Second, age-adjusted prevalence rates for severe dementia were calculated for 1982 and 1994 by superimposing the older age structure found for 1999. Third, the number of severe dementia cases was estimated for 1999 assuming the age-specific prevalence rate for 1982. T-tests were used to compare the prevalence of dementia in earlier years to 1999. Since the sample weights are fixed by the pre-specified sample design they do not contribute to the sample validity in the testing of the weighted rates in two years.

3. Results

3.1 The absolute number of severe dementia cases

Table 1 (top) displays the number of severely demented older Americans in 1982, 1994, and 1999—overall and for each disability group. Overall, there were 1.26 million elderly Americans who were severely demented in 1982 compared to 0.88 million cases in 1999 – an absolute decline of 380,000 cases despite 1) the rapid growth of the U.S. elderly population over the interval from 27 million persons in 1982 to 33 million in 1994 and to 35 million in 1999, and 2) the higher average age of recent cohorts.

Absolute declines were distributed fairly equally over the disability groups. There were 130,000 fewer cases for subjects having no ADL limitations, 100,000 fewer for those having ADL limitations, and 150,000 fewer cases among nursing home residents. The majority of severely demented persons were living in the community, although help with basic activities of daily living was frequently needed.

The overall decline in the absolute number of severely demented older Americans was substantially attributable to younger subjects aged 65 to 79 (Table 1, middle). The younger group had 633,000 cases in 1982 and 325,000 in 1999 – a decline of 308,000 distributed across the disability groups. In the younger group, cases most frequently lived in the community despite ADL limitations.

For the older group aged 80+ (Table 1, bottom), there were 48,000 fewer cases in 1999 compared to 1982. This small decline was primarily among nursing home residents, the most common group. Community residents usually had ADL limitations. In terms of absolute numbers, in 1982 cases were approximately equally divided between the two age groups. By 1999 with the aging of the population, there were twice as many cases in the older age group.

3.2 Prevalence

The percentage of older Americans who were severely demented was 4.7% in 1982, 2.7% in 1994 and 2.5% in 1999--a 42% decrease from 1982 to 1994, with a subsequent small decrease between 1994 and 1999. The decline in the prevalence over the interval was statistically significant at well past the 0.001 level (t = 11.6).

Significant declines in the prevalence of severe dementia over 17 years from 1982 to 1999 were found for each disability group: 1) from 0.74% to 0.20% among community residents who had no ADL limitations (t = -7.7), 2) from 2.14% to 1.35% among community residents who had ADL limitations (t = -6.1), and 3) from 1.8% to 0.95% for nursing home residents (t = -7.7).

Both age groups demonstrated a large decrease in prevalence for the interval 1982 to 1994, and a small decrease for 1994 to 1999. For the younger group aged 65 to 79, severe dementia prevalences were 3.0%, 1.5%, and 1.3% for the respective years. Severe dementia was 4 times more common at later ages throughout the interval: Prevalence for the age 80+ group decreased from 11.7% in 1982 to 7.3% in 1994 and to 6.4% in 1999. Only a small proportion of severely demented persons aged 80 and older lived at home and had no limitations in activities of daily living.

3.3 Age-standardized estimates

Superimposing the older age distribution found in 1999 on earlier years, the declines in the 1) number of cases and 2) dementia prevalence since 1982 were more evident. Table 2 demonstrates a decline of half a million cases from 1.4 in 1982 to 0.9 million in 1999 distributed fairly equally over disability groups.

After age-standardization, the number of severe dementia cases shown in Table 2 (middle) for the younger age group was similar to that found in Table 1. There were almost 300,000 fewer

cases in 1999 than 1982 distributed over the disability groups. Cases most frequently lived in the community with ADL limitations.

Age-standardization markedly increased the estimated number of cases in the older age group for 1982 and 1994 -- overall, in nursing homes, and living in the community with ADL limitations (Table 2). Before standardization (Table 1), cases in the older age group demonstrated little change in absolute number over time. After age-standardization, almost 300,000 fewer cases were found in 1999 than in 1982 (a decline from 850,000 to 587,000). The decrease was evident for subjects with ADL limitations or living in nursing home. Few dementia cases aged 80 or older were not debilitated.

Age-standardized prevalence declined from 5.25% in 1982 to 2.89% in 1994 and to 2.50% in 1999 (t = -11.2). The overall prevalence of cases at ages 65 to 79 was much lower in recent years (3.1% versus 1.24%; t = -10.3). The decline for "oldest-old" disabled community residents (from 4.7% to 3.0%; t = -4.6) and the institutional population (6.5% to 3.3%; t = -7.8) were also very large.

3.4 Projected number of cases

The 1999 elderly population was larger, as well as relatively older, than in earlier years. The age-standardized 1982 rate of 5.25% would predict that 1.85 million of the 35 million Americans age 65 and older in 1999 would be demented -- instead of the 0.88 million cases found. The difference between what would have occurred in 1999 with the 1982 risks, and what was observed, is almost one million cases.

4.1 Discussion

The results from the 1982, 1994, and 1999 NLTCS show that we can perhaps be more optimistic about future changes in the prevalence of severe dementia than had been expected even five years ago. This study demonstrated that the prevalence of dementia has declined substantially over the last two decades. The estimated declines were large absolutely, i.e. 380,000 cases, before accounting for the older average age and larger numbers of elderly Americans in recent years. Adjusting for the older age and larger size of recent cohorts, there are a million fewer cases of severe dementia than would be expected based on prevalence in 1982. In relative terms severe dementia prevalence was almost 50% lower in 1999 than 1982, i.e. 2.5% found vs 5.25% expected.

The declines were significant, both overall and for the two age groups, distributed over the disability levels for the 65 to 79 age group and most evident for nursing home residents for the 80 and older age group. Confirmation of this observation is found both in decline in the prevalence of dementia between the 1985 and 1995 National Nursing Home Surveys and as reported by analysis of Supplements on Aging to the 1984 and 1994 National Health Interview Surveys (Freedman and Martin 2000).

The dementia criteria employed in this study did not likely include persons with mild and moderate dementia able to at least attempt the brief cognitive test and/or able to respond to the survey without assistance from another person. The study involved no medical examinations. Persons not previously diagnosed as senile or with Alzheimer disease – those especially in the early stages of dementia -- would not have fulfilled criteria for dementia in this study. Thus the declines reported in this study likely truly represent declines in severe dementia.

The formal methods to detect severe dementia cases were comparable across time. The NLTCS for each year employed essentially the same survey instruments, sample design and field methods. This uniformity no doubt was helpful in obtaining comparable responses from participants and their proxy respondents over time. Nonetheless, there is no guarantee that the methods for judging dementia really were comparable over time. The greater awareness of Alzheimer's disease and the need to rapidly treat stroke argue that dementia may have been reported more completely for recent years. This suggests that any bias would be toward the null hypothesis of no decline in dementia prevalence, minimizing rather than exaggerating declines in the prevalence of dementia over time. Response rates were over 95% for each survey indicating that it is unlikely that the results were strongly influenced in any year by non-response.

Through dementia, especially severe dementia, is associated with high mortality, differential mortality does not likely bias our prevalence estimates in this study because the sampling strategy delivers a current cross-section for each year. In generating a true cross-section the sample has to be augmented to accurately portray dementia incidence to compensate for the likely more rapid loss of severely demented persons due to elevated mortality risks. This was done by screening roughly 12,000 previously non-disabled persons (5,000 persons passing age 65 between survey and 7,000 persons not previously disabled who were aged 70 and above in each year). This screening was done by telephone interview with the screening set up to tolerate significant false positive rates on the detailed interview to minimize the false negative rate. Thus a significant portion of cases identified as possibly disabled on the screen proved non-disabled on the community interview. Tests conducted of persons who screened using mortality data, and Medicare expenditure records, suggest that very few persons with significant chronic impairment are missed in the screening process.

The dementia decline over 17 years coincides with decreases observed in chronic disability. However, the rate of disability decline is smaller and accelerating over time: The rate of decline was 1% per year from 1982 to 1989, 1.6% per year from 1989 to 1994, and 2.6% per year from 1994 to 1999. The 48% decline in dementia was concentrated earlier in the interval. Moreover the largest declines in dementia were found for the most disabled group of persons, i.e. those living in institutions. Thus the dementia declines, while they plausibly contribute to the overall rate of disability decline, e.g. in the late stages of dementia, do not simply echo the fact that recent cohorts are healthier.

The dementia decline raises two questions:

The first is what caused the declines? There are various hypotheses. The educational level of the oldest-old population has been increasing. In 1980 roughly 60% of the population aged 85 to 89 had less than 8 years of education. By 2015 this will decrease to 15% (Preston 1992). The Boston EPESE Study indicates that the higher education level is expected to halve the future dementia rate (Evans et al. 1992). Numerous explanations for the lower rate of dementia among educated persons have been put forth ranging from better fetal nutrition and less alcohol and tobacco use, stroke, and head trauma to the benefits of affluence and keeping the mind active.

A second hypothesis is that resources devoted to improved medical care and specific treatments, for the old as well as the young, have been paying dividends. There may be less, and better managed, stroke and heart disease. The cognitive sequalae from these problems may be better medically managed. Specific medications, (e.g. statins lowering cholesterol synthesis) may well reduce the risk of dementia (Jick et al. 2000, Wolozin et al. 2000). Sight and hearing problems contributing to lack of orientation and perceived dementia may also be better managed. Other possible causes include long-term use of nonsteriodal anti-inflammatory drugs (NSAIDs).

A meta analysis of 17 studies showed that the use of NSAIDs to treat arthritis was associated with almost a 50% reduction in Alzheimer's prevalence (McGeer et al.1996). Another study showed hormone replacement therapy might have a beneficial affect on dementia. Estrogen use appeared to reduce the risks of Alzheimer's by almost 50% in some epidemiological studies (Tang et al. 1996). To date clinical trials have not confirmed the effect. Other studies suggest that physical activity and improved nutrition (increased vitamin E consumption) might reduce the risk of dementia (Ericksson et al. 1998). Most intriguing are reports to the effect that, not only are there stem cells in the human brain, but that, combined with various growth factors, there may be significant re-growth of brain cells after injury (Horner and Gage 2000).

The second question, related to the first, is if declines in severe cognitive impairment have, and continue to, occur, what will their impact be on society and on long term care costs? Clearly these effects will be generally positive. Of most benefit will be the reduction in the need for institutional care.

Acknowledgments

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Table 1. Estimated absolute numbers of severely demented older Americans in 1982, 1994, and 1999.

	Disability Level			
	No ADL limitations	ADL limitations	Nursing home resident	Total
All ages				
1982	200,496	573,306	484,418	1,258,220
1994	40,483	440,510	419,132	900,125
1999	70,242	474,724	334,239	879,205
Ages 65 to 79				
1982	171,412	311,470	149,993	632,875
1994	32,158	209,106	125,636	366,900
1999	55,503	204,436	64,891	324,830
Ages 80+				
1982	29,088	261,836	344,423	635,347
1994	8,325	231,398	332,088	571,811
1999	15,505	270,288	301,254	587,047

Table 2. Estimated number of dementia cases for each year after age-standardization of 1982 and 1994 to 1999.

	Disability Level			
	No ADL Limitations	ADL Limitations	Nursing Home Resident	Total
All ages				
1982	194,714	637,388	581,830	1,413,932
1994	40,246	463,072	455,657	958,975
1999	70,242	474,724	334,239	879,205
Ages 65-79				
1982	159,790	302,820	148,823	611,433
1994	31,304	207,385	126,840	365,529
1999	55,503	204,436	64,891	324,830
Ages 80+				
1982	34,926	334,569	480,891	850,386
1994	8,958	255,687	371,510	636,155
1999	15,505	270,288	301,254	587,047