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Prevalence and Correlates of Dementia: Survey of the Last Days of Life

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S Y N O P S I S

Objectives. To estimate the prevalence and correlates of dementia at death and to assess the usefulness of death certificate data in the reporting of dementia.

Methods. The authors analyzed next-of-kin interviews for 599 male and 628 female decedents using data from the National Institute on Aging's Survey of the Last Days of Life.

Results. Death certificate data in this population show the prevalence of dementia to be less than 1%, consistent with previous reports based on death certificates but a substantial underestimate compared to the 11.9% reported in a national survey. Using a dementia index based on the informant's report of whether the decedent had been diagnosed with a dementing illness and the extent of her or his cognitive and functional limitations, this study found a prevalence of dementia of 8.5%.

A high score on the dementia index was significantly associated with older age, Parkinson's disease, and incontinence. Lower relative odds for dementia at death were found for people with either a lifetime history or a death certificate report of cancer. Similarly, people with a lifetime history of coronary heart disease were found to have lower relative odds for dementia at death.

Conclusion. These results suggest that informant interviews may be a useful source of data to examine factors associated with dementia and to estimate the prevalence of dementia in the last year of life.

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The prevalence of dementing illnesses among older Americans is difficult to estimate. Surveys have established a prevalence of chronic dementing illnesses among Americans ages 65 and older in the range of 4% to 11%, with an approximately exponential curve starting from 1%–2% at age 60 and doubling with every five to seven years of increasing age.^{1,2} These surveys have usually not included institutionalized people, although it is known that a very high proportion of older people in nursing homes have dementing illnesses. A second factor likely to lead to low prevalence estimates is non-response bias since it seems likely that people with early or mild cases of progressive dementia may fail to respond to such surveys.

Death certificates are another potential source of data on the prevalence of dementia at death. Analyses of death certificate data have typically shown a less than 1% prevalence of dementing illnesses among Americans ages 65 and older. Since the common dementing illnesses are irreversible, the prevalence at death should be identical with the age-specific cumulative incidence and with prevalence in the population, yet death certificates have been shown to be an unreliable source of prevalence estimates.^{3–8} Many deaths from dementing illnesses are not recorded as such on death certificates. In recording cause of death, physicians tend to minimize the importance of cognitive impairment and dementia. Dementia is usually not listed as a contributing cause on death certificates and may not be mentioned in the hospital record from the final hospital admission. People who are profoundly demented are likely to die of pneumonia, sepsis, or some other infectious process, although the dementing illness is often a contributing factor.

There is now good evidence that people with dementia have higher mortality rates than the general population and that the increased risk of dying may vary with the type of dementia (Alzheimer's disease, vascular dementia, or other), the age of onset, and other factors.⁹ Yet it is often unclear if comorbid conditions influence the appearance or course of dementing illnesses or if dementia influences the course of other terminal illnesses or other aspects of functioning.

A large proportion of dementia cases remain unrecognized by family, friends, and health care providers until relatively late in the clinical course, also contributing to the problem of under-reporting. In the case of Alzheimer's disease, the standardized diagnostic criteria include the requirement that the clinical manifestations be apparent for at least six months;¹⁰ thus efforts to

assess the true prevalence of dementia at death are made more difficult. Further, the description of the contribution the dementing illness makes to death or to reduced health and functioning during the final weeks and months of life is more complicated for dementing illnesses than for other illnesses.

Accurately estimating the prevalence of dementia in general populations would require careful, comprehensive surveys that include a full and detailed evaluation of a representative sample of the population or of a sample of the population selected with the use of screening instruments whose sensitivities and specificities are precisely known for the specific population in which they are employed. Because of these requirements, and because of a nonresponse bias common in such surveys, it seems unlikely that precise estimates of the lifetime prevalence of dementia and of the age-specific prevalence of dementing illnesses developing in the final year or two of life would ever be possible.

In an attempt to approximate the prevalence of dementing illnesses near the time of death, we undertook the present study, which was designed to: (a) assess the usefulness of death certificate data in deriving estimates of the prevalence of dementing illnesses by comparing prevalence estimates based on death certificates and informants' recall and (b) to describe the symptoms and demographic characteristics associated with dementing illnesses in the final year of life.

METHODS

Survey of the Last Days of Life. In 1985 to 1986, the National Institute on Aging conducted the Survey of the Last Days of Life (SLDOL), in which data were collected on 1500 death certificates, a stratified random sample of the approximately 4000 death certificates registered between October 1, 1984, and September 30, 1985, for people ages 65 years and older in Health Service Area Number 1 (HSA-1), part of Fairfield County, Connecticut.

The purpose of SLDOL was to describe the circumstances of death for the population studied—such as who died peacefully while asleep, who died in great pain, who died in the presence of family and friends, who died after a long illness with full awareness of impending death, and who died suddenly with no warning. In addition, the study obtained descriptive data on the decline in physical, cognitive, and sensory functioning and the use of hospitals and nursing homes in the last year of life. Finally, the study was designed to pro-

“Our findings appear to confirm a substantial underreporting of dementia on death certificates.”

vide information on the lifetime history of a variety of medical conditions present at the time of death—among them the dementing illnesses that are the focus of the analyses conducted for the present study.

The SLDOL field staff stratified death certificates by age and sex of the decedent and abstracted the following information: all listed causes of death, the date and time of death, and the name of the death certificate informant.

Using a structured questionnaire, trained interviewers interviewed the death certificate informant, usually the spouse (for 33% of decedents) or an adult child (38%), approximately three months after the death. Interviews were completed for 1227 decedents, representing 82% of the selected sample. Questions included items related to health, residence, use of health care, orientation, recognition of friends and family members, and activities and functional abilities. Further details of the study design and methodology have been described elsewhere.¹¹

Identifying dementia based on death certificates.

For the present analyses, we defined a medical diagnosis of dementia as the appearance anywhere on the death certificate as a contributing cause of death of the following *International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM)* codes: 290 (“senile and presenile organic psychotic conditions”), 294 (“other organic psychotic conditions” [chronic]), 310 (“specific nonpsychotic mental disorders due to organic brain damage”), or 331 (“other cerebral degenerations”; this category includes Alzheimer’s disease).¹²

Identifying dementia based on informant interviews.

For the present analyses, we developed a composite dementia symptomatology index based on the answers to questions concerning the decedent’s medical diagnosis of dementia, cognitive function on a typical day one year before death and a typical day one month before death, and functioning in activities of daily living

one year before death. While the index has not been independently validated, abundant information supports declines in cognitive and physical functioning as usual manifestations of the common dementing illnesses.¹³⁻¹⁶

The questions were as follows:

(a) To determine whether the person had been given a medical diagnosis of dementia: “Was (the decedent) diagnosed by a physician to have Alzheimer’s disease, chronic brain syndrome, dementia, senility, or any other memory or orientation impairment?” (0 = no, 1 = yes)

(b) To assess the decedent’s cognitive function on a typical day one year before death and on a typical day one month before death: “On that day how often did he/she have difficulty in any of the following areas: (1) recognizing family members or good friends; (2) understanding where he/she was or what year it was?”

For each time frame, responses were given a single cognitive function score between 0 and 2 (0 = “hardly ever or never,” 1 = “sometimes,” 2 = “most of the time”).

(c) To determine the decedent’s level of physical functioning one year before death: We asked informants how the person performed on six items from the Katz Activities of Daily Living (ADL) Scale (feeding, bathing, personal grooming, transferring from bed to chair, using the toilet, and dressing).¹⁶

Responses were scored as follows: 0 = “independently,” 1 = “required assistance from another person,” 2 = “was totally dependent.” Thus the highest possible score was 12; however, to ensure that a decedent could not be classified as demented based on ADLs alone, we collapsed the total ADL score into four categories (0, 1 = 1–2, 2 = 3–5, 3 = 6–12) before summing the total dementia index score.

We then summed the scores for the three questions at one year before death. For the analyses presented

here, we have employed an index value of 4 or higher one year before death with no improvement in cognitive function a month before death as evidence of the existence of dementia one year before death. Thus a diagnosis of Alzheimer's disease alone was not sufficient to define a person as having a dementing illness; nor would a person be defined as demented who had a significant impairment in ADLs a year before death that had improved by a month before death.

Comparing prevalence estimates. To examine underreporting of dementia on death certificates, we compared the rate of death certificate diagnoses with the rate of informant-reported medical diagnoses and the rate of dementia scores of 4 or higher for the SLDOL. We also compared our prevalence rates with the rate of informant reports of a dementia diagnosis in the National Mortality Followback Survey (NMFS) conducted in 1986 by the National Center for Health Statistics.¹⁷

Association of age and sex with dementia. To assess the effects of age and sex on the prevalence of indicators of dementia in the last year of life, we tabulated the frequencies of a reported dementia diagnosis, of cognitive and physical functioning in the last year of life, and of a dementia index score of 4 or higher by age and sex of the decedent. We also examined the reported diagnosis of dementia in NMFS by age and sex.

Health factors associated with dementia. We obtained the following information on decedents' medical history from the informants: (a) whether the decedent had ever been diagnosed with Parkinson's disease, hip fracture, stroke, cancer, or heart disease, (b) incontinence, as measured by asking the informant how often the subject had had difficulty controlling his/her urination or bowel movements. The decedent was classified as incontinent if unable to control his/her urination or bowel movements on a typical day one year prior to death.

From death certificates we identified decedents for whom the following were listed among the causes of death: coronary heart disease, cancer, pneumonia, and stroke among people with no prior history (according to informants) of that condition.

We obtained information on decedents' occupation and years of education from death certificates.

We used logistic regression models to look at the association between dementia scores of 4 or higher and

the following variables: education, occupation, and informant-reported history of antemortem stroke, Parkinsonism, coronary heart disease, cancer, hip fracture, incontinence, and hearing impairment. Each variable was examined in a separate model adjusted for age and sex.

RESULTS

The mean age at death for the 1227 decedents was 77.9 years for men and 81.6 for women.

Prevalence of dementia. Dementia was listed as the primary (underlying) cause or a contributing cause of death on the death certificate for only 10 (0.8%) of the 1227 decedents, of whom 6 (0.5% of 1227) were also reported by the informant to have received a medical diagnosis consistent with dementia. Informants reported a medical diagnosis of dementia for a total of 114 of the 1227 decedents (9.3%) (see Table 1).

We calculated a dementia symptomatology index score of 4 or higher for 104 (8.5%) of the 1227 decedents; of this group, 71 had been diagnosed with a dementing illness during their lives, according to informants.

The prevalence of a dementia index score of 4 or higher one month before death (14%) was approximately double the prevalence one year before death (8.5%).

Age and sex effects. As shown in Table 2, the frequency of both a diagnosis of dementia, as reported by informants, and reported difficulty with orientation or recognition of family members or friends one year before death increased with advancing age.

The prevalence of non-independence in three or more activities of daily living one year before death was substantially higher than the prevalence of cognitive difficulties but showed a similar pattern of increasing with advancing age, as did the prevalence of a dementia index score of 4 or higher one year before death.

Problems with orientation, person recognition, and daily activities increased with advancing age and were reported more often for women than men. These problems were more prevalent one month before death than one year before death.

Health factors associated with dementia. Decedents with a dementia symptomatology index score of 4 or higher tended to be older, female, less educated, and to have had a stroke, Parkinson's disease, hip fracture, and incontinence. In addition, cancer and coronary heart dis-

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ease were found to have been reported less frequently in decedents with higher dementia index scores than in decedents with lower scores (Table 3). The death certificate data supported a modestly higher prevalence of coronary heart disease but dramatically higher prevalence of cancer among decedents with lower (<4) dementia symptomatology indices.

The association of high dementia symptomatology with female sex failed to reach statistical significance when logistic regression methods were utilized to control for age. Controlling for both age and sex, statistically significant associations were observed with incontinence, Parkinson’s disease, coronary heart disease (inverse), and cancer (also inverse). In these logistic models, associations with higher dementia index scores did not reach sta-

tistical significance for stroke, hip fracture, low education, or occupation (Table 3).

DISCUSSION

Our findings appear to confirm a substantial underreporting of dementia on death certificates.⁴ The prevalence of a death certificate diagnosis of dementia in our sample (0.8%) was much lower than the 4.7% reported in NMFS,¹⁷ suggesting that differences may occur across communities in the frequency with which a diagnosis of dementia is recorded on the death certificate, even though the prevalence in the population may be relatively similar. Similarly, a diagnosis of dementia was mentioned on the death certificate but not reported by the informant

Table 1. Prevalence of dementing illnesses, Survey of the Last Days of Life, 1985, and National Mortality Followback Survey, 1986

Source	Survey of the Last Days of Life, 1985 n = 1227		National Mortality Followback Survey, 1986 ^a n = 9891	
	Number	Percent	Number	Percent
Diagnosed with dementing illness by physician, according to informant	114	9.3	1179	11.9
Dementia diagnosis on death certificate ^b	10	0.8	465	4.7
Diagnosed with dementing illness, according to informant	6	0.5	255	2.6
No diagnosis of dementing illness, according to informant	4	0.3	210	2.1
Dementia index score $\geq 4^c$	104	8.5	—	—

^aSOURCE: Reference 17.

^bPresence anywhere on the death certificate of any of the following ICD-9 codes 290 (“senile and presenile organic psychotic conditions”), 294 (“other organic psychotic conditions” [chronic]), 310 (“specific nonpsychotic mental disorders due to organic brain damage”), 331 (“other cerebral degenerations” [including Alzheimer’s disease]).

^cThe dementia index score was a composite score based on the informant’s report that the decedent had been diagnosed with a dementing illness and informant-reported cognitive and functional limitations.

Table 2. Indicators of dementia in the last year of life, Survey of the Last Days of Life, 1985, and National Mortality Followback Survey, 1986

Age (years)	Sample size	Survey of the Last Days of Life (N = 1227)								National Mortality Followback Survey (N=6369)	
		Diagnosed with dementing illness, according to informant ^a		Difficulty with orientation or recognition ^b		Limitations in activities of daily living ^c		Dementia index score $\geq 4^d$		Diagnosed with dementing illness, according to informant ^a	
		Number	Percent	Number	Percent	Number	Percent	Percent	Percent	Number	Percent
Men	599	—	100.0	—	—	—	—	—	—	—	100.0
65–74	297	6	2.0	5	1.7	25	8.4	1.7	4.1	79	6.5
75–84	183	21	11.5	11	6.0	35	19.1	7.2	13.0	160	13.2
≥ 85	119	24	20.2	9	7.7	51	42.9	18.5	24.5	106	17.3
Women	628	—	100.0	—	—	—	—	—	—	—	100.0
65–74	300	14	4.7	5	1.7	41	13.7	2.3	6.3	77	8.9
75–84	141	14	10.0	17	12.1	37	26.2	12.8	19.8	223	17.8
≥ 85	187	35	18.8	32	17.1	80	42.8	20.9	30.1	267	21.9

^aInformant responded affirmatively to: “Was [subject] diagnosed by a physician to have: Alzheimer’s disease, chronic brain syndrome, dementia, senility, or any other memory or orientation impairment?”
^bInformant answered affirmatively to one or both of the following questions with regard to a typical day one year before death: “On that day how often did he/she have difficulty in any of the following areas: (1) recognizing family members or good friends; (2) understanding where he/she was or what year it was?” In addition, informant reported no improvement in these areas at one month before death.
^cInformant described the decedent as non-independent a year before death in three or more activities of daily living from among six activities: feeding, bathing, grooming, getting from bed to chair, using the toilet, and dressing. (Non-independent was defined as a score greater than 0.)
^dThe dementia index score was a composite score based on the informant’s report that the decedent had been diagnosed with a dementing illness and informant-reported cognitive and functional limitations.

in only a few cases in our study, but in 2% in NMFS.

We observed an informant-reported prevalence of a medically diagnosed dementing illness of 9.3% in a sample with a mean age at death of 79.8 years. The corresponding figure from NMFS was 11.9%. These figures are similar and are very close to prevalence estimates generated by population-based surveys for people ages 75 to 80.² The findings are especially remarkable in light of the reports in previously published community surveys that most of the people in whom a dementing illness is identified clinically have not previously received a medical diagnosis of dementia and that a substantial proportion may not even have been recognized as having a problem with thinking or memory by family members.¹⁸ If the ratio of clinically recognized to unrecognized dementia is similar in the final year of life to the ratio observed in larger population surveys, the true prevalence of dementia may be higher than indicated either by our estimates or by other community surveys.

The fact that families and medical providers often fail to recognize or acknowledge dementing illnesses in

such community studies is a limitation of our study. However, the use of the index of dementing illnesses seems to have alleviated that limitation to some degree. Another possible limitation is in the validity and reliability of the responses provided by informants for the decedents. Recall, however, that for some 70% of the decedents the informants were either the spouse or offspring, and almost 90% of the informants had seen the decedent in the last three days of life. If the informants had not been particularly knowledgeable of the circumstances surrounding the death, we would have expected a high rate of “Don’t know” responses in the survey. In fact, the percentage of “Don’t know” responses for physical and mental functioning one year prior to death ranged from about 1% to 3%. A third possible limitation of the study concerns how representative the geographic location of the study is. Whereas Fairfield County as a whole is known to be a high-income area, some sections of HSA-1 included in our sample are low-income inner-city areas of Bridgeport and Norwalk. While no single geographic area could be

Table 3. Characteristics of sample, by dementia index score, and relative odds for factors associated with a score >4, Survey of the Last Days of Life, 1985 (N = 1227)

Characteristic	Sample size	Dementia index score $\geq 4^a$		Dementia index score < 4		Relative odds	95% CI	P-value
		n=104	n=1123	Number	Percent			
Age (years)^b								
65-74	597	6	5.8	396	35.3	1.00	—	
75-84	324	33	31.3	383	34.1	5.29	2.67,10.46	< 0.001
85+	306	65	62.9	344	30.6	11.76	6.22,22.26	< 0.001
Sex^c								
Male	599	32	33.7	518	46.1	1.00	—	
Female	628	72	69.3	605	53.9	1.41	0.91,2.16	
Education (years)								
≤ 7	179	27	26.5	197	17.5	1.03	0.49,2.17	
8-11	341	34	32.2	377	33.6	1.09	0.55,2.16	
12	292	22	21.1	296	26.4	1.52	0.75,3.10	
>12	241	21	20.2	253	22.5	1.00	—	
Education data missing ^{d,e}	174	26	25.1	161	14.4	1.79	0.89,3.59	
Occupational category^d								
Professional	157	14	13.3	142	12.6	1.00	—	
Manager or sales/clerical	254	20	19.3	222	19.8	1.14	0.54,2.42	
Housewife	278	36	34.7	285	25.4	1.01	0.48,2.12	
Semiskilled/skilled service/unskilled work	322	24	23.2	281	25.0	1.08	0.52,2.26	
214	10	9.5	193	17.2	0.72	0.31,1.68		
History of (according to informants):^d								
Dementing illnesses	114	66	63.7	53	4.7	—	—	
Stroke	307	33	31.8	298	26.5	1.04	0.66,1.63	
Parkinsonism	41	8	8.0	36	3.2	2.90	1.28,6.59	< 0.05
Coronary disease	503	30	28.6	505	45.0	0.49	0.31,0.77	< 0.01
Cancer	461	19	17.8	404	36.0	0.45	0.26,0.76	< 0.01
Hip fracture	111	15	14.8	118	10.5	0.93	0.49,1.75	
Incontinence ^f	151	74	70.8	91	8.1	23.89	14.47,39.44	< 0.001
Hearing impairment	142	15	14.1	150	13.4	0.68	0.36,1.25	
Mentioned on death certificate:^d								
Stroke (if no prior history, according to informant)	12	2	2.0	11	1.0	1.70	0.34,8.49	
Coronary disease	576	41	39.1	557	49.6	0.62	0.40,0.96	< 0.05
Cancer	335	3	2.5	290	25.8	0.12	0.04,0.39	< 0.001
Pneumonia	128	11	10.8	120	10.7	1.23	0.66,2.30	

^aThe dementia index score was a composite score based on the informant's report that the decedent had been diagnosed with a dementing illness and informant-reported cognitive and functional limitations.

^bRelative odds adjusted for sex.

^cRelative odds adjusted for age.

^dRelative odds adjusted for age and sex. For medical history, as reported by informants and mentioned on death certificates, the reference group was defined as individuals without the characteristic.

^eAn indicator variable for missing education data was included to avoid having to delete people with missing education data from the logistic regression models.

^fUnable to control urination or bowel movements one year prior to death

CI = confidence interval

presumed to be totally representative of the nation as a whole, many of our findings have been confirmed in NMFS, a national study.¹⁷

Based on informants' reports of behavior one year before death, we calculated a dementia score of 4 or greater for 81 (71%) of the 114 decedents in our study who were reported to have been diagnosed as demented during life. Thirty-seven others met our criterion of a dementia score of 4 or higher at one year before death without improvement at one month before death but reportedly never received a medical diagnosis of a dementing disease. It is likely that some of the people diagnosed with a dementing illness in the final year of life were functioning at a fairly high level a year before death; in addition, the presence of dementia may not have been recognized by medical providers in some people whose personal and social functioning one year before death was consistent with a diagnosis of dementia.

Our age-specific prevalence values for a dementia score of 4 or higher approximate previously published estimates encompassing a wide range of severity.¹⁹⁻²² Since an index of 4 probably corresponds to a moderate level of dementia, it seems likely that our estimates are

conservative. The results presented here, interpreted in light of these several issues, suggest that the lifetime prevalence of dementia may be substantially higher than has been supposed on the basis of community surveys.

The strong associations of a high dementia score with older age, Parkinson's disease, and incontinence were expected. Our failure to find a statistically significant association between dementia symptomatology and stroke, while troubling, may be attributable to stroke being commonly associated with death even among non-demented people. The inverse relationship observed between a high dementia symptomatology index and cancer and coronary heart disease indicates that in this sample, cancer and coronary heart disease were more common among people dying without symptoms of dementia. We do not interpret this as evidence that cancer and heart disease protect older people from becoming demented. Rather, it may reflect an increased risk of dying from conditions such as pneumonia or infected decubitus ulcers in demented people—that is, conditions not likely to be so life-threatening in ambulatory, non-demented people without another serious illness such as cancer or heart disease.

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