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Reporting Dementia on the Death Certificates of Nursing Home Residents Dying With End-Stage Dementia

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To the Editor: In 2004, the National Center for Health Statistics (NCHS) ranked Alzheimer disease as the fifth leading cause of death among US residents older than 65 years, an increase from prior years.¹ NCHS data are derived from death certificates. Retrospective studies of patients who died at various stages of dementia suggest this condition is under-reported on death certificates.^{2,3} We prospectively observed a cohort of nursing home residents who had been diagnosed with end-stage dementia to describe which conditions were documented on their death certificates.

Methods. Data were collected between 2003 and 2007 from the Choices, Attitudes, and Strategies for Care of Advanced Dementia at the End-of-Life study, a prospective study of 323 residents of 22 Boston-area nursing homes with advanced dementia, each followed up for up to 18 months.⁴ Eligibility criteria included age older than 60 years and advanced dementia (based on physician documentation of dementia in chart and Global Deterioration Scale stage 7 determined by a nurse).⁵ The Hebrew SeniorLife institutional review board approved this study. Written consent was provided by participants' health care proxies.

Descriptive data included age, sex, race (reported by proxies using predefined categories), dementia type (Alzheimer, vascular, or other, from medical records), nursing home length of stay, living in a dementia special care unit, location of death, and functional status at study entry (from nurses; Bedford Alzheimer Nursing Severity Subscale⁶). Descriptive variables, including race, were ascertained to allow for comparability with other samples.

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Study concept and design: Wachterman, Mitchell.

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Massachusetts death certificates, obtained for all participants who died during follow-up, have 3 sections. In part 1, line A requests the “immediate cause of death.” Lines B through D request the “sequence of conditions resulting in the immediate cause of death.” Part 2 asks for “other significant conditions contributing to death” (no limit on number). Two research assistants who were unaware of the study aims independently abstracted causes of death verbatim from the death certificates. Conditions were categorized into predefined clinically relevant groups and quantified using proportions. Exact binomial 95% confidence intervals (CIs) were calculated using SAS version 9.1 (SAS Institute, Cary, North Carolina).

Results. Of the 323 participants, 165 died during follow-up (Table 1). Among all decedents, dementia documentation on their death certificates was none, 37.0% (95% CI, 29.6%–44.8%); listed in part 1 line A, 15.8% (95% CI, 10.6%–22.2%); listed in part 1 lines B–D, 35.2% (95% CI, 27.9%–43.0%); and listed in part 2, 16.4% (95% CI, 11.2%–22.9%) (Table 2). Seven participants had dementia listed in parts 1 and 2. Among the 114 decedents with a premortem diagnosis of Alzheimer disease, documentation of dementia anywhere on their death certificates was none, 33.3% (95% CI, 24.8%–42.8%); Alzheimer disease, 27.2% (95% CI, 19.3%–36.8%); “dementia” without further specification, 37.7% (95% CI, 28.8%–47.3%); and vascular dementia, 0.9% (95% CI, 0.2%–4.8%).

Comment. In this study, dementia, and specifically Alzheimer disease, was underreported on death certificates, raising concerns about the accuracy of mortality statistics based on these documents. Despite the terminal stage of dementia in our cohort, dementia was not recorded on 37% of death certificates. The absence of Alzheimer disease on three-quarters of death certificates of decedents with this premortem diagnosis is a particular problem because among the causes of dementia, NCHS ranks only Alzheimer disease among its leading causes of death.

This study is limited in that 94% of the cohort died in nursing homes where dementia is more likely to be reported on death certificates compared with hospitals.² There may be some inaccuracies in the clinical dementia subtypes obtained from the chart. The findings may not be generalizable outside Boston; however, the study sample and nursing homes are comparable with those in the rest of the United States.⁴

An appreciation that patients die from and with dementia is necessary to inform end-of-life decision making. Underestimation of the burden of dementia as a major fatal illness may hamper planning of health services needed for persons dying with this condition.

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Table 1

Characteristics of Nursing Home Decedents With Advanced Dementia (N = 165)

Characteristic	No. (%)
Age at death, mean (SD), y	86.5 (7.2)
Nursing home length of stay, mean (SD), y	4.8 (3.6)
BANS-S score, mean (SD) ^a	21.5 (2.1)
White race	147 (89.1)
Female	138 (83.6)
Premortem clinical etiology of dementia ^b	114 (69.1)
Alzheimer	
Vascular	29 (17.6)
Other	24 (14.6)
Resided in dementia special care unit	76 (46.1)
Location of death	155 (93.9)
Nursing home	
Hospital	9 (5.5)
Free-standing hospice	1 (0.6)

Abbreviation: BANS-S, Bedford Alzheimer Nursing Severity Subscale.

^a Bedford Alzheimer Nursing Severity Subscale scores range from 7 to 28; higher scores indicate more functional disability.^b Two decedents had both Alzheimer disease and vascular dementia.

Table 2

Causes of Death of Decedents With Advanced Dementia in Nursing Homes, Recorded According to Location on Death Certificates (N = 165)

Condition	No. (%) [95% CI] ^a			
	Part 1 of Certificate		Part 2 of Certificate ^d	Not Listed
	Line A ^b	Lines B, C, or D ^c		
Pneumonia	44 (26.7) [20.1–34.1]	13 (7.9) [4.3–13.1]	2 (1.2) [0.2–4.3]	111 (67.3) [59.6–74.4]
Cardiopulmonary arrest	38 (23.0) [16.8–30.2]	0 [0.0–2.0]	2 (1.2) [0.2–4.3]	125 (75.8) [68.5–82.1]
Dementia (any type)	26 (15.8) [10.6–22.2]	58 (35.2) [27.9–43.0]	27 (16.4) [11.2–22.9]	61 (37.0) [29.6–44.8]
Chronic cardiovascular disease ^e	18 (10.9) [6.6–16.7]	16 (9.7) [5.6–15.3]	21 (12.7) [8.0–18.8]	115 (69.7) [62.1–76.6]
Alzheimer dementia	14 (8.5) [4.7–13.8]	19 (11.6) [7.1–17.4]	5 (3.1) [1.0–6.9]	128 (77.6) [70.4–83.7]
Failure to thrive	14 (8.5) [4.7–13.8]	10 (6.1) [2.4–10.9]	1 (0.6) [0.0–3.3]	140 (84.8) [78.4–90.0]
Dementia (not specified)	12 (7.3) [3.8–12.4]	36 (21.8) [15.8–28.9]	21 (12.7) [7.6–18.1]	102 (61.8) [54.0–69.3]
Stroke	6 (3.6) [1.4–7.8]	7 (4.2) [1.7–8.6]	3 (1.8) [0.4–5.2]	151 (91.5) [86.2–95.3]
Sepsis	4 (2.4) [0.7–6.1]	2 (1.2) [0.2–4.3]	0 [0.0–2.0]	159 (96.4) [92.2–98.6]
Renal disease	4 (2.4) [0.7–6.1]	1 (0.6) [0.0–3.3]	0 [0.0–2.0]	160 (97.0) [93.1–99.0]
Dehydration	4 (2.4) [0.7–6.1]	1 (0.6) [0.0–3.3]	0 [0.0–2.0]	160 (97.0) [93.1–99.0]
Extrapyramidal disease ^f	2 (1.2) [0.2–4.3]	3 (1.8) [0.4–5.2]	1 (0.6) [0.0–3.3]	159 (96.4) [92.2–98.6]
Other ^g	2 (1.2) [0.2–4.3]	9 (5.5) [2.3–10.1]	3 (1.8) [0.4–5.2]	NA
Liver disease	1 (0.6) [0.0–3.3]	1 (0.6) [0.0–3.3]	0 [0.0–2.0]	164 (99.4) [96.7–100.0]
Vascular dementia	0 [0.0–2.0]	3 (1.8) [0.4–5.2]	1 (0.6) [0.0–3.3]	162 (98.2) [94.8–99.6]
Decubitus ulcer	0 [0.0–2.0]	2 (1.2) [0.2–4.3]	1 (0.6) [0.0–3.3]	163 (98.8) [95.7–99.8]
Peripheral vascular disease	1 (0.6) [0.0–3.3]	1 (0.6) [0.0–3.3]	4 (2.4) [0.7–6.1]	159 (96.4) [92.2–98.6]
Diabetes	0 [0.0–2.0]	8 (4.9) [2.1–9.3]	6 (3.6) [1.4–7.8]	152 (92.1) [86.9–95.7]
Depression	0 [0.0–2.0]	0 [0.0–2.0]	2 (1.2) [0.2–4.3]	163 (98.8) [95.7–99.8]
Arthritis	0 [0.0–2.0]	0 [0.0–2.0]	2 (1.2) [0.2–4.3]	163 (98.8) [95.7–99.8]

Abbreviations: CI, confidence interval; NA, not available.

^aThe denominator for all values is N=165. Total percentages for each condition exceed 100 when the condition is listed in more than 1 part of the death certificate.

^bImmediate cause of death.

^cSequence of conditions leading to immediate cause of death. The condition listed last on lines A–D is considered the underlying cause of death.

^dOther significant conditions contributing to death but not resulting in underlying cause.

^eIncluded hypertension, congestive heart disease, atherosclerotic heart disease, and atrial fibrillation.

^fIncluded Parkinson disease and progressive supranuclear palsy.

^gIncluded cancer, osteomyelitis, syphilis, multiple sclerosis, hypopituitarism, hip fracture, multisystem failure, fatty embolization, chronic obstructive pulmonary disease, hypothyroidism, metabolic acidosis, normal pressure hydrocephalus, urinary tract infection, and other infections.