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Dementia in community-dwelling elderly patients: A comparison of survey data, medicare claims, cognitive screening, reported symptoms, and activity limitations

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Abstract

Background and Objective: Population-based estimates of dementia can vary widely depending on the data source and methodology used to assess cognitive impairment. The aim of this study was to assess individual and composite measures of dementia constructed using survey and administratively collected medical data for the purpose of improving insight into inherent and avoidable biases and the interpretation of these measures.

Methods: A national survey of 5089 community-dwelling elderly persons was linked to 5 years of Medicare claims. Kappa coefficients were used to assess dementia agreement between survey, cognitive screen, and claims. Odds ratios (ORs), adjusted for age, gender, and education, were computed to assess the relation of single- and multi-source dementia variables to cognitive symptoms and activity limitations.

Results: Dementia prevalence among persons aged 65 and over ranged from 4.5% to 16.8% across sources. Agreement in case identification between data sources was low, ranging from 0.15 to 0.41. Despite low agreement, ORs were consistently increased for limitations in cognitively related activities/symptoms and non-overlapping dementia sources.

Conclusion: The finding that non-overlapping dementia data sources are associated with significantly increased limitations in cognitive activities suggests that forecasts of national dementia-related resource use based on single-source data could produce serious underestimates of future need.

Keywords: Dementia; Medicare; Aged; Health surveys; Epidemiologic methods

1. Introduction

Millions of dollars are spent each year on federally funded national surveys that provide essential information for tracking health status and current health care needs in the United States and for forecasting future needs, especially among the growing elderly population. Despite reported trends of declining disability among the elderly population, dementia-related demands on health care systems in industrialized countries can be expected to grow substantially [1,2]. Prevalence figures for dementia in the fastest growing segment of the population, those aged 85 and over, are reported to be as high as 48%, but estimates vary widely [3–5]. Although use of data from several individual sources, such as survey reports, cognitive tests, and billing records, is available for estimates of dementia [1,3,4,6], there is little information on the comparability or the capacity of these measures to capture population-level limitations in cognitively related activities.

The aim of this study was to improve insight into the conceptualization, interpretation, and inherent and avoidable biases of cognitive measures constructed from secondary survey data merged with administrative claims data. We examine how well cognitive measures, including reports of dementia and scores on a cognitive screening test administered as part of the National Long-Term Care Survey (NLTCS), agree with dementia-related diagnoses obtained from Medicare claims data and cognitive symptoms and activities from the survey. We report agreement among sources and age-gender-education adjusted odds ratios (ORs) for several activities containing a cognitive component across non-overlapping dementia groups.

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2. Methods

The NLTCS is a longitudinal survey funded by the National Institute on Aging to study chronically impaired persons aged 65 and over [7–9]. A national sample of 19,907 persons was obtained from Medicare eligibility rosters using a multistage sampling technique with clustering that has been described elsewhere [8,9]. From this national sample of 19,907 persons, 5089 participants completed a detailed community interview [7]. This group of 5089 persons was subgrouped according to their dementia status. All persons who completed a detailed community interview were included in one of five subgroups formed for analytic purposes: four cognitively impaired/dementia categories and a nondemented category.

The primary modes of entry into the detailed survey of community-dwelling elderly persons included participation in an earlier wave of the survey, being a member of a randomly selected cohort of healthy community-dwelling elders, or reporting a limitation in any of nine activities of daily living (ADLs) or seven instrumental activities of daily living (IADLs) during the screening interview. Details of the addition of a cohort of healthy community-dwelling elders (to improve the ability to study nondisabled persons) and oversampling of persons aged 95+ (to improve precision of estimates for persons at extreme ages) have been previously described [8]. Survey interviewers, used by the Bureau of the Census and trained using standardized interview techniques [7], interviewed study participants when possible and proxy respondents when study participants were unavailable or unable to answer survey questions. Proxy respondents were asked questions related to cognitive status and physical disabilities, such as limitations in ADLs and IADLs, but the cognitive screening instrument, the Short Portable Mental Status Questionnaire (SPMSQ), was not administered to proxies on behalf of study subjects [7].

Medicare claims were provided by the Health Care Financing Administration with anonymous linkages specifically designed to allow merging of encounter-level Medicare claims data with the NLTCS study population [9]. The survey data of 5089 community-dwelling elderly persons who participated in the 1994 NLTCS were linked to all available Medicare claims for the period 1 January 1991 to 31 December 1995.

2.1. Single-source dementia variables

Several categorical variables were derived using individual and combinations of data sources that contained direct or indirect measures of cognitive impairment in the study population. The categorical variables for dementia included (1) survey-reported dementia, based on the response to direct questions or the reporting of dementia as a cause of activity limitations; (2) moderate or severe impairment on the cognitive screening test (the SPMSQ); and (3) a Medicare claim for dementia (single-year and multi-year). Medicare dementia (single-year) included dementia-related WHO International Classification of Disease, ninth revision, Clinical Modification (ICD-9-CM) [10] diagnoses during the survey year (1994), and Medicare dementia (multi-year) contained identical codes for the years 1991 to 1995.

From survey data, a frank report of dementia was defined as a positive response to either of two direct questions: "Does [sample person] now have Alzheimer's disease?" or "Does [sample person] now have senility?" Dementia was said to be a cause of activity limitation(s) if "dementia, senility, or Alzheimer's disease" was answered to any questions related to "What health conditions, either mental or physical, cause [sample person] to have trouble…?" Questions related to frank reports and activity limitations were combined to generate the variable "survey-reported dementia."

Dementia by SPMSQ was derived from this short cognitive screening instrument with 10 questions related to orientation (date today, day of the week, name of this place, state, age, birth date); memory (current and past president); and concentration and mental tracking (subtracting 3 from 20). Adjusted SPMSQ scores were calculated based on Pfeiffer's original work [11], which adjusts raw scores of blacks and whites for race and education. In this study, individual scores were grouped into three categories: normal, mildly impaired, and demented. For black and white study participants, a person was categorized as demented if his/her SPMSQ score fell into the moderate or severely impaired ranges after race and educational adjustment [11]. Of the 241 study participants of Hispanic or other ethnicity not covered by Pfeiffer's adjustment, 139 (57.7%) scored in the normal range by correctly answering at least 8 of 10 SPMSQ questions. Although cells were sparsely populated at the border cut points for demented (moderate-to-severe dementia) versus nondemented, six persons of other ethnicity fell into possibly questionable cells at the border points between demented and not demented. We used Pfeiffer's adjustment for blacks to categorize these six subjects into the nondemented category.

Dementia by Medicare claims was derived using diagnostic information available in the format of ICD-9-CM codes [10] found in Medicare billing records. All six categories of claims data (inpatient, outpatient, physician supplier Part B, home health, skilled nursing facility, and hospice) were analyzed for the following ICD-9-CM dementia-related codes: 290.0–290.3 (senile dementia uncomplicated; presenile dementia; senile dementia with delusional or depressive features; senile dementia with delirium); 290.4 (arteriosclerotic dementia); 291.2 (alcoholic dementia); 292.82 (drug-induced dementia); 294.1 (dementia in conditions classified elsewhere); 331.0–331.2 (Alzheimer disease and senile degeneration of the brain); and 797 (senility without mention of psychosis) [10]. Single-year Medicare claims included dementia for calendar year 1994, and multiple-year claims included dementia before the survey (1991–1993),

during the survey year (1994), and during the year after the survey (1995).

2.2. Multi-source composite variables

Two composite variables were created to capture dementia from all sources. "Dementia, any source (single year)" included any report of dementia from survey, SPMSQ, or single-year (1994) Medicare claims. "Demented, any source (multi-year)" combined dementia reports from survey, SPMSQ, or 5-year Medicare claims (1991–1995).

2.3. Non-overlapping dementia groups

We used variables from all sources to examine five groups of interest based on whether the sample person was demented from survey report only (group A), Medicare claims only (group B), SPMSQ only (group C), by two or more independent sources (group D), and any source (group E).

2.4. Assessment of cognitive symptoms and activity limitations

Information regarding cognitively related symptoms or difficulties with cognitive or memory-related tasks/activities was elicited primarily during the detailed community interview. Among the activities examined were difficulty using a calculator, using a map, using directions to operate a microwave, taking medicines, using a telephone, reading, doing hobbies, playing games, and others. Difficulty performing a specific activity was defined to include persons reporting difficulty at any point during the 1994 survey year. We created summary variables for difficulties in any IADL and in any cognitively related activity by collapsing severity categories of difficulty into a dichotomous response and summing across activities. Although we use symptoms and limitations in cognitively related activities to somewhat validate our non-overlapping dementia groups, these measures did not enter into our original classification of dementia.

2.5. Missing data

Several categories of data had missing data—notably the SPMSQ test and cognitive activities, such as using a computer, microwave, and calculator. We examined all missing data for evidence of bias. Scores on the SPMSQ were missing nonrandomly and varied by outcomes of interest. We characterized this population in a separate category termed "no SPMSQ test." We also performed sensitivity analyses on cognitive symptoms and cognitively related activities to assess the impact of missing data and imperfect agreement between data sources. In general, adjusted ORs were fairly robust; the OR was stable across most activities under differing assumptions for missing or conflicting data. In activities affected by missing data assumptions, ORs varied in magnitude, but coefficients did not change sign.

2.6. Statistical methods

Kappa coefficients were computed to correct for chance agreement among data sources for dementia, the main outcome of interest [12]. ORs were calculated to determine the risk of a person exhibiting a particular symptom or activity limitation given that he/she had cognitive impairment compared with the likelihood of those with no cognitive impairment having the symptom or activity limitation. ORs were age-gender-education adjusted to control for the known association of the outcome variable (dementia) with age and education and for the potential gender bias associated with some tasks used to validate cognitive function. Although we use the term "cognitive impairment" to include mild, moderate, or severely impaired individuals, we considered only those with SPMSQ scores in the moderate or severe range as demented. In addition, we excluded mildly impaired individuals from the denominator of ORs comparing impaired persons with those with normal cognitive function.

All confidence intervals reported were calculated at the 95% level. The chi-square test was used in univariate analyses of categorical variables with statistical significance defined as $P = .05$ or lower [13]. We used SAS 7.0 for processing Medicare claims and survey data [14].

3. Results

3.1. Population characteristics

Using all sources of data available to us, we categorized the population by dementia status and grouped demented study participants according to the source of information on cognitive status (Fig. 1). Of the 5089 subjects in the study population, 86.1% were white, and 65.8% were women. Nearly one fourth were aged 85 years or older (Table 1). The modal education group was 9 to 12 years; approximately one third had an education of eighth grade or lower. Older cohorts were less educated than younger ones ($\chi^2 = 109.7, P < .0001$) and more likely to have dementia ($\chi^2 = 272.9,\ P < .0001$) (Table 1).

Population characteristics for the total population and five groups of interest are shown in Table 1. Three groups were categorized according to the source of their independent, but non-overlapping, dementia information (groups A, B, and C). Dementia reported from two or more independent sources is represented in group D, and dementia from any source comprised group E. Of 5089 elderly study subjects, 855 (16.8%) were demented by one or more sources. Of these, 178 (20.8%) were demented by survey report only (group A), 293 (34.3%) by Medicare diagnosis only (group B), 107 (12.5%) by moderate-to-severe scores on the SPMSQ only (group C), and 277 (32.4%) by two or more independent sources (group D). Of the 4234 subjects not categorized as demented, 3025 (71.4%) had a normal SPMSQ score, and 315 (26.1%) scored mildly impaired but had no Medicare diagnosis or survey report of dementia. Persons with no

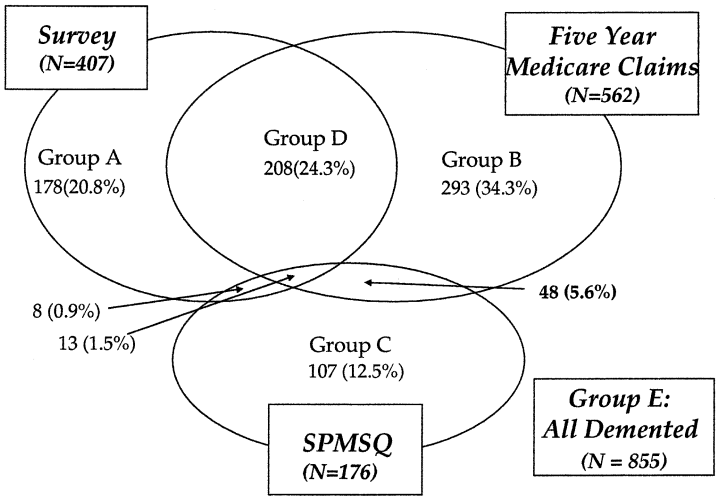

Fig. 1. Venn diagram of dementia assessed using 5-year medicare diagnoses; survey reports; and the SPMSQ (frank reports or dementia as a cause of activity limitations), moderate-to-severe scores of the SPMSQ, or dementia as a diagnosis in Medicare Claims for 1991 to 1995. Three groups of dementia subjects were formed from the non-overlapping regions: Group A was comprised of those with survey dementia only, group B was comprised of those with Medicare dementia only, and group C was comprised of those with SPMSQ dementia only. Group D consisted of all persons with overlapping reports of dementia, and Group E was total dementia from all sources.

dementia are included in the analyses involving the total population but are not grouped separately.

3.2. Proxy reporting

Nearly 19% (945) of survey participants reported by proxy respondent. Overall proxy use among those demented by any source was 48.2%, with proxy reporting highest among those with survey-reported dementia (73.6%) and dementia from two or more sources (68.6%) (Table 1). Of the 368 study participants for whom relationship to the proxy was available, nearly 90% were related: spouse/ex-spouse (39.1%), son/daughter (32.3%), and other relative (16.7%). Nonrelatives reported for 11.4% of study participants. Proxy use nearly tripled in the oldest versus youngest age groups: 11.9% (65–74 years), 15.1% (75–84 years), and 34.1% (85 years and over) ($\chi^2 = 247.6$, $P < .0001$). Women were older than men and tended to have higher proxy use (21.2% versus 17.2%; $\chi^2 = 11.4$, $P = .0007$). Proxy use also tended to be lower in whites than in blacks and other ethnicities (18.3%, 21.8%, and 28.4%, respectively) ($\chi^2 = 8.5$, $P = .01$). An inverse relation was observed between proxy use and education, with 11.4% in those with 12 or more years of education versus 25.0% in those with 8 or fewer years of education ($\chi^2 = 98.1$, $P < .0001$).

3.3. Prevalence of dementia by data source

Prevalence of dementia ranged from 4.5% to 16.8% depending on the data source(s) (Table 2). The SPMSQ cognitive screen and single-year Medicare claims data produced

Table 1
Population characteristics for demented and non-demented study participants by groups of interest

	Group A: Demented, survey only (n = 178)	Group B: Demented, Medicare claims only (n = 293)	Group C: Demented, SPMSQ only (n = 107)	Group D: Demented by two or more sources (n = 277)	Group E: All demented, any source (n = 855)	Nondemented (normal SPMSQ) (n = 3185)	Total population (n = 5089)
Age distribution, yr							
65–74	31 (17.4)	45 (15.4)	17 (15.9)	21 (7.6)	114 (13.3)	983 (30.9)	1382 (27.2)
75–84	85 (47.8)	142 (48.5)	48 (44.9)	117 (42.2)	392 (48.8)	1683 (52.8)	2538 (49.9)
85 and over	62 (34.8)	106 (36.2)	42 (39.2)	139 (50.2)	349 (40.8)	519 (16.3)	1169 (23.0)
Gender							
Male	62 (34.8)	96 (32.7)	29 (27.1)	90 (32.5)	277 (32.4)	1071 (33.6)	1741 (34.2)
Female	116 (65.2)	197 (67.2)	78 (72.9)	187 (67.5)	578 (67.6)	2114 (66.4)	3348 (65.8)
Race							
White, not Hispanic	150 (84.2)	255 (87.0)	85 (79.4)	238 (85.9)	728 (85.1)	2908 (92.3)	4382 (86.1)
Black, not Hispanic	21 (11.8)	31 (10.6)	19 (17.8)	34 (12.3)	105 (12.3)	277 (8.7)	466 (9.2)
All other/unknown	5 (2.8)	7 (2.4)	3 (2.8)	5 (1.8)	22 (2.5)	-	241 (4.8)
Education, yr							
1–8	81 (45.5)	114 (38.9)	38 (35.5)	114 (41.1)	347 (40.6)	952 (29.9)	235 (4.6)
9–12	59 (33.1)	108 (36.9)	44 (41.1)	101 (36.4)	312 (36.5)	1512 (47.5)	1657 (32.6)
12 or more	24 (13.4)	48 (16.4)	25 (23.3)	42 (15.2)	139 (16.3)	721 (22.6)	2144 (42.1)

Table 2
Prevalence of dementia in a sample of community-dwelling elderly persons by source of dementia status

	Age (yr)			
	65–74	75–84	85+	Total
Total population	1382 (27.2%)	2538 (49.9%)	1169 (23.0%)	5089 (100%)
Frank survey reported (Alzheimer disease or senility)[a]	1.9 (1.2–2.6)[b]	5.2 (4.3–6.0)	14.5 (12.4–16.5)	6.4 (5.7–7.1)
Dementia as a cause of activity limitation(s)[c]	2.5 (1.7–3.4)	4.5 (3.7–5.3)	8.6 (7.0–10.2)	4.9 (4.3–5.5)
Survey reported dementia (frank report and as cause of activity limitation[s])	3.6 (2.6–4.6)	6.9 (5.6–7.9)	15.5 (13.4–17.6)	8.0 (7.3–8.7)
Cognitive screen, moderate-to-severe (SPMSQ)	1.7 (1.6–2.4)	4.4 (3.5–5.2)	9.4 (7.3–11.5)	4.5 (3.9–5.1)
Medicare claims, single-year[d]	1.9 (1.2–2.6)	4.4 (3.6–5.2)	9.2 (7.5–10.8)	4.8 (4.2–5.4)
Medicare claims, multi-year[e]	4.8 (3.7–5.9)	10 (8.8–11.1)	20.8 (18.5–23.1)	11.0 (10.2–11.9)
All sources, single-year Medicare[d]	5.9 (4.6–7.1)	11.7 (10.5–13.0)	24 (21.6–26.4)	13.0 (12.0–13.9)
All sources, multi-year Medicare[e]	8.3 (6.8–9.7)	15.5 (14.0–16.9)	29.9 (27.2–32.5)	16.8 (15.8–17.8)

[a] Two survey questions asked about Alzheimer disease and senility; survey participants were not asked a frank question regarding "dementia."
[b] Values are percent with 95% confidence intervals in parentheses.
[c] Study participants were asked to name reasons for their activity limitations; dementia, senility, and Alzheimer disease responses were classified as dementia.
[d] Single-year Medicare claims included the calendar year of the survey.
[e] Multiple-year Medicare claims included 4 years before the survey and the calendar year after the survey.

estimates on the low end of the range. Combinations of data sources produced estimates of 13.0% using survey data, SPMSQ, and single-year Medicare data for 1994 and 16.8% using survey data, SPMSQ, and multiple-year Medicare claims. In subjects aged 65 to 74 years, rates of dementia ranged from 1.9% to 8.3%; rates of dementia for subjects aged 85 years and over ranged from 8.6% to 29.9%. In contrast to the youngest age group, single-year Medicare claims for the oldest-old group produced lower reports of dementia than frank survey reports (Table 2). Medicare claims for a single year were just over half the level observed from all survey-reported dementia (4.8% versus 8.0%). Although prevalence was similar between SPMSQ and Medicare claims, the SPMSQ's ability to detect population-level dementia was biased by high rates of missing test information among subgroups of interest (Table 3).

3.4. Population characteristics for the SPMSQ

Assessments of population-level dementia using only SPMSQ scores were biased downward: Approximately 40% of persons with dementia from other sources did not have SPMSQ scores (Table 3). There were higher rates of missing test scores for the older study subjects ($\chi^2 = 227.5$, $P < .0001$), subjects with less education ($\chi^2 = 85.2$, $P < .0001$), and subjects who were more severely physically disabled ($\chi^2 = 715.5$, $P < .0001$). Of those missing an SPMSQ score, 40.3% were 85 years old or older (see Table 3), and nearly half had 8 or fewer years of education (not shown). In addition, missing scores varied among sources of dementia reporting. The majority of persons (91.1%) with a frank report of Alzheimer disease or senility by survey had missing SPMSQ scores as did more than half of those with a Medicare diagnosis of dementia.

3.5. Dementia agreement among data sources

Agreement between SPMSQ dementia ($n = 176$) and frank reports (answers to questions "Do you have senility?" or "Do you have Alzheimer disease?") ($n = 326$) was low (kappa 0.13, 95%CI 0.06–0.19; $n = 3912$). Agreement with the SPMSQ was similarly low when frank reports and reports of dementia, Alzheimer disease, or senility as a cause of activity limitations were considered (kappa 0.15, 95%CI 0.08–0.21; $n = 3912$). Agreement was somewhat better when 1994 survey data for any report of dementia, Alzheimer disease, or senility ($n = 407$) was compared with 1994 Medicare claims for dementia ($n = 244$) (kappa 0.35, 95%CI 0.31–0.40; $n = 5089$). The agreement between Medicare and any non-Medicare data source for dementia was increased slightly when multiple-year Medicare claims were used versus single-year claims (kappa 0.41, 95%CI 0.37–0.45; $n = 5089$ versus 0.32, 95%CI 0.27–0.36; $n = 5089$). The kappa for agreement between single- versus multiple-year claims data indicated relatively good agreement (0.58, 95%CI 0.54–0.62; $n = 5089$).

3.6. Adjusted ORs for cognitive symptoms/activities by SPMSQ

The relation between the SPMSQ and selected cognitive symptoms and activities are shown in Fig. 2. Persons who scored in the possible mild cognitive impairment range had ORs that were intermediate between those who scored in the normal range and those who scored in the demented range for nearly all difficulties in cognitive activities. Similarly, persons who did not take the SPMSQ had ORs for cognitive symptoms and difficulty performing activities that were comparable to or greater than those who took the SPMSQ and scored in the moderate-to-severely demented range (Fig. 2). One exception to this was interviewer-rated confusion, which was more closely aligned with study participant performance on the SPMSQ than other measures of dementia.

3.7. Adjusted ORs for cognitive symptoms/activities by dementia category

Demented study participants demonstrated higher adjusted ORs for cognitive symptoms and difficulty in cognitively related activities than the group with normal SPMSQs

Table 3
Population characteristics by completion of the Short Portable Mental Status Questionnaire (SPMSQ)

	No SPMSQ test, *n* (%)	SPMSQ test, *n* (%)	Total population, *n* (%)
Population	1,051 (20.7)	4,038 (79.4)	5,089 (100)
Age distribution, yr			
65–74	197 (18.7)	1,185 (29.4)	1,382 (27.2)
75–84	431 (41.0)	2,107 (52.2)	2,538 (49.9)
85 and over	423 (40.3)	746 (18.5)	1,169 (23.0)
Gender			
Male	399 (38.0)	1,342 (33.2)	1,741 (34.2)
Female	652 (62.0)	2,696 (66.8)	3,348 (65.8)
Race			
White, non-Hispanic	875 (83.3)	3,507 (86.9)	4,382 (86.1)
Black, non-Hispanic	110 (10.5)	356 (8.8)	466 (9.2)
Hispanic	26 (2.5)	100 (2.5)	126 (2.5)
Other	40 (3.8)	75 (1.9)	115 (2.3)
Education, yr			
Missing data	109 (10.4)	126 (3.1)	235 (4.6)
1–8	435 (41.4)	1,222 (30.3)	1657 (32.6)
9–12	373 (35.5)	1,771 (43.9)	2144 (42.1)
12 or more	134 (12.8)	919 (22.8)	1053 (20.7)
Functional status			
No limitations	182 (17.3)	1,710 (42.4)	1,892 (37.2)
Limitations in IADL only	157 (14.9)	653 (16.2)	810 (15.9)
Mild limitations (1 or 2 ADL)	208 (19.8)	934 (23.1)	1,142 (22.4)
Moderate limitations (3 or 4 ADL)	142 (13.5)	516 (12.8)	658 (12.9)
Severe limitations (5 or 6 ADL)	362 (34.4)	225 (5.6)	587 (11.5)
Dementia source			
Frank survey reported (Alzheimer disease or senility)[a]	297 (28.3)	29 (0.7)	326 (6.4)
Dementia as a cause of activity limitation(s)[b]	193 (18.4)	57 (1.4)	250 (4.9)
Frank report and cause of activity limitation(s)	329 (31.3)	78 (1.9)	407 (8.0)
Medicare claims, single-year[c]	149 (14.2)	95 (2.4)	244 (4.8)
Medicare claims, multi-year[d]	296 (28.2)	266 (6.6)	562 (11.0)
All sources, single-year Medicare claims	367 (34.9)	293 (7.3)	660 (13.0)
All sources, multi-year Medicare claims	430 (40.9)	425 (10.5)	855 (16.8)

Abbreviations: ADL, activities of daily living; IADL, instrumental activities of daily living.

[a] Two survey questions asked about Alzheimer disease and senility; survey participants were not asked a frank question regarding "dementia."

[b] Study participants were asked to name reasons for their activity limitations; dementia, senility, and Alzheimer disease responses were classified as dementia.

[c] Single-year claims included the calendar year of the survey.

[d] Multiple-year claims included 4 years before the survey and the calendar year after the survey.

(Table 4). This pattern varied considerably in the degree of increased association but was otherwise consistent across all data sources evaluated (see Table 4). In general, persons demented by two or more sources had higher ORs than those with dementia documented by only one source. Among the three categories demented by one source (groups A, B, and C), distinct patterns emerged among the age-gender-education adjusted ORs. Those with dementia in group A (survey only) generally demonstrated the highest odds, those in group B (Medicare only) demonstrated the second highest odds, and those in group C (SPMSQ only) demonstrated the lowest odds.

4. Discussion

The results of this study suggest that any single source among several examined fail to adequately capture population-level dementia in this elderly population. Agreement between data sources is relatively low, which, in the absence of additional information, might suggest poor reliability of one or more sources. However, each data source seems to identify a group of individuals with limitation in the performance of cognitive activities. The finding of consistently increased difficulty in the performance of cognitively related activities/symptoms and non-overlapping dementia reports from surveys, Medicare claims, and the SPMSQ suggests that each source contributes unique and essential information to the identification of dementia. Thus, these findings seem to provide validation that each data source captures cognitively impaired persons missed by other sources and suggests possible sources of variability in literature reports for dementia.

Because this study calls into question the use of single-source variables to measure dementia prevalence in secondary survey data, the use of each source alone to forecast a nation's dementia-related health care needs could be expected to produce widely varying national estimates of dementia-related costs and resource needs. Current population trends in industrialized countries include a fast growing old-old population for whom dementia prevalence is highest

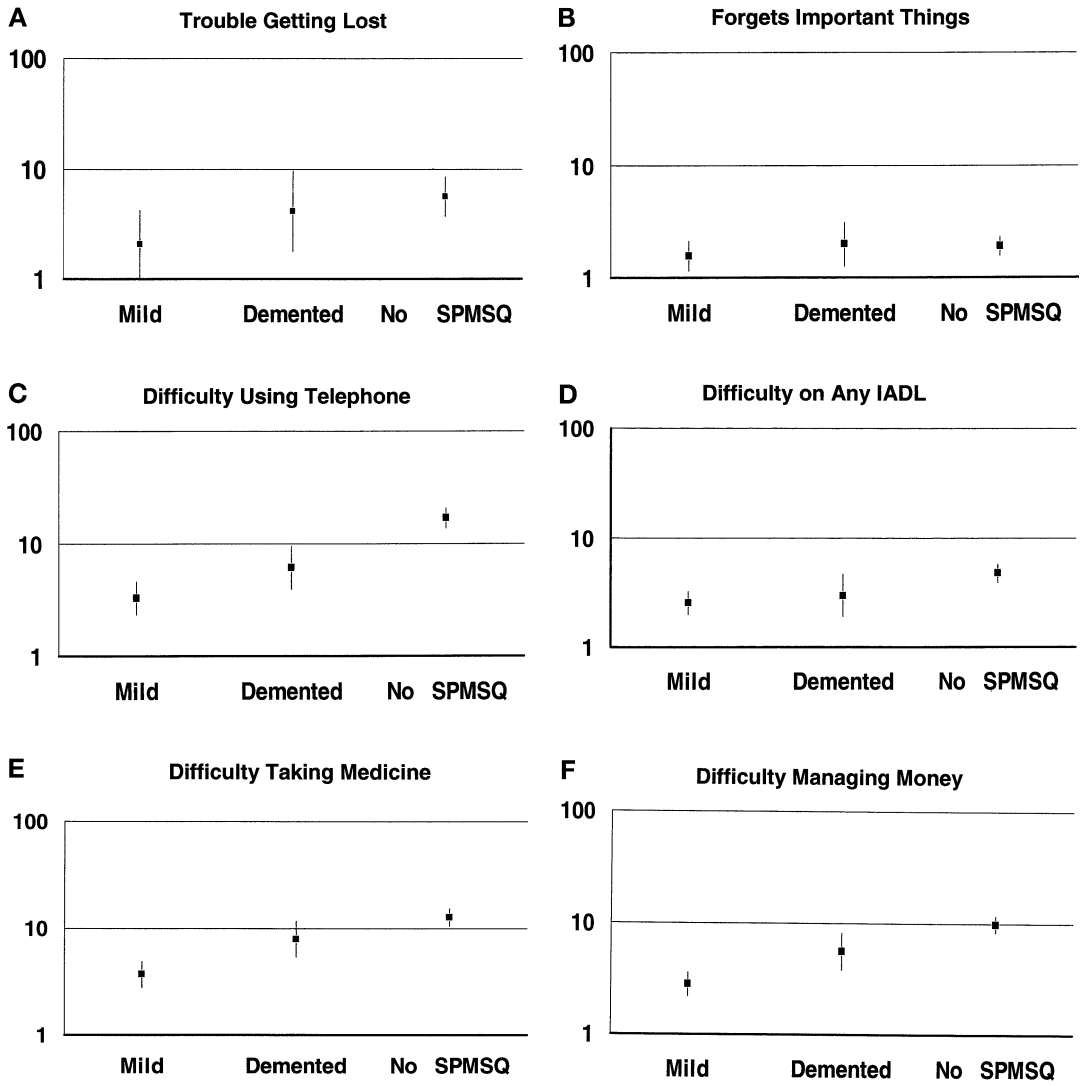

Fig. 2. ORs (shown on a logarithmic scale with 95%CIs) age-gender-education adjusted for select cognitive symptoms/activity limitations. Normal ($n = 3185$) is the reference group, all of whom scored in the normal range on the SPMSQ. Mild ($n = 385$) is the group who scored in the possibly mild impairment range. Demented ($n = 176$) includes those who scored in the moderate-to-severely impaired range on the SPMSQ. No SPMSQ includes those who did not complete the SPMSQ.

and in whom frailty issues contributing to measurement difficulties are amplified. As populations continue aging, study designs and methodologies should be reevaluated to assess how to avoid the frailty bias observed in current studies [15]. Requiring multiple overlapping sources for dementia seems to capture a more impaired population than single non-overlapping reports. However, this restrictive method creates an unacceptably large group of false negatives, rendering this method unsuitable for forecasting dementia-related demands on health care systems. The consistently increased odds for difficulty in performing cognitive activities among those in non-overlapping dementia categories provides strong support for pursuing a more inclusive method. These increases are present after controlling for reported hearing and visual difficulties.

Although there are isolated methodologic issues specific to the NLTCS, the great variability in dementia prevalence observed in this study is not unique to the NLTCS or to Medicare claims data. Other studies based on diverse samples report widely ranging dementia prevalence: between 2.2% and 8.4% for those aged 65 to 74 years, between 10.5% and 16.0% for those aged 75 to 84 years, and between 15.2% to 48% for those aged 85 years and over [1,2]. Our levels of survey-reported dementia are at the low end of the range of studies of dementia for persons 65 to 74 years and 85 years and over and are lower than the lowest reported prevalence estimates for those aged 75 to 84 years. For all three age groups, the cognitive screen and single-year Medicare claims produce estimates that are lower than our survey-reported dementia and lower than the lowest prevalence in the cited studies.

Several factors may have contributed to prevalence underestimates and lower agreement among the survey reports, Medicare, and the cognitive screening instrument. First, it

Table 4
Odds ratios for cognitive symptoms/activities for demented and nondemented study participants (age-gender-education adjusted with 95% confidence intervals)

	Group A: Demented, survey only (n = 178)	Group B: Demented, Medicare claims only (n = 293)	Group C: Demented, SPMSQ only (n = 107)	Group D: Demented by two or more sources (n = 277)	Group E: All demented, any source (n = 855)
Lose way and not find way back	8.4 (4.6–15.5)	1.3 (0.5–3.4)	1.3 (0.3–5.6)	16.5 (10.0–27.3)	7.0 (4.5–10.7)
Forget to do important things	3.9 (2.8–5.5)	1.8 (1.3–2.5)	1.3 (0.7–2.3)	5.9 (4.4–7.9)	3.3 (2.7–4.1)
Forgetting as a cause of activity limitations	1.6 (1.0–2.6)	2.7 (1.9–3.9)	4.0 (2.5–6.5)	2.6 (1.9–3.7)	2.7 (2.2–3.5)
Difficulty taking medicine	20.4 (14.3–29.1)	7.6 (5.7–10.1)	7.1 (4.6–10.8)	40.3 (28.7–56.5)	15.9 (12.9–19.5)
Difficulty using telephone	19.2 (13.2–27.8)	6.6 (4.8–9.3)	5.4 (3.3–9.0)	40.7 (29.0–57.3)	15.0 (11.9–18.8)
Difficulty managing money	16.6 (11.5–24.0)	6.4 (4.9–8.5)	5.3 (3.5–8.0)	37.4 (25.5–54.9)	12.8 (10.6–15.4)
Difficulty using a calculator	11.1 (5.2–23.6)	2.6 (1.6–4.1)	3.0 (1.4–6.3)	49.7 (19.3–127.9)	6.3 (4.6–8.6)
Difficulty using a computer	9.0 (1.9–42.0)	2.2 (0.9–5.4)	1.2 (0.2–5.8)	41.2 (5.4–311.2)	5.2 (2.9–10.2)
Difficulty using directions to operate a microwave	8.9 (5.4–14.7)	3.5 (2.4–5.2)	2.9 (1.6–5.3)	22.0 (13.0–37.1)	6.7 (5.2–8.6)
Difficulty making meals	9.7 (6.9–13.6)	6.2 (4.7–8.1)	3.3 (2.1–5.0)	24.0 (17.2–33.4)	9.6 (7.9–11.5)
Difficulty shopping for groceries	7.4 (4.9–11.1)	3.7 (2.8–4.9)	2.3 (1.5–3.5)	16.8 (10.5–26.9)	5.8 (4.8–7.0)
Difficulty with travel	4.5 (3.2–6.4)	3.6 (2.7–4.7)	2.4 (1.6–3.6)	6.9 (5.0–9.4)	4.5 (3.8–5.4)
Difficulty doing laundry	7.2 (5.1–10.2)	4.5 (3.4–5.8)	2.4 (1.6–3.5)	11.1 (8.1–15.1)	6.1 (5.1–7.3)
Difficulty doing light housework	8.4 (6.0–11.7)	5.0 (3.8–6.6)	2.6 (1.6–4.0)	9.5 (7.2–12.7)	6.6 (5.5–8.0)
Difficulty with any IADL	15.9 (8.1–31.5)	3.8 (2.7–5.2)	2.8 (1.8–4.5)	17.2 (9.3–31.7)	6.5 (5.1–8.1)
Reads	0.19 (0.14–0.27)	0.32 (0.24–0.42)	0.28 (0.18–0.42)	0.13 (0.10–0.18)	0.21 (0.17–0.25)
Does hobbies	0.38 (0.23–0.61)	0.43 (0.30–0.61)	0.65 (0.40–1.04)	0.17 (0.10–0.29)	0.36 (0.29–0.46)
Plays games	0.31 (0.1–0.50)	0.43 (0.31–0.60)	0.24 (0.13–0.45)	0.29 (0.19–0.43)	0.33 (0.26–0.41)

Abbreviation: IADL, instrumental activity of daily living.

is possible that differences in diagnostic terminology and codes used by clinicians, health surveys, and in administrative data could have led to lower detection of dementia by survey report. As an example, the NLTCS, originally designed in the early 1980s for the first administration in 1982, continues to use only the terms "senility" or "Alzheimer's disease" (added in 1989) in the list of questions about specific conditions. Senility is the term used in the ICD-9-CM for dementia [10]; however, with their patients, most clinicians currently use the term "dementia," which is consistent with the diagnostic criteria used in the Diagnostic and Statistical Manual of Mental Disorders, fourth edition, (DSM-IV) classification scheme [16]. As long as these differences exist in commonly used coding systems, questions in surveys of elderly populations should include the term "dementia" to be consistent with common clinically used terminology.

A related coding issue with potential to contribute to lower detection of dementia is rooted in the overlapping use of numerical codes for different clinical diagnoses between the DSM-IV [16] and the ICD-9-CM [9]. Some physicians, such as psychiatrists and neurologists, may use the DSM-IV exclusively for neurologic and psychiatric diagnoses but are required to use ICD-9-CM classification in submission of Medicare claims. Although many of the codes are identical across dementia diagnoses, the same code can represent a different diagnosis in the two systems. We performed a crosswalk by comparing codes and diagnoses between the DSM-IV and ICD-9-CM dementia codes used in this study to check the potential impact of such possible errors. If data-coding errors arose from confusion between the coding systems, the crosswalk revealed that these would have been errors of omission of diagnoses of dementia rather than erroneous inclusion of nondemented persons as demented.

Newcomer et al. showed the underestimation of Alzheimer disease was partially remedied by lengthening the study time span [3]. Our study also found that lengthening the time frame improved detection of dementia and agreement with non-Medicare dementia sources. However, a large portion of dementia continued to be identified only through sources other than Medicare claims.

Although the SPMSQ seems to detect under-reporting of cognitive impairment by each other source, it was infrequently administered in the oldest-old, in the demented, and in the most severely physically impaired subjects. The low performance of the SPMSQ in relation to survey-reported dementia is due in part to this infrequent administration. There was a high rate of proxy use among demented individuals for the other data sources, but proxies did not take the SPMSQ on behalf of study participants. Although high rates of proxy use and missing cognitive screening information may be inevitable in surveys of the elderly, reliance on family and nursing home staff to report cognitive impairment has previously been shown to underestimate dementia [6]. Some have hypothesized that memory decline may go unreported because it is seen as a normal process of aging or that it may carry a stigma through the "fear of being labeled" that contributes to lower reporting. Because clinical trials and prospective studies may rely on screening questions for

inclusion, many of the issues identified here are not limited to secondary data. Further attention should be directed toward the design and testing of auxiliary sources of information. The addition of a question to surveys that differentiates those who used a proxy due to being physically incapable, mentally incapable, both physically and mentally incapable, or for indeterminate reasons could be helpful. During the time frame of this study, there were few pharmacologic treatments available for the person with early or advanced memory decline. However, future studies may be affected by new pharmacologic agents for mild cognitive impairment, dementia, and associated memory problems.

Despite its low administration in high-risk groups, the cognitive screen represents an important component of assessment of cognition in secondary surveys. Although some researchers have questioned the SPMSQ's capacity to capture the mental aspects necessary for daily functioning in some populations [17,18], others have noted that any errors on the SPMSQ were associated with increased cognitive impairment [19]. Previous studies have tried to validate the SPMSQ through comparative studies with the Clinical Dementia Rating Scale or the Mini Mental State Examination [20–23]. Roccaforte et al. [22] reported a sensitivity of 0.74 and a specificity of 0.91, and Erkinjuntti et al. [23] found a sensitivity and specificity of 0.67 and 1.00, respectively, in community-dwelling subjects. In this study, increasing impairment as indicated by SPMSQ score was associated with increasing risk of cognitive symptoms and limitations in cognitively related activities.

In addition to the potential sources of lower agreement listed above, the lack of a cognitive screening instrument to determine who gets the detailed community-dwelling survey could have led to missed cases by all sources examined. Approximately 14% of all dementia in the larger group of over 19,000 study participants had Medicare claims for dementia but seem to have missed detection by the screening questions used to determine who should receive the detailed community questionnaire. This study used IADLs as a screening tool for cognitive impairment and dementia, which have been found to have a sensitivity of approximately 0.6 [24]. Support for adding a cognitive screening component to secondary surveys is found in the work of Fillenbaum [25], who suggested that 47% of the 50% variance explained by the SPMSQ is accounted for by three questions (date of birth, previous president, and day of the week), suggesting that these or a similarly small number of questions suitable for administering by telephone [25,26] might be worth the increased screening time. These findings are not intended to be used for clinical, diagnostic, treatment, or "labeling" of individual persons but rather to further our understanding of issues crucial to improved measurement of population-level health.

In summary, we identified several areas where refinement of survey methodologies could provide better data to disentangle measures of active life expectancy into its components: cognitively active life expectancy and physically active life expectancy. Because essential health and community service needs vary for populations who are primarily cognitively versus physically disabled, continued improvement in survey designs and improved measures of cognitively versus physically active life expectancy are key to refining our ability to forecast associated demands on health systems in industrialized countries.

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