Estimated Prevalence of People With Cognitive Impairment: Results From Nationally Representative Community and Institutional Surveys

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Purpose: We address how the national prevalence of cognitive impairment can be estimated from two nationally representative surveys. Design and Methods: Data are from the 1999–2001 National Health Interview Survey (NHIS) and the 1999 National Nursing Home Survey (NNHS). The NHIS represents all community-dwelling people living in the United States, and the NNHS is representative of all nursing home residents. Results: NHIS data show that there are approximately 800,000 community-based elders aged 65 and older with reported confusion or memory loss, and 2.3 million elders with reported limitation of activity caused by senility or dementia. There are an estimated 632,000 nursing home residents aged 65 and older with a reported diagnosis of dementia. Implications: Estimates of the prevalence of cognitive impairment that are based on nationally representative data are rare, because comprehensively evaluating a national sample by using standard, validated cognitive-impairment assessment methods is difficult and expensive, and because most national surveys are broad based and designed to cover a wide variety of topics. Crude measures of cognitive impairment, such as the presence of confusion or memory loss or limitations caused by senility or dementia, that are included in these multipurpose surveys may be only rough proxies for clinically evaluated cognitive impairment, but they do appear to produce prevalence estimates that are similar to estimates found with the use of more precise case-ascertainment methods. These nationally representative data sets may be used to generate hypotheses related to the prevalence, epidemiology, and health care utilization patterns of people with cognitive impairment that can be tested in studies using more specific case-ascertainment criteria. Key Words: Dementia, Prevalence, Limitation of activity, National surveys

Cognitive impairment is often, although not always, a precursor to dementia later in life (Leifer, 2003; Panza et al., 2005; Richie & Touchon, 2000). An accurate estimate of the number of people with identifiable cognitive impairment, along with their health status, comorbid conditions, and use of health care services, can provide a baseline for forecasting the health care and social resources needed to care for people with this increasingly common condition. Dementia can be difficult to diagnose, particularly in its early stages. This imprecision in diagnosis translates into difficulty in identifying individuals with clinical dementia in either person-based surveys or in surveys that rely on medical or administrative records. Cognitive impairment, however, is more of a symptom than a diagnosis, and it can be determined by respondent report or clinical observation. Our analysis addresses how the prevalence of cognitive impairment can be estimated from two national health surveys, the National Health Interview Survey (NHIS), which was designed to track the overall health status and determinants of health status and health care of the civilian noninstitutionalized population, and the National Nursing Home Survey (NNHS) resident sample, which was designed to track changes in nursing home use, characteristics of nursing home residents, and nursing home facility
characteristics. This is one of a very few studies that includes people with cognitive impairment in both institutional and community-based nationally representative data sets and compares results based on different case-ascertainment methods. Although the method of identification of patients with cognitive impairment differs between the surveys, when the surveys are taken together, they provide a more comprehensive picture of the total prevalence of cognitive impairment than each survey does on its own. More often, researchers derive prevalence estimates of cognitive impairment from small studies in which investigators screen people by using various assessment scales that assess various domains of cognition (e.g., memory, problem solving, wording finding), and then apply the prevalence estimates from screened respondents to population data. This raises questions about the generalizability of the population screened (Government Accountability Office [GAO], 1999; Suthers, Kim, & Crimmins, 2003).

**Design and Methods**

**Data**

Data for this analysis come from two nationally representative surveys: the NHIS and the NNHS, resident sample, sponsored by the Centers for Disease Control and Prevention’s National Center for Health Statistics. Because elderly people comprise the large majority of patients with cognitive impairment and diagnosed dementia, we include only those people aged 65 and older in this analysis.

The NHIS monitors the health of the U.S. population through the collection and analysis of data on a broad range of health topics. The NHIS is a continuous survey of the civilian, noninstitutionalized population of the United States. It obtains information through in-person interviews with household respondents and one selected adult and one child per household. Since 1997, the sample has included about 100,000 people per year. In order to have a sufficiently robust sample size for people with a limitation caused by dementia, we combined data from 3 separate years (1999–2001) for this analysis. The 1999–2001 NHIS included 33,134 people aged 65 or older in the family component of the survey and 18,331 people aged 65 and older in the sample adult component.

The NNHS is a series of national probability sample surveys of nursing homes, their residents, and their staff. Data from the 1999 NNHS provide point-in-time estimates of residents from a sample of people currently residing in nursing homes. A staff member familiar with the sampled residents, referring to medical and facility records, provided resident data through on-site interviews. The 1999 sample consisted of 1,496 nursing homes and 8,215 current residents (7,383 individuals who were aged 65 and older).

**Identification of Cases**

Table 1 displays how we identify people in the two surveys as having cognitive impairment. We derive two measures of cognitive impairment from the limitation-of-activity component of the family core questionnaire of the community-based NHIS (see Table 1).

The full set of limitation of activity questions elicits whether anyone in the household has a limitation in his or her everyday activities as a result of a physical, mental, or emotional health problem. The responses may be self-reported or reported by proxy from an adult household member for other household members not present at the interview. Respondents are asked about limitations in activities of daily living, instrumental activities of daily living, play, school, and work; difficulties in walking or in remembering; and any other activity limitations. The first NHIS measure assessed the self-report of limitations caused by confusion or memory loss.

The second measure of cognitive impairment used for NHIS participants is based on the specific condition or disease that causes activity limitations identified by any of the aforementioned limitation-of-activity questions. When limitations are reported, the causal health conditions are determined and respondents are considered limited if one or more of these conditions is chronic. Interviewers asked only the subset of NHIS respondents who identified a limitation of activity to identify the cause or condition that caused the limitation. Interviewers then asked respondents what condition caused each limitation identified and recorded this condition as “senility” if the respondent reported that the limitation was due to senility, Alzheimer’s disease, or another aging-related cognitive impairment. People with a “yes” response to this question are included in the Senility cognitive-impairment category.

The respondent-reported confusion or memory loss-measure casts a wide net and is probably an overestimate of the total prevalence of people who would be diagnosed with dementia if they were clinically assessed. Conversely, the number of people who report a limitation caused by senility is probably an underestimate of the total number of community-dwelling elderly persons who could be diagnosed with dementia if they were assessed by a clinician, because it excludes many people in the early stages of dementia who do not yet have a reported dementia-related limitation of activity. Among older people with a limitation caused by senility (NHIS Measure 2), 87% also reported a limitation caused by confusion or memory loss, and approximately 30% of the people who reported confusion or memory loss (NHIS Measure 1) also reported a limitation caused by senility.

We considered cognitive impairment or dementia to be present in persons in the NNHS on the basis of whether they had a diagnosis of dementia recorded on...
the medical record or reported to the NNHS interviewer by a knowledgeable staff person. Up to six conditions could be recorded for nursing home residents; which were coded to the appropriate ICD-9-CM diagnostic dementia codes (i.e., those listed by the International Statistical Classification of Diseases, ninth revision, clinical modification; see Table 1).

All differences noted in this paper are statistically significant at the \( p, .05 \) level and are tested by use of the two-tailed \( z \) test. We computed estimates of standard errors by using SUDAAN software, which takes into account the complex survey designs of both the NHIS and the NHHS (more detail about all of the NCHS surveys, including downloadable publications, can be found on the NCHS website at http://www.cdc.gov/nchs).

### Results

Using the NHIS Confusion or Memory loss—measure of cognitive impairment, we found that, on average, approximately 2.3 million community-dwelling people aged 65 and older had cognitive impairment at the time of the survey during the 3-year period between 1999 and 2001 period (Table 2). Using the Senility measure, however, we found that the estimated number of community-dwelling elderly people with cognitive impairment was only 800,000 people.

Although only 4% of noninstitutionalized people aged 65 to 74 years had confusion or memory loss, this increased to 9% for people aged 75 to 84 years and to almost 20% of people aged 85 and older. Less than 1% of noninstitutionalized people aged 65 to 74 years reported a limitation caused by senility, compared with 9% of people aged 85 and older.

About 623,000 nursing home residents aged 65 and older had a dementia diagnosis at the time of the survey in 1999. For nursing home residents, the prevalence of diagnosed dementia was similar to that for people aged 75 to 84 and people aged 85 and older (approximately 43% to 45%), but this rate was considerably higher than the rate for people aged 65 to 74 (approximately 30%).

### Discussion

This analysis shows that it is possible to make estimates of cognitive impairment from general-purpose health surveys that do not specifically set out to assess cognitive impairment. It also shows that these

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**Table 1. Measures of Cognitive Impairment From Two National Surveys**

<table>
<thead>
<tr>
<th>Survey</th>
<th>Mode of Data Collection</th>
<th>Data Element or Question</th>
<th>Sample for Which Question Is Asked</th>
</tr>
</thead>
<tbody>
<tr>
<td>NHIS  Measure 1: confusion or memory loss</td>
<td>In-person survey; proxy responses allowed</td>
<td>Are you LIMITED IN ANY WAY because of difficulty remembering or because you experience periods of confusion?</td>
<td>All people age 18 and older</td>
</tr>
</tbody>
</table>
| NHIS  Measure 2: senility or dementia | In-person survey; proxy responses allowed | For people with any limitation: What conditions or health problems cause your limitations?  
| | | (A “senility” response is coded if the person responded with senility, Alzheimer’s disease, and other aging-related cognitive problems.) | People 18 and older who have at least one of the following limitations: Any ADL  
| | | | Any IADL  
| | | | Difficulty remembering because of confusion  
| | | | Physical, mental, or emotional problem keeps you from working at a job or business  
| | | | Limited in kind or amount of work because of physical, emotional, or mental problem |
| NNHS—resident sample Measure based on ICD-9-CM coded diagnosis of dementia | In-person interview with nursing home staff person knowledgeable about the sampled resident; may use medical records and administrative data | Any diagnosis (up to 6) recorded on the medical record and classified into ICD-9-CM codes:  
| | | Alzheimer’s disease (331.0)  
| | | Senile dementia (290; includes  
| | | 290.4 Arteriosclerotic Dementia)  
| | | Unspecified organic psychotic syndrome (294) | All sampled nursing home residents |

Notes: NHIS = National Health Interview Survey; NNHS = National Nursing Home Survey; ICD-9-CM = International Statistical Classification of Diseases, ninth revision, clinical modification; ADL = activity of daily living; IADL = instrumental activity of daily living.
estimates are consistent with other studies that focus more specifically on measuring clinical dementia prevalence in small, nonnationally representative studies (e.g., Brookmeyer, Gray, & Kawas, 1998; GAO, 1998; Hendrie, 1998; Herbert, Scherr, Bienias, Bennett, & Evans, 2003; Kukull et al., 2002; Magaziner et al., 2000). For example, a meta-analysis produced by the GAO estimated that approximately 5.7% of the people aged 65 years had any Alzheimer’s disease dementia—not including other types of dementia—in 1995, and 3.3% had moderate or severe Alzheimer’s disease (GAO). In a study using nationally representative data, Suthers and colleagues found a cognitive-impairment prevalence rate of 5.5% to 6.5% for people aged 70 and older who were living in the community and a rate of approximately 50% among institutionalized elders aged 70 and older (Suthers et al., 2003). These researchers used two out of seven symptoms related to cognitive impairment as their classification criteria, which is considerably more stringent than the single question or item that we used for the three measures of cognitive impairment presented in this analysis.

Our study is subject to several limitations. Surveillance for cognitive impairment typically uses assessment scales that assess various domains of cognition (e.g., memory, problem solving, and word finding; see Rosenberg, Johnston, & Lyketsos, 2006); therefore, the use of a single item is a crude or imprecise method to ascertain cognitive impairment. Second, people with cognitive impairment in the NHIS are classified on the basis of self-report or proxy report, and prevalence may be underreported because of possible stigma or embarrassment. Cognitive impairment in the nursing home sample is determined by staff members who refer to sampled residents’ medical records, and this too is subject to misreporting or underreporting. Cognitive impairment is a complex condition, and researchers cannot make a definitive determination of it on the basis of one question about cognition or limitation of activity. Further analyses comparing results from these questions with other validated measures would have to be conducted. Without further validation, results using the NHIS measures would have to be interpreted with caution and replicated with additional studies. Our analysis also does not include any data on cognitive impairment within the small (but increasing) number of people living in alternative long-term-care residential settings, such as assisted living facilities, who are not included in either household surveys of noninstitutionalized persons (such as the NHIS) or surveys of persons in institutional settings (such as the NNHS).

However, the fact that results based on these simple measures are consistent with other studies using more detailed measures means that researchers may be able to use these national studies to generate hypotheses related to the prevalence and determinants of cognitive impairment, comorbid conditions, or health care utilization of people with cognitive impairment that can be tested in studies with more specific cognitive-impairment case-ascertainment criteria. It is our hope that the NHIS and the NNHS, which include these indicators of cognitive impairment but...
also contain a myriad of other data on sociodemographics, health status, use of services, and access to medical services, will be used for this purpose.

References

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