Overestimation of Chronic Disability Among Elderly Persons

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Background: Although there is no generally accepted definition for the term short-term disability, chronic disability has been defined as disability lasting or expected to last at least 90 days according to a protocol that was established by the National Long-Term Care Survey. We evaluated the validity of the established protocol and determined the accuracy of prevalence estimates of chronic disability among elderly persons in the United States.

Methods: Chronic disability was ascertained during a comprehensive assessment using the established protocol. Participants were subsequently classified as having chronic disability (the gold standard) based on the presence of disability during consecutive monthly interviews immediately before or after the comprehensive assessment.

Results: Of the 552 participants, 120 (21.7%) met criteria for chronic disability according to the established protocol. Of these, 30 (25.0%) and 39 (32.5%) did not meet criteria according to the gold standard under assumptions that were favorable and unfavorable (ie, stringent) to the established protocol, respectively. Conversely, of the 95 participants (17.2%) who met the gold standard criteria for chronic disability according to the favorable strategy and the 89 (16.1%) who met the criteria according to the stringent strategy, 5 (5.3%) and 8 (9.0%), respectively, did not meet criteria for chronic disability according to the established protocol. Relative to the established estimate of 7.0 million, our projections yielded about 2.0 million fewer chronically disabled elderly Americans in 1999.

Conclusion: Our results threaten the validity of the currently established protocol for ascertaining chronic disability and suggest that the burden of chronic disability among elderly Americans has been substantially overestimated.

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mates that were based on the presence of disability during consecutive monthly interviews immediately before and after the 54-month assessment (the gold standard).

METHODS

STUDY POPULATION

Participants were members of the Precipitating Events Project, an ongoing longitudinal study of 754 community-living persons, 70 years or older, who were initially nondisabled in 4 essential activities of daily living—bathing, dressing, walking inside the house, and transferring from a chair. The assembly of the cohort has been described in detail elsewhere; the participation rate was 75.2%. Participants completed comprehensive assessments at 18-month intervals and monthly telephone interviews for the ascertainment of disability. The study protocol was approved by the Yale Human Investigation Committee, and all participants provided verbal informed consent.

The analytic sample for the current study included participants who completed the comprehensive assessment at 54 months. Of the 754 participants, 166 (22.0%) had died before the 54-month assessment, and 27 (3.6%) had dropped out of the study after a median follow-up period of 22 months. Of the remaining 561 participants, 3 (0.5%) refused to complete the assessment, and 6 (1.1%) had incomplete information on their disability status, leaving 552 participants in the analytic sample. Compared with these participants, the 202 cohort members who were not included in the analytic sample were (at baseline) older (80.4 vs 77.7 years; P<.001), had more chronic conditions (2.3 vs 1.7; P<.001), and were more likely to be male (42.6% vs 32.8%; P=.01) and physically frail (59.9% vs 36.4%; P<.001). There were no significant baseline differences according to race or ethnicity, living situation, education, or cognitive status.

DATA COLLECTION

The research nurses who completed the 54-month assessments were kept blind to the results of the monthly assessments. As described in 2 earlier reports, the comprehensive assessments and monthly telephone interviews were completed with a designated proxy for participants with significant cognitive impairment. At 54 months, 68 (12.3%) of the comprehensive assessments were completed by a designated proxy.

54-MONTH ASSESSMENT

During the 54-month assessment, data were collected on living situation; self-reported, physician-diagnosed chronic conditions; cognitive status as assessed by the Folstein Mini-Mental State Examination; and physical frailty, defined on the basis of slow gait speed as previously described. Chronic disability, defined as disability lasting at least 90 days (ie, 3 months), was ascertained for the first time during the 54-month assessment using the protocol established by the National Long-Term Care Survey hereafter referred to simply as the established protocol. To our knowledge, alternative protocols for assessing chronic disability have not been reported. For each of the 4 essential activities of daily living, participants were asked, “At the present time, do you need help from another person to (complete the task)?” Participants who answered “No” were considered to be nondisabled for that task. Participants who answered “Yes” were subsequently asked up to 3 questions, shown in the following tabulation, to determine whether the disability was chronic.

<table>
<thead>
<tr>
<th>Subtype</th>
<th>Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Previous 3 months</td>
<td>Have you needed help (to complete the task) for 3 months or longer?</td>
</tr>
<tr>
<td>Next 3 months</td>
<td>Do you expect to need help (with the task) for the next 3 months or longer?</td>
</tr>
<tr>
<td>Combination</td>
<td>All together, from beginning to end, will you have needed help (with the task) for 3 months or longer?</td>
</tr>
</tbody>
</table>

The criterion for chronic disability was met if participants answered “Yes” to any of the 3 questions for 1 or more of the 4 activities of daily living. Among a subgroup of 28 participants with chronic disability at 54 months, we found that only 1 (3.6%) did not meet the criterion based on a subsequent telephone interview that was completed independently within 5 days (mean, 1.8 days) by a second interviewer.

MONTHLY TELEPHONE INTERVIEWS

Complete details regarding the monthly assessments of disability, including formal tests of reliability and accuracy, are provided elsewhere. During the monthly telephone interviews, participants were assessed for disability using standard questions that were identical to those used during the comprehensive assessments. For each of the 4 essential activities of daily living, we asked, “At the present time, do you need help from another person to (complete the task)?” Participants who needed help with any of the tasks were considered to be disabled. Participants were not asked about eating, toileting, or grooming. Disability in these activities of daily living is uncommon in the absence of disability in bathing, dressing, walking, or transferring from a chair; hence, these omissions will have little appreciable effect on our estimates of chronic disability. The reliability of our disability assessment was substantial (κ=0.75) for reassessments completed within 48 hours and excellent (κ=1.00) for reassessments performed the same day. The accuracy of proxy reports, compared with reports from cognitively intact participants, was also found to be excellent, with κ=1.00.

STATISTICAL ANALYSIS

The prevalence of chronic disability was determined on the basis of the 54-month assessment, and the number of chronically disabled activities of daily living was tabulated. Participants with chronic disability were subsequently classified according to the specific subtypes (shown in the tabulation in the “54-Month Assessment” subsection).

The overall objective of our analysis was to determine the validity of the established protocol for ascertaining chronic disability as implemented during the 54-month assessment. Data from the monthly telephone interviews were used to define the gold standard. Participants were classified as having chronic disability based on the presence of disability during consecutive monthly telephone interviews immediately before or after the 54-month assessment. To bolster the validity of the gold standard, we evaluated a subgroup of 186 participants who had no disability “at the present time” and found that only 2 (1.1%) reported disability “at any time during the last month.” To be conservative, we did not require that the subtype designation for the established protocol match that for the gold standard. Because the telephone interviews and 54-month assessments were completed independently of one another, the corresponding time intervals for ascertaining chronic disability usually did not coincide perfectly, as illustrated in Table 1 (discussed in the next 2 subsections). Hence, we performed 2 sets of analyses, under assumptions that were initially favorable to the established protocol and,
subsequently, under assumptions that were more stringent, that is, unfavorable. These assumptions differed depending on whether chronic disability was present or absent according to the established protocol, as summarized in Table 2 and described in detail in the next 2 subsections.

### PRESENCE OF CHRONIC DISABILITY ACCORDING TO ESTABLISHED PROTOCOL

For the favorable strategy, the gold standard for chronic disability required disability during consecutive telephone interviews for intervals that could have potentially spanned 90 days or longer relative to the time of the 54-month assessment. For the stringent strategy, the gold standard required disability during consecutive telephone interviews for intervals of at least 90 days. To illustrate, for the first subtype of “previous 3 months” in Table 1, the gold standard required disability during months 52 to 54 for the favorable strategy and months 51 to 54 for the stringent strategy. For the second subtype of “next 3 months,” the gold standard required disability during months 55 to 57 for each of the 2 strategies. For the third subtype of “combination,” the gold standard required disability in consecutive months during any interval within 90 days of the 54-month assessment. This included months 52 to 54, 53 to 55, 54 to 56, or 55 to 57 for the favorable strategy and months 52 to 55, 53 to 56, or 54 to 57 for the stringent strategy.

### ABSENCE OF CHRONIC DISABILITY ACCORDING TO ESTABLISHED PROTOCOL

In contrast, for this scenario the gold standard for chronic disability required disability during consecutive telephone interviews for intervals of at least 90 days relative to the time of the 54-month assessment for the favorable strategy and for intervals that could have potentially spanned 90 days or longer for the stringent strategy. To illustrate, in the last 2 columns of Table 1, the gold standard was achieved if disability was present during months 51 to 54, 52 to 55, 53 to 56, 54 to 57, or 55 to 58 for the favorable strategy and during months 52 to 54, 53 to 55, 54 to 56, or 55 to 57 for the stringent strategy. For both strategies, participants needed to report disability in 1 or more of the 4 essential activities of daily living during the 54-month assessment because this served as the reference point for the gold standard. Of the 432 participants who were non-disabled at 54 months, only 1 (0.2%) reported disability in the month immediately before and the month immediately following the 54-month assessment.

### ESTIMATES OF CHRONIC DISABILITY ACCORDING TO ESTABLISHED PROTOCOL AND GOLD STANDARD

The validity of the established protocol for chronic disability was determined relative to the gold standard definitions for the favorable and stringent strategies, respectively. The 2 metrics of validity were sensitivity and specificity, which were defined, per convention, as the ability of the established protocol to correctly identify the presence (ie, true positive) and absence (ie, true negative) of chronic disability, respectively.

<table>
<thead>
<tr>
<th>Strategy</th>
<th>Chronic Disability According to Established Protocol</th>
<th>Duration of Disability According to Monthly Interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td>Favorable</td>
<td>Present</td>
<td>Could have spanned 90 days or longer</td>
</tr>
<tr>
<td></td>
<td>Absent</td>
<td>At least 90 days</td>
</tr>
<tr>
<td>Stringent</td>
<td>Present</td>
<td>At least 90 days</td>
</tr>
<tr>
<td></td>
<td>Absent</td>
<td>Could have spanned 90 days or longer</td>
</tr>
</tbody>
</table>

*The monthly interviews were used to define the gold standard. A complete description is provided in the “Statistical Analysis” subsection in the “Methods” section.
same intervals (ie, established protocol), our estimates should not be affected appreciably by differences in the characteristics of the 2 study populations, the specific activities of daily living evaluated, or the methods used to define disability as long as the rates of chronic disability are comparable in our study and the National Long-Term Care Survey. Unlike sensitivity and specificity, positive and negative predictive values are highly dependent on the prevalence of the specific disorder.23

All analyses were performed using the statistical software SAS (version 8.2; SAS Institute, Cary, NC).

## RESULTS

The characteristics of the analytic sample, at the time of the 54-month assessment, are shown in Table 3. The majority of participants were white women who did not live alone; about half were physically frail.

Of the 552 participants, 120 (21.7%) met criteria for chronic disability according to the established protocol. The mean (SD) number of chronically disabled activities of daily living was 2.1 (1.2); the most common subtype designation (per the tabulation in the “54-Month Assessment” subsection in the “Methods” section), involving 234 (93.6%) of the 250 chronically disabled activities of daily living, was “previous 3 months.” The subtype designation was “next 3 months” for 11 tasks (4.4%) and “combination” for 5 tasks (2.0%). Only 4 (3.3%) and 2 (1.7%) of the participants with chronic disability, respectively, met criteria based exclusively on the latter 2 subtype designations.

Of the 120 participants who met criteria for chronic disability according to the established protocol, 30 (25.0%) and 39 (32.5%) did not meet criteria according to the gold standard definitions for the favorable and stringent strategies, respectively (Table 4). Conversely, of the 95 participants who met criteria for chronic disability according to the favorable strategy and the 89 participants who met criteria according to the stringent strategy, 5 (5.3%) and 8 (9.0%), respectively, did not meet criteria for chronic disability according to the established protocol. The sensitivity and specificity of the established protocol, relative to the gold standard, were 94.7% and 93.4% for the favorable strategy and 91.0% and 91.6% for the stringent strategy. Based on these values, the number of chronically disabled elderly Americans in 1999 was reduced from 7.0 million according to the established protocol to 5.3 million for the favorable strategy and 4.8 million for the stringent strategy (Table 4).

Using data from a unique longitudinal study, we found that up to a third of elderly persons deemed to have chronic disability and 1 of 11 deemed not to have chronic disability were misclassified by the protocol established for use in the National Long-Term Care Survey.1 Relative to the published estimate of 7.0 million,3 our projections yielded about 2.0 million fewer chronically disabled elderly Americans in 1999. These results threaten the validity of the currently established protocol for ascertaining chronic disability and suggest that the burden of chronic disability among elderly Americans has been substantially overestimated.

Accurate estimates of chronic disability are important for several reasons. From a policy perspective, these estimates are often used to inform decisions regarding the current and future health care needs of elderly persons and to forecast the likely demand for long-term care.24-26 From an epidemiological perspective, the etiology of chronic disability, including predisposing risk factors and subsequent precipitants, may differ from that of short-term disability.27 Finally, from a personal perspective, the likelihood of recovery is considerably lower for a person with a chronic disability than for a person with a short-term disability,12 and chronic disability likely confers a higher risk of subsequent morbidity and mortality.

Although our results suggest that prevalence estimates of chronic disability have been spuriously inflated, they do not refute the relative reductions in chronic disability that have been documented over the past 2 decades. The protocol established to ascertain chronic disability in the National Long-Term Care Survey has been used consistently from 1982 to 1999.3 Moreover, several other studies, which have evaluated any disability rather than chronic disability, have demonstrated relative reductions of comparable magnitude during this time period.3,28 These reductions have been documented most consistently for disability in essential activities of daily living, defined, as in our study, as the need for personal assistance.10

We have previously reported11 that the occurrence of disability has been underestimated by longitudinal studies with long assessment intervals. A likely explanation for these seemingly disparate findings, with overestima-

### Table 3. Characteristics of Analytic Sample of 552 Participants at 54 Months

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>No. (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, median (range), y</td>
<td>81.5 (75-101)</td>
</tr>
<tr>
<td>Women</td>
<td>371 (67.2)</td>
</tr>
<tr>
<td>Non-Hispanic white</td>
<td>495 (89.7)</td>
</tr>
<tr>
<td>Lives alone</td>
<td>210 (38.0)</td>
</tr>
<tr>
<td>Education, median (range), y</td>
<td>12 (0-17)</td>
</tr>
<tr>
<td>Chronic conditions*†</td>
<td></td>
</tr>
<tr>
<td>Hypertension</td>
<td>350 (63.4)</td>
</tr>
<tr>
<td>Arthritis</td>
<td>255 (46.2)</td>
</tr>
<tr>
<td>Cancer</td>
<td>114 (20.7)</td>
</tr>
<tr>
<td>Diabetes mellitus</td>
<td>110 (19.9)</td>
</tr>
<tr>
<td>Myocardial infarction</td>
<td>99 (17.9)</td>
</tr>
<tr>
<td>Fractures other than hip since age 50 years</td>
<td>67 (12.1)</td>
</tr>
<tr>
<td>Stroke</td>
<td>66 (12.0)</td>
</tr>
<tr>
<td>Chronic lung disease</td>
<td>65 (11.8)</td>
</tr>
<tr>
<td>Hip fracture</td>
<td>38 (6.9)</td>
</tr>
<tr>
<td>Congestive heart failure</td>
<td>41 (7.4)</td>
</tr>
<tr>
<td>Mini-Mental State examination score</td>
<td></td>
</tr>
<tr>
<td>Median</td>
<td>27</td>
</tr>
<tr>
<td>Range</td>
<td>0-30</td>
</tr>
<tr>
<td>Physical frailty†</td>
<td>279 (50.5)</td>
</tr>
</tbody>
</table>

*Presented in descending order according to prevalence.
†As defined in the “Methods” section.
tion of chronic disability prevalence but underestimation of disability occurrence, is the high rate of recovery among newly disabled elderly persons. Increasingly, disability has been viewed as a dynamic process, often characterized by multiple recurrent episodes rather than an enduring condition or progressive disorder. Our results indicate that many elderly persons cannot accurately estimate the duration of their disability episodes.

Despite differences in study populations and methods used to define disability, the established protocol yielded a rate of chronic disability in the current study (21.7%) that was comparable to that in the 1999 National Long-Term Care Survey (19.7%). Comparable rates enhance the likelihood that our projections are accurate. Our primary intent was to rigorously evaluate the validity of the currently established protocol for ascertaining chronic disability, whereas our more narrowly focused definition of disability, which required personal assistance in at least 1 of 4 essential activities of daily living, likely led to a lower rate. Had we used a more expansive definition of disability that included instrumental activities of daily living or the need for special equipment, the validity of the established protocol may have been diminished further.

To address the modest asynchrony in time periods between the established protocol and monthly telephone interviews, we considered 2 gold standard definitions for chronic disability. Hence, our results provide upper and lower bounds for the number of chronically disabled elderly Americans. Because we could not account for the complex sample design of the National Long-Term Care Survey, these estimates should be interpreted cautiously. Our primary intent was to rigorously evaluate the validity of the currently established protocol for ascertaining chronic disability rather than to generate precise population-based estimates of chronic disability.

Even though it is difficult, if not impossible, to exclude the possibility of measurement error, we believe that it is an unlikely explanation for our findings because our disability assessments were highly reliable, our rate of proxy reports was lower than that reported in the National Long-Term Care Survey, and the accuracy of our proxy reports was high. Although our participants are older than those in the National Long-Term Care Survey, there is no evidence that the accuracy of self-reported disability differs by age in the absence of cognitive impairment. Further reducing the possibility of bias, our 2 strategies for ascertaining chronic disability were completed independently of one another in the context of an ongoing longitudinal study. Our results cannot be attributed to underreporting of disability during the monthly telephone interviews because individuals who report no disability at the present time are unlikely to have had any disability during the past month.

In summary, the results of our study suggest that prevalence estimates of chronic disability have been spuriously inflated. Given the dynamic nature of disability, new strategies are needed to adequately capture the true burden of chronic disability among elderly persons.

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REFERENCES


