Evaluating Disability Over Discrete Periods of Time

Thomas M. Gill and Evelyne A. Gahbauer

Yale University School of Medicine, Department of Internal Medicine, New Haven, Connecticut.

**Background.** To advance the field of disability assessment, additional developmental work is needed. The objective of this study was to determine the potential value of participant recall when evaluating disability over discrete periods of time.

**Methods.** We studied 491 residents of greater New Haven, Connecticut, who were 76 years old or older. Participants completed a comprehensive assessment that included several new questions on disability in four essential activities of daily living (bathing, dressing, transferring, and walking). Participants were also assessed for disability in the same activities during monthly telephone interviews before and after the comprehensive assessment. Chronic disability was defined as a new disability that was present for at least three consecutive months.

**Results.** We found that up to half of the incident disability episodes, which would otherwise have been missed, can be ascertained if participants are asked to recall whether they have had disability “at any time” since the prior assessment; that these disability episodes, which are ascertained by participant recall, confer higher risk for the subsequent development of chronic disability, with an adjusted hazard ratio of 2.5 (95% confidence interval, 1.1–5.8); and that participant recall for the absence of disability becomes increasingly inaccurate as the duration of the assessment interval increases, with 2.2%, 6.0%, 6.9%, and 9.1% of participants having inaccurate recall at 1, 3, 6, and 12 months, respectively.

**Conclusions.** Our results demonstrate both the promise and limitations of participant recall and suggest that additional strategies are needed to more completely and accurately ascertain the occurrence of disability among older persons.

**Key Words:** Disability evaluation—Activities of daily living—Cohort studies.

In most longitudinal studies, the frame of reference for assessing disability in activities of daily living, such as bathing, dressing, and walking, is “at the present time,” and an incident episode of disability is noted when a nondisabled person reports disability at a subsequent follow-up interview (1). As shown in an earlier report (2), however, incident episodes of disability are often not ascertained by longitudinal studies with assessment intervals longer than 3–6 months. In an accompanying editorial (3), Guralnik and Ferrucci called for additional developmental work to help advance the field of disability assessment.

An alternative strategy for ascertaining incident episodes of disability is to ask participants to recall whether they have had disability “at any time” since the prior assessment. In the current study, we set out to determine the potential value of participant recall when evaluating disability over discrete periods of time. We used data from a unique longitudinal study that includes monthly assessments of disability in activities of daily living in a large cohort of older persons (2,4).

**METHODS**

**Study Population**

Participants were members of the Precipitating Events Project, an ongoing longitudinal study of 754 community-living persons, 70 years old or older, who were initially nondisabled in four essential activities of daily living—bathing, dressing, transferring, and walking (5). The assembly of the cohort has been described in detail elsewhere (5). Among the 1002 persons who were eligible, 75.2% agreed to participate. Participants have completed comprehensive assessments at 18-month intervals and have been interviewed monthly over the phone for the ascertainment of disability, with nearly 100% completion (6). The study protocol was approved by the 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 72 months, which included several new questions on disability (as described below). Of the 754 participants, 231 (30.6%) had died prior to the 72-month assessment and 27 (3.6%) had dropped out of the study after a median follow-up of 27 months. Of the remaining 496 participants, 3 (0.6%) refused to complete the assessment and 2 (0.4%) had incomplete information on disability, leaving 491 participants in the analytic sample. Compared with these participants, the 263 cohort members who were not included in the analytic sample were (at baseline) older (80.0 vs 77.5 years; \( p < .001 \)), had more chronic conditions (2.1 vs 1.6; \( p < .001 \)), had more physical frailty (1.1 vs 1.3; \( p < .001 \)), and were more likely to be physically frail (59.3% vs 40.7%; \( p < .001 \)). There were no significant baseline differences according to gender, race/ethnicity, living situation, education, or cognitive status.

**Data Collection**

The research nurses who completed the 72-month assessments were kept blinded to the results of the monthly assessments. As described previously (2,5), the comprehensive assessments and monthly interviews were completed with a designated proxy for participants who had marked cognitive impairment.
**Monthly Telephone Interviews**

During the monthly interviews, participants were assessed for disability using a set of standard questions that were identical to those used during the comprehensive assessments (2). The stem of each question was, “At the present time, do you need help from another person to (complete the task)?” Response options included “No,” “Yes,” and “Unable to do.” The specific wording for each of the four tasks was, “to bathe (wash and dry your whole body),” “to dress (like putting on a shirt or shoes, buttoning, and zipping),” “to get in and out of a chair,” and “to walk around your home or apartment,” respectively. Participants who needed help with (or were unable to do) 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, transferring, or walking (7–9). The reliability of our disability assessment was substantial (kappa = 0.75) for reassessments completed within 48 hours and excellent (kappa = 1.0) for reassessments performed the same day (2). The accuracy of proxy reports, as compared with reports from cognitively intact participants, was also found to be excellent, with kappa = 1.0 (2).

**72-Month Assessment**

During the 72-month assessment, data were collected on living situation, 10 self-reported, physician-diagnosed chronic conditions (5), cognitive status as assessed by the Folstein Mini-Mental State Exam (10), and physical frailty, as denoted by a timed score of >10 seconds on the rapid gait test (i.e., walk back and forth over a 10-foot course as quickly as possible) (7,8,11). Cognitive impairment was defined as a score of <24 on the Mini-Mental State Exam (10).

To address the specific aim of the current study, several new questions, which had not been included in the prior assessments, were added. For each of the four essential activities of daily living, participants who did not need help from another person “at the present time” were asked (as indicated) to recall whether they needed help from another person to (complete the relevant task) “at any time” during the last month, 3 months, 6 months, and 12 months, respectively. Participants were not asked these questions if they needed help “at the present time” because they would have needed help, by definition, “at any time” during each of the four time intervals. Participants who needed help during an earlier time interval were not asked about subsequent intervals for the same reason.

**Statistical Analysis**

To determine the potential value of participant recall when evaluating disability over discrete periods of time, we performed three sets of analyses. First, we evaluated how often incident episodes of disability, which are missed when disability is assessed “at the present time” (i.e., the usual strategy), can be ascertained if participants are asked to recall whether they have had disability “at any time” since the prior assessment (i.e., the alternative strategy), that is, during the last month, 3 months, 6 months, and 12 months, respectively. Second, we evaluated the prognostic significance of these incident disability episodes that are ascertained by participant recall, but not by the usual strategy. Third, we evaluated whether older persons can accurately recall the absence of disability over discrete periods of time. Figure 1 provides a schematic diagram for the three sets of analyses, which are described in detail below. All analyses were performed using SAS version 9.1.3 (SAS Institute, Cary, NC), and all tests of statistical significance were two-sided.

**Incidence of Disability**

Using data from the monthly interviews, we identified participants who were nondisabled at 1, 3, 6, and 12 months prior to the 72-month assessment, respectively. The corresponding time windows for these “zero-time” assessments of disability were operationalized as 27–33 (i.e., 30 ± 3), 86–96 (91 ± 5), 172–192 (182 ± 10), and 350–380 (365 ± 15) days prior to the 72-month assessment. For each of the four time intervals (i.e., 1, 3, 6, and 12 months), we determined the incidence of disability, as ascertained at the 72-month assessment, based first on disability “at the present time,” and second on recall of disability “at any time” since the zero-time assessment. To illustrate, for the 6-month interval, we identified 261 participants who were nondisabled during the monthly interview that was completed 172–192 days prior to the 72-month assessment. We then determined the number (%) of these participants who reported at the 72-month assessment that they had disability at the present time and (among the remainder) had disability at any time during the past 6 months. Participants who did not have a monthly interview during the relevant time window were excluded. Our results did not change appreciably after the participants who had proxy assessments at 72 months were omitted from the analysis. We considered using the responses from the monthly interviews to determine the validity of participant recall for disability at any time during the relevant time intervals, but our preliminary analyses revealed that the duration of many of the disability episodes was short relative to the duration of the intervals, indicating that the monthly interviews, which assessed disability at the present time, would make a poor gold standard.

**Prognostic Significance**

For this set of analyses, we focused on the 12-month time interval because it provided the largest number of participants, thereby enhancing power. Of the 373 participants who were nondisabled during the monthly interview that was completed 12 months prior to the 72-month assessment, 320 had no disability “at the present time” during the 72-month assessment, which served here as zero-time, the time at which prognostic estimations are made (12). Among these participants, who did not have incident disability according to the usual strategy, we compared the time to onset (in days) of chronic disability, defined as a new disability that was present for at least three consecutive months, using data from the monthly interviews (13), between those who reported (i.e., recalled) disability at any time during the past 12 months and those who did not. We chose chronic disability as the primary outcome because it is clinically...
meaningful (4) and often used to forecast the demand for long-term care services (14–16).

The primary analytic technique was survival analysis; participants were followed for an additional 18 months, that is, until the next comprehensive assessment at 90 months. The Kaplan–Meier method was used for the unadjusted analysis (17), whereas the Cox proportional hazards method was used for the multivariable analysis. As in a prior report (18), the covariates for the multivariable analysis included sex (female vs male), race/ethnicity (non-Hispanic white vs other), living situation (alone vs with others), cognitive impairment (yes vs no), and physical frailty (yes vs no), which were each analyzed as a dichotomous variable that was coded as 1 versus 0, and age, years of education, and number of chronic conditions, which were each analyzed as a continuous variable. These factors, most notably slow gait speed (i.e., physical frailty) and cognitive impairment, have been most strongly associated with the development of disability in prior studies (7,19–22).

Data on participants without chronic disability were censored at the time of death (n = 15) or the last completed interview prior to the end of the follow-up period. Data on disability were available for 99.9% of the 5509 monthly interviews subsequent to zero-time.

Absence of Disability

Participants were included in these analyses if they reported at the 72-month assessment that they had no disability at the present time and during the relevant time interval (i.e., last month, 3 months, 6 months, and 12 months). For each of the four time intervals, we determined the number (%) of participants who incorrectly recalled having no disability, using data from the monthly interviews as the “gold” standard. To illustrate, recall was considered inaccurate if the participant reported (during the 72-month assessment) no disability at any time during the last month, but had previously reported disability during the telephone interview that was completed within the last month. Telephone interviews completed within 30, 91, 182, and 365 days were considered for each of the four time intervals, respectively.

Among the 338 participants who were classified as not disabled at 72 months, only 16 (4.7%) of the comprehensive assessments were completed by a proxy, and only 96 (2.3%) of the monthly interviews in the year prior to the 72-month assessment were completed by a proxy. Our results did not change appreciably after the 16 participants who had proxy assessments at 72 months were omitted from the analysis.

RESULTS

The characteristics of the participants, at the time of the 72-month assessment, are shown in Table 1. The majority of participants were female, white, and did not live alone; and about half were physically frail. There was a wide range of ages, education, and scores on the Mini-Mental State Exam, although the majority of participants completed high school and were cognitively intact. The most common chronic conditions were hypertension and arthritis. Disability was reported “at the present time” by 153 (31.2%) of the participants.
Table 2. Incidence of Disability in Activities of Daily Living

<table>
<thead>
<tr>
<th>Interval Prior to 72-Month Assessment</th>
<th>Number of Participants Nondisabled at Start of Interval</th>
<th>Nondisabled at Present Time</th>
<th>Disability at Present Time</th>
<th>Disability at Any Time During Interval</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Month</td>
<td>89</td>
<td>6</td>
<td>6.7%</td>
<td>7.9%</td>
<td>7</td>
</tr>
<tr>
<td>3 Months</td>
<td>133</td>
<td>13</td>
<td>9.8%</td>
<td>12.9%</td>
<td>20</td>
</tr>
<tr>
<td>6 Months</td>
<td>261</td>
<td>36</td>
<td>13.8%</td>
<td>19.9%</td>
<td>52</td>
</tr>
<tr>
<td>12 Months</td>
<td>373</td>
<td>53</td>
<td>14.2%</td>
<td>27.1%</td>
<td>101</td>
</tr>
</tbody>
</table>

Notes: *As described in the text, the corresponding time windows for the zero-time assessments of disability were operationalized as 27–33, 86–96, 172–192, and 350–380 days prior to the 72-month assessment. Time windows are wider for longer intervals than for shorter intervals to accommodate likely reductions in precision when recalling more distant events.

1Participants were included only if they had a monthly interview during the corresponding time window. As the duration of the time window increased, the number of participants increased, reflecting the greater opportunity for interviews to have been completed within the wider time windows.

2The denominator for these rates included participants who were nondisabled at the start of the relevant interval.

3Participants were asked to recall the occurrence of disability during the relevant interval only if they were not disabled at the present time.

Figure 2. Kaplan–Meier curves for the development of chronic disability according to whether participants, who were nondisabled at the 72-month assessment, reported disability at any time during 12 months prior to the 72-month assessment. These reports were based on participant recall during the 72-month assessment, as described in the text. There were 272 participants with no disability and 48 participants with disability during the prior 12 months. The log-rank test was used for statistical comparisons.
prior 12 months was significantly associated with the development of chronic disability, with a hazard ratio of 2.5 (95% confidence interval, 1.1–5.8).

Table 3 provides the number (%) of participants who incorrectly recalled having no disability for each of the four time intervals prior to the 72-month assessment. As the duration of the interval increased, the percentage of participants with inaccurate recall increased in a graded manner, from 2.2% for 1 month to 9.4% for 12 months.

**DISCUSSION**

We have previously demonstrated that disability among older persons is a complex and highly dynamic process, characterized by frequent transitions between states of independence and disability (4,6,23,24). The inherent complexity of disability has historically not been well appreciated or understood, largely because prior longitudinal studies have almost invariably included long intervals, ranging from 6 months to 6 years, between disability assessments (7,25–34). The availability of monthly data has allowed us to evaluate questions about the assessment of disability that cannot be easily addressed by other epidemiologic studies (2,13,18,35).

The objective of the current study was to determine the potential value of participant recall when evaluating disability over discrete periods of time. We found that up to half of the incident disability episodes, which would otherwise have been missed, can be ascertained if participants are asked to recall whether they had disability ‘at any time’ since the prior assessment; that these disability episodes, which are ascertained only by participant recall, confer high risk for the subsequent development of chronic disability, even after accounting for potential confounders; and that participant recall for the absence of disability becomes increasingly inaccurate as the duration of the assessment interval increases. These results demonstrate both the promise and limitations of participant recall and suggest that additional strategies are needed to more completely and accurately ascertain the occurrence of disability among older persons.

In most longitudinal studies, the occurrence of a specific event, such as a myocardial infarction, is ascertained by asking participants to recall whether they have experienced the event since their last interview. For disease-specific events, these reports can often be confirmed through review of medical records. In contrast, an incident episode of disability is usually noted when a nondisabled person reports disability ‘at the present time’ during a subsequent follow-up assessment (1). When we asked nondisabled participants whether they had experienced disability at any time over four discrete intervals, we found that the percentage of participants with inaccurate recall was low for 1-month intervals (i.e., about 2%), but increased progressively over longer intervals, such that nearly 10% of nondisabled participants had inaccurate recall for the absence of disability over the course of 12 months, which is a common assessment interval for studies of disability. Even over the course of only 3 months, the percentage of participants with inaccurate recall was 6.0. These values are likely conservative for two reasons. First, because the study participants had been answering questions about disability every month for 6 years, they may have been more likely to recall prior episodes of disability. Second, because the ‘gold standard’ was based on disability at the present time, as ascertained during the monthly interviews, episodes of disability occurring between the monthly interviews may have been missed. For this reason, we could not formally evaluate whether older persons can accurately recall the presence of disability over discrete periods of time.

Nonetheless, we found that participants often recalled episodes of disability that would not have otherwise been ascertained by the usual strategy of asking about disability ‘at the present time.’ The ascertainment of disability by participant recall was substantial, representing about a third of the incident episodes at 3 and 6 months and nearly half at 12 months. These values are likely underestimates because participants who needed help during an earlier time interval were not asked about and, hence, were not included in the analyses of subsequent intervals. The current study provides strong evidence that ascertaining these incident episodes of disability is clinically important because they confer more than a 2-fold adjusted elevation in risk for the development of chronic disability, a major determinant for the use of long-term care services (14–16). Although an extended discussion is beyond the scope of the current article, there may be circumstances when assessing disability at the present time is indicated, e.g., when the goal is to establish temporal precedence between a time-varying exposure and the onset of disability (36).

The assessment of disability poses many challenges, including the reliance on self-reported information (37). Although we have previously demonstrated that our monthly assessments of disability are highly reliable and accurate (2), we did not formally evaluate the reliability of the questions that were added to our disability assessment at 72 months. We have previously reported, however, that the inter-rater reliability for our assessment of disability lasting at least
acknowledgments

The work for this report was funded by grants from the National Institute on Aging (R37AG17560, R01AG022993). Dr. Gill is the recipient of a Midcareer Investigator Award in Patient-Oriented Research (K24AG021507) from the National Institute on Aging.

The study was conducted at the Yale Claude D. Pepper Older Americans Independence Center (P30AG121342).

We thank Denise Shepard, BSN, MBA, Andrea Benjamin, BSN, Paula Clark, RN, Shirley Hannan, RN, Barbara Foster, Alice Van Wie, BSW, Patricia Fugal, BS, and Amy Shelton, MPH for assistance with data collection; Wanda Carr and Geraldine Hawthorne for assistance with data entry and management; Peter Charpentier, MPH for development of the participant tracking system; Linda Leo-Summers, MPH for assistance with Figure 1 and 2; and Joanne McGloin, MDiv, MBA for leadership and advice as the Project Director.

correspondence

Address correspondence to: Thomas M. Gill, MD, Yale University School of Medicine, Dorothy Adler Geriatric Assessment Center, 20 York Street, New Haven, CT 06504. E-mail: thomas.gill@yale.edu

References


Received July 5, 2007
Accepted August 29, 2007
Decision Editor: Luigi Ferrucci, MD, PhD