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## **EVALUATING DISABILITY OVER DISCRETE PERIODS OF TIME**

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## Abstract

**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 aged 76 years 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 high 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.

## INTRODUCTION

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 three to six months. In an accompaning 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 on a large cohort of older persons (2,4).

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## METHODS

#### Study population

Participants were members of the Precipitating Events Project, an ongoing longitudinal study of 754 community-living persons, aged 70 years 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 < 0.001), had more chronic conditions (2.1 vs. 1.6; P < 0.001), and were more likely to be physically frail (59.3% vs. 40.7%; P < 0.001). 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 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, ten 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 greater than 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 less than 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" since 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), i.e. 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.  $30 \pm 3$ ),  $86 - 96 (91 \pm 5)$ ,  $172 - 192 (182 \pm 10)$ , and 350 - 380 $(365 \pm 15)$  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 to 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 since 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, i.e. until the next comprehensive assessment at 90 months. The Kaplan-Meier method was used for the unadjusted analysis (17), while 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 vs. 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 5,509 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 shows the incidence of disability in activities of daily living for the four time intervals according to how disability was ascertained at the 72-month assessment. Of the 89 participants who were nondisabled 1 month (i.e. 27 to 33 days) prior to the 72-month assessment, 6 (6.7%) reported disability at the present time at the 72-month assessment, and 1 (who was nondisabled at the present time) reported disability at any time during the month preceding the 72-month assessment. As expected, the incidence of disability at the present time increased as the duration

of the interval preceding the 72-month assessment increased, from 6.7% for 1 month to 14.2% for 12 months. Similarly, the incidence of disability based on recall, i.e. "at any time during interval", increased progressively as the duration of the interval preceding the 72-month assessment increased, from 1.1% for 1 month to 12.9% for 12 months, so that nearly half (48/101 or 47.5%) of the participants with incident disability for the 12-month interval were ascertained by "at any time during interval".

Figure 2 provides Kaplan-Meier curves for the development of chronic disability according to whether participants, who were nondisabled at the 72-month assessment, reported (i.e. recalled) disability at any time during the 12 months prior to the 72-month assessment. Higher rates of chronic disability were observed for participants who reported disability at any time during the prior 12 months than for those who did not. In the fully adjusted Cox proportional hazards model, reporting disability at any time during the 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 six months to six 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 have 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 known disability episodes were

not recalled 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 six 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 since 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 since 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 manuscript, 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). While 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 90 days, which used a similar set of procedures, was high (13). In the current study, our results did not change appreciably after participants who had proxy assessments of disability were omitted.

Our assessment of disability did not include eating, toileting or grooming. While these omissions could lead to an underestimate of disability severity, they would have had relatively little effect on our ascertainment of disability. Our participants included nondecedents who completed the comprehensive assessment at 72 months. While the use of a "residual" cohort could affect the generalizability of our findings, it is unlikely to threaten their validity. Generalizability is enhanced by low attrition for reasons other than death and the completeness of follow-up for disability, as assessed during the monthly interviews (38).

Our results raise important questions about the assessment of disability, which for most older persons is a reversible event, more similar to falls and delirium than to progressive disorders such as Alzheimer's disease. In their editorial, Guralnik and Ferrucci suggested that an assessment interval of six months may be sufficient (3). Based on our results, the ascertainment of disability would be more complete if older persons were asked to recall whether they had disability at any time since the last assessment. Given the complexity and recurrent nature of disability, additional developmental work is greatly needed to more accurately ascertain the onset and duration of disability among older persons.

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#### Figure 1.

Schematic diagram for the three sets of analyses. Participants completed a comprehensive assessment at 72 months, which included several new questions on disability in four essential activities of daily living, and were assessed for disability in the same activities during monthly interviews both before and after the comprehensive assessment. For each set of analyses, the arrows denote the direction of follow-up.



#### 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 the 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.

#### Table 1

## Characteristics of Participants at 72 Months

Characteristic*	N=491
Age, years	
Median	83
Range	77 – 103
Female	325 (66.2)
Non-Hispanic white	439 (88.4)
Lives alone	192 (39.1)
Education <sup><math>\dot{T}</math></sup> , years	
Median	12
Range	0 - 17
Chronic conditions <sup><math>\ddagger</math></sup>	
Hypertension	319 (65.0)
Arthritis	255 (51.9)
Cancer	112 (22.8)
Diabetes mellitus	96 (19.6)
Chronic lung disease	96 (19.6)
Myocardial infarction	89 (18.3)
Stroke	61 (12.4)
Fractures other than hip since age 50	57 (11.6)
Congestive heart failure	42 (8.6)
Hip fracture	40 (8.2)
Mini-Mental State Exam Score	
Median	26
Range	0 – 30
Physical frailty <sup>§</sup>	227 (46.5)
Disability at present time	153 (31.2)

\* Data are presented as No. (%) unless otherwise indicated.

 $^{\dagger}$ 17 years denotes postgraduate education.

 $\ddagger$  Presented in descending order according to prevalence.

<sup>§</sup>As defined in the Methods.

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Table 2

Incidence of Disability in Activities of Daily Living

	Number of			at 72-month	it of disability assessment <sup>‡</sup>		
Interval prior to 72-month assessment*	participants nondisabled at start of interval <sup>†</sup>	At pr ti	esent ne	At ar during	ay time interval <sup>§</sup>	T	otal
		No.	%	No.	%	No.	%
1 month	89	6	6.7	-	1.1	L	6.7
3 months	133	13	9.8	7	5.3	20	15.0
6 months	261	36	13.8	16	6.1	52	19.9
12 months	373	53	14.2	48	12.9	101	27.1

 $\dot{\tau}$ greater opportunity for interviews to have been completed within the wider time windows.

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

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

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#### Table 3

Number and Percentage of Participants with Inaccurate Recall for the Absence of Disability Over Discrete Periods of Time\*

Interval prior to 72-month assessment	Number of participants with no disability at 72 months and during preceding interval	Number of participants with inaccurate recall	Percentage of participants with inaccurate recall
1 month	318	7	2.2
3 months	317	19	6.0
6 months	303	21	6.9
12 months	286	27	9.4

As determined during the 72-month assessment. The monthly telephone interviews served as the "gold standard", as described in the text.