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FACTORS ASSOCIATED WITH ACCURATE RECALL OF PRIOR DISABILITY AMONG OLDER PERSONS

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Abstract

Objective—To identify the factors associated with accurate recall of prior disability.

Design, Setting and Participants—Using two analytic samples, we evaluated 92 participants from an ongoing cohort study who were nondisabled “at the present time” in four essential activities of daily living (bathing, dressing, transferring and walking), but who had at least one month of disability during the prior year as determined from monthly telephone interviews.

Measurements—Participants who did not need help from another person “at the present time” were asked to recall whether they had needed help from another person to complete the relevant activity of daily living “at any time” during the last 12 months.

Results—Forty-five (48.9%) and 46 (50.0%) of the 92 participants accurately recalled having had disability in the prior year in the first and second analytic samples, respectively. Having at least a high school education was the only factor independently associated with accurate recall in the first analytic sample, with an adjusted odds ratio of 3.03 (95% confidence interval, 1.11–8.31), while a composite disability scale, which considered both the timing and severity of prior disability, was the only factor independently associated with accurate recall in the second analytic sample, with an adjusted odds ratio of 5.38 (1.81–16.1).

Conclusions—The results of the current study, coupled with those of previous studies, suggest potential strategies that could be used to more completely and accurately ascertain the occurrence of disability among older persons.

Keywords

aged; cohort studies; risk factors; disability evaluation; activities of daily living

INTRODUCTION

Disability in activities of daily living, such as bathing, dressing and walking, is a key outcome in many studies of older persons. Nonetheless, a standard strategy for ascertaining the occurrence of disability does not currently exist. In most longitudinal studies, an incident episode of disability is noted when a nondisabled person reports disability “at the present time” during a subsequent follow-up assessment (1). Prior research has shown, however, that incident episodes of disability are often not ascertained by longitudinal studies with assessment intervals longer than six months (2). More recently, we have shown that up to half of the incident disability episodes, which would otherwise have been missed by asking only about disability “at the present time”, can be ascertained if nondisabled persons are also asked to recall whether

they have had disability “at any time” since the prior assessment (3). Importantly, these additional episodes of disability, which are ascertained by participant recall, confer high risk for the subsequent development of chronic disability, a major determinant for the use of long-term care services (3).

Despite this potential advance in the assessment of disability, a large proportion of older persons do not recall episodes of disability that occurred during the prior year (3). The objective of the current study was to identify the factors that are associated with accurate recall of prior disability. We hypothesized that intact cognition and the timing/severity of the prior disability would be the factors most strongly associated with accurate recall.

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 (ADLs)—bathing, dressing, transferring, and walking (4). The assembly of the cohort, including baseline characteristics, have been described in detail elsewhere (4,5). 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.

Potential participants for the current study included cohort members who completed the comprehensive assessment at 72 or 90 months, each of which included new questions on recall of prior disability (as described below). Of the 754 cohort members, 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 members, 3 (0.6%) refused to complete the assessment and 2 (0.4%) had incomplete information on disability, leaving 491 potential participants at 72 months. At 90 months, the number of decedents and dropouts were 286 and 27, respectively. Of the remaining 441 members, 2 (0.5%) refused to complete the assessment, leaving 439 potential participants at 90 months.

Data collection

The research nurses who completed the comprehensive assessments were kept blinded to the results of the monthly assessments. Information on age, sex, race and education was collected during the baseline comprehensive assessment.

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 ADLs is uncommon in the absence of disability in bathing, dressing, transferring, or walking (7–9). The reliability of our monthly disability assessment was substantial (Kappa=0.75) for reassessments completed within 48 hours; and there was complete agreement for reassessments performed the same day (10). The accuracy of self-reported disability among participants with

mild cognitive impairment, defined as a score of 20 to 23 on the Folstein Mini-Mental State Exam (MMSE) (11) and a score of one or two on short-term memory testing, was high, i.e. Kappa = 1.0 (2).

72- and 90-month comprehensive assessments—During the 72- and 90-month assessments, data were collected on nine self-reported, physician-diagnosed chronic conditions (hypertension, myocardial infarction, congestive heart failure, stroke, diabetes mellitus, arthritis, hip fracture, chronic lung disease, and cancer) and cognitive status, as assessed by the Folstein Mini-Mental State Exam (MMSE) (11). Participants were considered to be cognitively intact if they scored 28 or higher on the MMSE and recalled all three items on short-term memory testing (12–15).

To address the specific aim of the current study, four new questions, which had not been included in the prior assessments, were added. For each of the four essential ADLs, participants who did not need help from another person “at the present time” were asked (as indicated) to recall whether they had needed help from another person to complete the relevant task “at any time” during the last 12 months. 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 the last 12 months.

Assembly of Analytic Samples

Potential participants were included if they were nondisabled at the 72-month or 90-month assessment, respectively, but had at least one month of disability during the year prior to the relevant comprehensive assessment, as determined during the monthly telephone interviews. Participants who completed the comprehensive assessment with a proxy informant were excluded since our objective was not to assess proxy recall of prior disability. The primary reason for the use of a proxy informant was the presence of significant cognitive impairment, defined either as recall of zero of three items on short-term memory testing or as score less than 20 on the MMSE and recall of one or two of three items on short-term memory testing (2).

Of the 338 potential participants who were nondisabled at 72 months, 58 had at least one month of disability during the prior year; and, of these, 52 did not require a proxy informant. Of the 292 potential participants who were nondisabled at 90 months, 59 had at least one month of disability during the prior year; and, of these, 48 did not require a proxy informant, including 8 who were also eligible at 72 months. Because the samples at 72 and 90 months were too small to analyze separately, we combined them into a single group to enhance power. To make full use of our data, we created two analytic samples. For the eight participants who were eligible at both 72 and 90 months, data were used from the 72-month assessment for the first analytic sample and the 90-month assessment for the second analytic sample.

Statistical analysis

Analyses were run separately for each of the two analytic samples. We first determined the number (%) of participants who accurately recalled having any disability in the prior year, using data from the monthly interviews as the reference standard. We then evaluated potential predictors for accurate recall, including participant- and disability-specific factors, which were dichotomized to enhance clinical interpretability. The participant-specific factors, ascertained from the relevant comprehensive assessment, included younger age, defined as 80 years or younger, male sex, white race, higher education, defined as 12 years or more, and intact cognitive status, as previously defined. The disability-specific factors, ascertained from the monthly interviews, included having had disability recently, defined as within three months of the comprehensive assessment; and, in the year prior to the comprehensive assessment, having

had at least one episode of severe disability, at least one episode of persistent disability, and more than one episode of disability (i.e. recurrent), respectively. To be considered severe, disability had to be present in three or more of the ADLs for at least one month (16,17). To be considered persistent, disability had to be present for at least two consecutive months (2). To be considered recurrent, two or more episodes of disability had to be separated by at least one month without disability (10).

As a final disability-specific factor, we created a composite scale that considered both the timing and severity of disability during the prior year, with higher scores on the scale denoting disability that occurred more proximate to the comprehensive assessment and/or was more severe. A total score was obtained by summing the monthly scores over the 12-month period, with each monthly score calculated as [number of ADLs disabled * (13 – months prior to comprehensive assessment)]. To illustrate, disability in a single ADL occurring 12 months prior to the comprehensive assessment yielded a monthly score = 1 [i.e. 1 * (13 – 12)], disability in two ADLs occurring 5 months prior to the comprehensive assessment yielded a monthly score = 16 [i.e. 2 * (13 – 5)], while no disability in a specific month yielded a monthly score = 0. Given the absence of a standard cut-point, the total score was dichotomized as highest quartile versus the other three quartiles.

Logistic regression analysis was used to evaluate the bivariate and multivariable associations between the potential predictors and accurate recall of prior disability. Factors that were associated with accurate recall in the bivariate analysis at $P < .20$ were considered for the multivariable analysis, which included an indicator variable denoting whether the factors were ascertained during the 72- or 90-month comprehensive assessment. When two factors were highly correlated, i.e. Kendall's tau-b correlation $> .40$, the factor that was most strongly associated with accurate recall was included in the multivariable analysis. Factors were entered into the model using forward selection.

All analyses were performed using SAS version 9.2 (SAS Institute, Cary, NC). All significance tests were two-sided, with $P < .05$ denoting statistical significance.

RESULTS

Forty-five (48.9%) and 46 (50.0%) of the 92 participants accurately recalled having had disability in the prior year in the first and second analytic samples, respectively. Table 1 provides information about the potential predictors and the bivariate associations with accurate recall of prior disability for the two analytic samples. Participants were predominantly White. The majority had at least a high school education and two chronic conditions. About a quarter to a third were 80 years or younger, male, and cognitively intact. Exposure for the disability-specific factors ranged from 19.6% for at least one episode of severe disability in the year prior to the comprehensive assessment to 40.2% for disability within three months of the comprehensive assessment.

For each of the two analytic samples, education and the composite disability scale were significantly associated with accurate recall of prior disability in the bivariate analysis (Table 1). Cognition was strongly associated with accurate recall in both analytic samples, but this association was statistically significant only for the first sample, with an unadjusted odds ratio of 2.96. For the other disability-specific factors, strong associations were observed in both analytic samples for at least one episode of severe disability and at least one episode of persistent disability, but these associations achieved statistical significance only for persistent disability in the second analytic sample, with an unadjusted odds ratio of 3.99. Neither recent disability nor more than one episode of disability was associated with accurate recall of prior disability. The bivariate results did not change substantively when alternative cut-points were

used for age, education, and chronic conditions or when these factors were analyzed as continuous variables.

The results of the multivariable analysis are provided in Table 2. Education was the only factor independently associated with accurate recall in the first analytic sample, with an adjusted odds ratio of 3.03, while the composite disability scale was the only factor independently associated with accurate recall in the second analytic sample, with an adjusted odds ratio of 5.38.

DISCUSSION

In epidemiologic studies and clinical trials, asking nondisabled older persons to recall whether they had disability at any time since their last assessment has the potential to greatly enhance the ascertainment of disability (3). In the current study of community-living older persons, we found that about half of the nondisabled participants accurately recalled having had disability in the prior year; and the factors most strongly associated with accurate recall were education and a composite disability scale, which considered both the timing and severity of the prior disability. Although our results must be interpreted carefully in light of the limitations discussed below, they provide important new insights into the ascertainment of disability and, together with the findings from earlier studies, suggest ways in which disability might be better ascertained.

The availability of monthly data on disability provided us with a unique opportunity to evaluate potential predictors of accurate recall. Our sample size, however, was relatively small, even after data were combined from two different time intervals. The small sample size reduced our power to detect statistically significant differences in risk that are likely clinically meaningful and likely led to the modest differences in p-values between the two analytic samples. We had hypothesized, for example, that intact cognition would be a strong predictor of accurate recall. In the bivariate analysis, the odds ratio for intact cognition was greater than 2 in both analytic samples, but was statistically significant only in the first. Furthermore, despite an adjusted odds ratio as high as 2.41, intact cognition did not achieve statistical significance in the multivariable analysis. Strong associations that failed to consistently achieve statistical significance were also observed in the bivariate analysis for having had at least one episode of severe disability and at least one episode of persistent disability, respectively.

We had hypothesized that the timing/severity of the prior disability would be one of the factors, in addition to cognition, that was most strongly associated with accurate recall. To test this hypothesis, we created a composite scale that accounted for both the timing and severity of the prior disability. Participants with scores in the upper quartile on this scale were considerably more likely to recall episodes of disability that occurred during the prior year than those with scores in the other three quartiles. Because the unadjusted odds ratios were much larger for the composite disability scale than for either recent disability or severe disability, particularly in the second analytic sample, accurate recall appears to depend on both the timing and severity of the prior disability.

Our finding that education was strongly associated with accurate recall was unexpected. In the setting of multiple comparisons, it is possible that this finding was spurious, but this possibility is diminished by the consistency of the results across the two analytic samples. Although education could be a proxy for cognitive status, the effect of education was not attenuated in the multivariable analysis, which included intact cognition as a covariate. Another possibility is that prior episodes of disability may be less notable to poorly educated older persons than to those with higher levels of education and, hence, are less likely to be recalled. In support of this supposition, Sarkisian and colleagues have shown that expectations regarding aging are considerably lower in older persons with low levels of education (18). Hence, these individuals

may be more likely than those with higher levels of education to accept disability as a normal part of aging.

In addition to concerns about power, several other limitations warrant comment. First, we reran our analysis for a second analytic sample that differed from the first only on the basis of eight participants. The results from these two samples, therefore, are not entirely independent. Nonetheless, this analytic strategy makes full use of the data available and provides useful information about the stability of our results for two somewhat different groups of participants. Second, the reference standard, by which accurate recall was judged, was based on disability at the present time, as ascertained during the monthly interviews. Although the reliability of our monthly disability assessment was substantial, it was not perfect. The ascertainment of disability, by its very nature, relies on self-reported information (19), suggesting that a true gold standard may not exist. Third, because episodes of disability occurring between the monthly interviews would have been missed by our reference standard, we could not evaluate risk factors for inaccurate recall of disability, which some might consider the more clinically relevant outcome. Finally, we evaluated recall of disability over the prior year. Hence, our results may not apply to recall of disability over shorter periods of time.

Despite these limitations, the availability of monthly data on disability has allowed us to address an important question that cannot be easily evaluated by other epidemiologic studies. To enhance the ascertainment of disability in future studies, we might suggest the following strategy based on the results of the current and previous studies (3,5,20). If a participant is not disabled at the present time, ask whether s/he has had disability at any time since the prior assessment. If no, probe further using a standard protocol, focusing on major illnesses or injuries that have occurred since the prior assessment. We have previously demonstrated, for example, that most episodes of disability, especially in persons who are not physically frail, are precipitated by an intervening event that leads to either hospitalization (most commonly) or restricted activity (5,20). Special attention may be warranted for participants with low levels of education and perhaps those who are not cognitively intact. Another way to possibly enhance the ascertainment of disability would be to adapt a calendar approach, which has been used successfully to ascertain falls (21). Participants might be instructed, for example, to complete an ADL calendar monthly (or weekly), by marking a “D” (for disabled) under a specific ADL if they needed help from another person or were unable to perform the task during the prior month (or week) and an “I” (for independent) if they performed the task without personal assistance.

To advance the field of disability assessment, additional developmental work is needed (22). The results of the current study, coupled with those of previous studies, suggest potential strategies that could be developed and subsequently validated to more completely and accurately ascertain the occurrence of disability among older persons.

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Study concept and design: Gill, Van Ness.

Acquisition of data: Gill.

Analysis and interpretation of data: Gill, Van Ness, Gahbauer.

Drafting of the manuscript: Gill, Van Ness.

Critical revision of the manuscript for important intellectual content: Gill, Van Ness, Gahbauer.

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Table 1

Bivariate Associations with Accurate Recall of Prior Disability (N=92)^{*}

Potential Predictors [†]	n (%) [‡]	Odds Ratio	First Analytic Sample 95% CI	P-value	Odds Ratio	Second Analytic Sample 95% CI	P-value
Participant-specific factors							
Age ≤ 80 years	23 (25.0)	1.19	0.46–3.06	.72	1.62	0.61–4.28	.33
Male	33 (35.9)	1.18	0.50–2.76	.71	1.10	0.47–2.58	.83
White	87 (94.6)	4.09	0.44–38.1	.22	4.29	0.46–39.9	.20
Education ≥ 12 years	65 (70.7)	3.14	1.20–8.20	.02	2.64	1.03–6.76	.04
Chronic conditions ≥ 2	69 (75.0)	1.70	0.65–4.44	.28	1.80	0.69–4.71	.23
Cognitively intact	25 (27.2)	2.96	1.12–7.81	.03	2.19	0.85–5.66	.11
Disability-specific factors							
Recent disability [§]	37 (40.2)	1.41	0.61–3.26	.42	1.58	0.68–3.65	.29
In year prior to comprehensive assessment							
At least 1 episode of severe disability	18 (19.6)	2.49	0.84–7.33	.10	2.89	0.93–9.03	.07
At least 1 episode of persistent disability	29 (31.5)	2.18	0.89–5.37	.09	3.99	1.53–10.4	.01
More than 1 episode of disability	29 (31.5)	1.18	0.49–2.84	.71	1.23	0.50–2.99	.65
Composite disability score in upper quartile	27 (29.4)	2.82	1.10–7.21	.03	5.60	1.99–15.8	.001

^{*} For the eight participants who were eligible at both 72 and 90 months, data were used from the 72-month assessment for the first analytic sample and the 90-month assessment for the second analytic sample.

[†] The participant-specific factors were ascertained at the time of the follow-up assessment (i.e. 72 or 90 months), while the disability-specific factors were ascertained from the monthly interviews as described in the Methods.

[‡] Values are the same for the two analytic samples with three exceptions: for the second analytic sample, values are 22 (23.9) for age ≤ 80 years, 17 (18.5) for at least 1 episode of severe disability, and 28 (30.4) for more than 1 episode of disability.

[§] Within 3 months of comprehensive assessment.

^{||} The mean (std) values were 18.7 (18.3) and 18.9 (18.5) for the first and second analytic samples, respectively.

CI: confidence interval.

Table 2

Multivariable Associations with Accurate Recall of Prior Disability (N=92)^{*}

Factors [†]	First Analytic Sample			Second Analytic Sample		
	Odds Ratio	95% CI	P-value	Odds Ratio	95% CI	P-value
Education ≥ 12 years	3.03	1.11–8.31	.03	2.56	0.93–7.03	.07
Cognitively intact	2.41	0.84–6.93	.10	1.89	0.64–5.55	.25
Composite disability score in upper quartile	2.46	0.89–6.81	.08	5.38	1.81–16.1	.003

^{*} For the eight participants who were eligible at both 72 and 90 months, data were used from the 72-month assessment for the first Analytic Sample and the 90-month assessment for the second Analytic Sample. An indicator variable was included in each model to denote whether the factors were ascertained during the 72- or 90-month assessment.

[†] Because of high correlations with the composite disability scale, severe disability and persistent disability were not included in the multivariable models.

CI: confidence interval.