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The Burden and Patterns of Disability in Activities of Daily Living Among Community-living Older Persons

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Background. The onset of disability in activities of daily living (ADLs) is considered a sentinel event in the life of an older person, but recent evidence suggests that newly disabled elders have high rates of recovery. We performed a longitudinal study to determine the burden and patterns of ADL disability among previously nondisabled, community-living older persons.

Methods. We studied 754 community-living persons, aged 70 years or older, who were categorized into three groups according to their risk for disability (low, intermediate, high). Participants were interviewed each month for 2 years to determine the presence and severity of disability in four key ADLs: bathing, dressing, walking, or transferring.

Results. Among the 690 nondecedents, the rates of any disability were 17.7%, 48.7%, and 65.2%, respectively, for the low-, intermediate-, and high-risk groups. Whereas only 6.9% of nondecedents in the low-risk group had more than 1 month of disability, 38.2% and 50.6% of nondecedents in the intermediate- and high-risk groups (i.e., physically frail), respectively, had multiple months and/or episodes of disability. The patterns of disability were quite diverse, with no single pattern representing the disability experience of more than half the decedents or nondecedents in any of the risk groups.

Conclusions. Disability among community-living older persons, particularly those who are physically frail, is a highly dynamic process with considerable diversity. Our results provide strong evidence to support an emerging paradigm of disability as a reversible, and often recurrent, event.

THE onset of disability in activities of daily living (ADLs) is considered a sentinel event in the life of an older person. ADL disability is associated with increased mortality (1) and often leads to additional adverse outcomes (2–4). Our current understanding of the disabling process is based largely on the results of longitudinal studies that have had long intervals between assessments of ADL function, ranging from 6 months to 6 years (2,5–14). In a recently completed study that included monthly assessments of ADL function (15), Gill and colleagues demonstrated that the occurrence of disability is substantially underestimated by longitudinal studies with long assessment intervals. The primary source of this underestimation was the high rate of recovery among newly disabled older persons. These results suggested that disability for many older persons is a reversible event, more similar to falls and delirium than to progressive disorders such as Alzheimer's disease.

Given the apparent dynamic nature of disability, further investigation is warranted to better characterize the epidemiology of disability among older persons (16). In the current study, we set out to determine the burden and patterns of ADL disability among previously nondisabled, community-living older persons over a 2-year period. We used data from a prospective cohort study, with nearly complete ascertainment of functional status each month, to characterize ADL disability along five major axes: quantity, duration and number of episodes, severity, and patterns.

Methods

Study Population

Participants were members of the Precipitating Events Project, a longitudinal study of 754 community-living persons, aged 70 years or older, who were nondisabled (i.e., required no personal assistance) in four key ADLs—bathing, dressing, walking inside the house, and transferring from a chair. The assembly of the cohort, which took place between March 1998 and October 1999, has been described previously in detail (17). Participants were enrolled in a 4:2:1 ratio for low, intermediate, and high risk for ADL disability, using a model developed and validated in an earlier study (18). Participants in the intermediate- and high-risk groups were physically frail based on objective testing of gait speed (8,17,19).

The participation rate was 75.2%. Persons who refused to participate did not differ significantly from those who were enrolled in terms of age or sex.

Data Collection

Baseline data were collected on demographic characteristics, cognitive status (20), and 13 self-reported, physician-diagnosed chronic conditions (17). Complete details regarding the follow-up assessments, including formal tests of reliability and accuracy, have previously been provided (15). During monthly telephone interviews, participants were assessed for ADL disability using standard questions that

were identical to those used during the screening telephone interview. For each of the four key ADLs, we asked, ''At the present time, do you need help from another person to (complete the task)?'' Participants who needed help with a specific task were considered to be disabled in that ADL. Participants were not asked about eating, toileting, or grooming. The incidence of disability in these three ADLs is low among nondisabled, community-living older persons (8,21). Furthermore, it is highly uncommon for disability to develop in these ADLs without concurrent disability in bathing, dressing, walking, or transferring (8,21,22).

Over the 2-year follow-up period, data on ADL disability were available for 97.5% of the 17,401 scheduled monthly telephone interviews. Deaths were ascertained by review of the local obituaries and/or from an informant during a subsequent telephone interview.

Statistical Analysis

ADL disability was characterized along five major axes: quantity, number and duration of episodes, severity, and patterns. The two indicators of quantity were the number of participants with at least 1 month of ADL disability during the follow-up period and the mean number of months disabled. Duration was measured as the number of consecutive months of ADL disability per disability episode. An episode of disability had to be preceded and followed by a month with no disability except in the case of death and at the end of the 2-year follow-up period. The two indicators of severity were the mean number of ADL tasks disabled during months with disability and the number of participants with at least 1 month of severe disability, defined as the need for personal assistance in three or more ADLs (23), during the follow-up period. For patterns, participants were categorized into one of seven distinct disability groups based on the quantity of disability, number and duration of disability episodes, and severity of disability. In addition, Kaplan-Meier survival curves (24) were used to examine temporal patterns for any ADL disability and for three alternative disability outcomes that have been included in prior epidemiologic studies: persistent disability, defined as a new disability that was present for at least two consecutive months (15); chronic disability, defined as a new disability that was present for at least three consecutive months (25); and severe disability, as previously defined.

For the small number of months (2.5%) during which data on ADL disability were unavailable, we imputed values using a nonparametric model (26). Months with missing ADL data were matched to nonmissing months using the following variables: decedent status, risk group, sex, mean number of months disabled, 6-month interval within the follow-up period, and ADL function in the adjacent months. When there was no match, these variables were dropped in reverse order. Imputed values were provided from samples drawn with replacement from the available donor observations. Single imputation was justified because the amount of missing data was small (i.e., less than 5% of observations) (27). Our results did not change substantively when the analyses were repeated using multiple imputation with three random draws per missing observation.

Because disability data for decedents were not available for the entire 2-year follow-up period, all results are reported separately for decedents and nondecedents, with the exception of the survival curves. To account for the stratified sampling strategy, all results were further categorized by risk group. Spearman rank correlations were used to estimate trends across risk groups. For pair-wise comparisons, the chi-square test of homogeneity was used for dichotomous variables, and the Wilcoxon rank sum test was used for continuous variables. The log-rank test was used for comparisons of the survival curves. All analyses were performed using SAS version 8.2 (Cary, NC) (28) and R version 1.4.1 (R Foundation, Vienna, Austria) (29).

Results

Of the 754 study participants, 64 (8.5%) died within the 2-year follow-up period. The baseline characteristics of the nondecedents and decedents are provided in Table 1.

Information on the burden of ADL disability for the nondecedents is provided in the second panel of Table 2. The low-risk group had the lowest burden of disability for each of the indicators except mean monthly severity, which did not differ by risk group. Compared with nondecedents in the intermediate-risk group, those in the high-risk group were more likely to develop both disability ($p = .009$) and severe disability ($p = .05$), but once disabled their burden of disability was similar. Both the number and duration of disability episodes suggest that the disability experiences of the nondecedents, particularly those in the intermediate- and high-risk groups, were highly fluid and diverse.

Table 1. Baseline Characteristics of Nondecedents and Decedents According to Risk for ADL Disability

	Nondecedents			Decedents		
Characteristic	Low Risk ($n = 402$)	Intermediate Risk ($n = 199$)	High Risk ($n = 89$)	Low Risk ($n = 30$)	Intermediate Risk ($n = 15$)	High Risk ($n = 19$)
Age (y), mean	76.8 ± 4.6	78.2 ± 3.8	84.6 ± 5.3	78.9 ± 5.2	77.5 ± 4.2	85.9 ± 5.0
Female, n (%)	245 (61.0)	149 (74.9)	62 (69.7)	15 (50.0)	6 (40.0)	10 (52.6)
White, n (%)	370 (92.0)	174 (87.4)	77 (86.5)	29 (96.7)	15 (100.0)	17 (89.5)
Education (y), mean	12.5 ± 2.7	11.6 ± 2.8	10.4 ± 2.9	12.5 ± 3.2	12.4 ± 2.7	11.1 ± 3.2
Lives alone, n (%)	137 (34.1)	94 (47.2)	44 (49.4)	11 (36.7)	6 (40.0)	6 (31.6)
Chronic conditions, mean	1.6 ± 1.2	2.2 ± 1.3	2.0 ± 1.4	2.0 ± 0.9	3.1 ± 1.7	2.1 ± 1.3
MMSE score, mean	27.1 ± 2.3	27.3 ± 1.7	24.2 ± 2.9	27.1 ± 2.7	27.3 ± 2.0	24.3 ± 3.2

Notes: All mean values are expressed ± standard deviation. ADL = Activities of Daily Living; MMSE = Mini-Mental State Examination.

Table 2. Burden of ADL Disability over 24 Months for Nondecedents and Decedents According to Risk for Disability

Indicator of Burden[†]	Nondecedents				Decedents[*]			
	Low Risk (n = 402)	Intermediate Risk (n = 199)	High Risk (n = 89)	p Value[‡]	Low Risk (n = 30)	Intermediate Risk (n = 15)	High Risk (n = 19)	p Value[‡]
All participants								
At least 1 month of disability, n (%)	71 (17.7)	97 (48.7)	58 (65.2)	< .001	19 (63.3)	10 (66.7)	15 (78.9)	.28
At least 1 month of severe disability, n (%)	20 (5.0)	34 (17.1)	24 (27.0)	< .001	13 (43.3)	9 (60.0)	13 (68.4)	.08
Months disabled, mean	0.6 (2.2)	3.5 (5.9)	4.5 (6.2)	< .001	1.8 (2.7)	2.9 (3.7)	3.4 (3.6)	.06
Participants with at least 1 month of disability								
Months disabled, mean	3.1 (4.5)	7.1 (6.8)	6.9 (6.5)	< .001	2.9 (2.9)	4.4 (3.8)	4.3 (3.5)	.09
Disability episodes, mean	1.6 (1.1)	2.3 (1.4)	2.2 (1.5)	.001	1.5 (0.8)	1.5 (0.7)	1.5 (0.5)	.57
Duration of disability episodes in months, mean	2.3 (4.3)	3.4 (4.1)	3.4 (4.1)	< .001	2.0 (1.8)	3.0 (1.9)	3.2 (3.4)	.08
Monthly severity of disability, mean	1.7 (1.0)	1.5 (0.7)	1.6 (0.8)	.34	2.4 (1.2)	2.6 (0.9)	2.6 (1.0)	.51

Note: ADL = Activities of Daily Living.

[*]The median lengths of follow-up were 16, 11, and 12 months for the low-, intermediate-, and high-risk groups, respectively.

[†]Standard deviations are included within parentheses for all mean values.

[‡]Test for trend across the low-, intermediate-, and high-risk groups, using Spearman rank correlation.

Nondecedents in the intermediate risk group, for example, had an average of 2.3 disability episodes lasting an average of 3.4 months, with moderate-to-large standard deviations for both estimates. Among the 226 nondecedents with at least 1 month of disability, 22.6% had two episodes of disability and 28.3% had three or more episodes. Of the 465 disability episodes, moreover, 56.6% lasted only 1 month, while 16.3%, 7.3%, and 19.8% lasted 2, 3, or 4 or more months, respectively. The results in the second panel of Table 3 further illustrate the fluidity and diversity of disability experiences among the nondecedents as well as the greater burden of disability in the intermediate- and high-risk groups relative to the low-risk group. Whereas only 6.9% of nondecedents in the low-risk group had more than 1 month of disability, 38.2% and 50.6% of nondecedents in the intermediate- and high-risk groups, respectively, had multiple months and/or episodes of disability, and 9.6% and 14.6% were disabled in at least half of the months.

Information on the burden and patterns of ADL disability for the decedents is provided in the third panels of Tables 2 and 3, respectively. The differences in burden across the three risk groups were less pronounced for the decedents than for the nondecedents. Furthermore, none of the differences among the decedents achieved statistical significance, in part because of small numbers. In each risk group, the majority of decedents had at least 1 month of disability, and a substantial proportion had at least 1 month of severe disability. In logistic regression analyses, after adjusting for risk group, decedents were more likely than nondecedents to have developed any disability ($p < .001$) and severe disability ($p < .001$). While the mean monthly severity of disability did not differ by risk group, it was greater among the decedents than the nondecedents ($p < .001$). In the month prior to death, 43%, 67%, and 68% of decedents in the low-, intermediate-, and high-risk groups were disabled, respectively, and 30%, 53%, and 58% had severe disability.

Figure 1 provides the survival curves for the four disability outcomes. For each outcome, the proportion of participants without disability over the 2-year follow-up period differed significantly by risk group. While unusual among participants in the low-risk group, persistent, chronic,

Table 3. Patterns of ADL Disability over 24 Months for Nondecedents and Decedents According to Risk for Disability[*]

Patterns	Nondecedents[†]			Decedents[‡]		
	Low Risk (n = 402)	Intermediate Risk (n = 199)	High Risk (n = 89)	Low Risk (n = 30)	Intermediate Risk (n = 15)	High Risk (n = 19)
No disability, %	82.3	51.3	34.8	36.7	33.3	21.1
Single month of disability						
Involving only 1 ADL, %	6.7	8.5	11.2	10.0	.0	5.3
Involving 2 or more ADLs, %	4.0	2.0	3.4	16.7	6.7	10.5
Single episode of disability of at least 2 months, %	1.7	7.0	14.6	16.7	33.3	26.3
Two or more single months of disability, %	2.0	7.5	3.4	6.7	6.7	5.3
Other pattern, disability in less than half the months, %	3.2	14.1	18.0	10.0	13.3	26.3
Other pattern, disability in at least half the months, %	.0	9.6	14.6	3.3	6.7	5.3

Note: ADL = Activities of Daily Living.

[*]The percentages in each column may not add up to 100 because of rounding.

[†]The p values for the chi-square test of independence were <.001 for the comparisons between the low- and intermediate-risk groups and the low- and high-risk groups and .06 for the comparison between the intermediate- and high-risk groups.

[‡]The median lengths of follow-up were 16, 11, and 12 months for the low-, intermediate-, and high-risk groups, respectively. Statistical testing between risk groups was not performed for the decedents because of the small cell sizes.

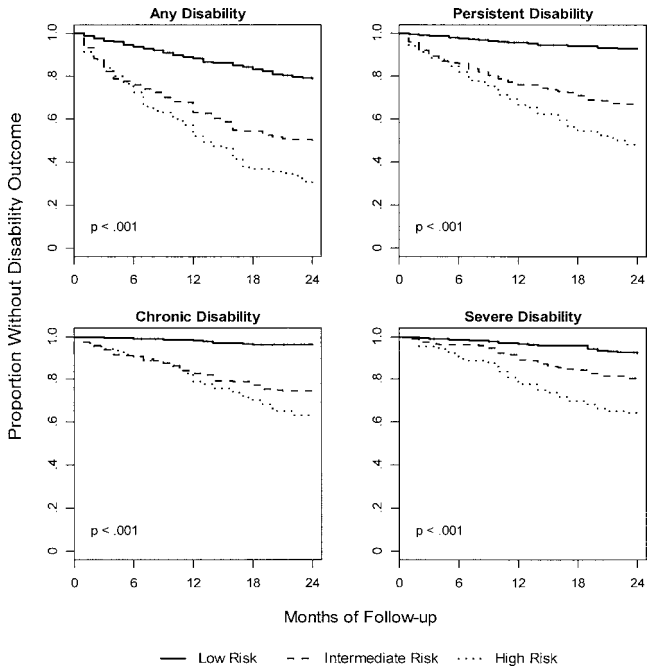

Figure 1. Proportion of participants without disability for each of four disability outcomes over the 2-year follow-up period using the Kaplan-Meier estimation method. Differences among survival curves for the three risk groups were established by the log-rank test.

and severe disability were all observed commonly among participants in the intermediate- and high-risk groups.

Discussion

In this prospective cohort study, we found that disability among community-living older persons, particularly those who are physically frail (i.e., at intermediate or high risk for disability), is a highly dynamic process with considerable diversity. Our results provide strong evidence to support an emerging paradigm of disability as a reversible, and often recurrent, event.

Because our study included monthly assessments of ADL function, we were able to characterize the burden and patterns of disability with great precision. Over a 2-year follow-up period, we found high rates of disability, even among participants in the low-risk group. These rates, not surprisingly, were substantially higher among decedents than nondecedents. Among the nondecedents, disability in the low-risk group usually lasted only 1 month and was unlikely to recur. The burden of disability was considerably greater among the nondecedents in the intermediate- and high-risk groups, who often experienced multiple months and/or episodes of disability. We also found that the patterns of disability were quite diverse, with no single pattern representing the disability experience of more than half the decedents or nondecedents in any of the risk groups.

Evidence supporting the dynamic nature of disability has emerged during the past decade with the availability of multiple waves of data from longitudinal studies such as the Established Populations for Epidemiologic Studies of the Elderly, which included annual assessments for up to 9 years (30), the Longitudinal Study on Aging, which included four biennial assessments (31,32), and the National Long-Term Care Survey, which included five assessments from 1982 to 1999 (33). Our study provides important new information about the disabling process by demonstrating that transitions into and out of disability are common over the course of only 2 years. Many of these transitions would likely go undetected by traditional surveys with long assessment intervals. To illustrate this point, we have provided the disability experiences of four nondecedents from the intermediate-risk group in Table 4. None of these participants was disabled at 12, 18, or 24 months, the lengths of most assessment intervals in previous longitudinal studies of disability (2,7–14). Hence, despite multiple months and episodes of disability over the course of 2 years, each of these persons would be considered nondisabled in most traditional surveys. The clinical relevance of prior episodes of disability is not known but will be the focus of a subsequent analysis.

From a public health perspective, an important implication of our study is that newly disabled older persons are likely to recover independent ADL function at rates far exceeding those that have been previously reported. Recovery rates of only 20% to 30% are based on longitudinal studies with assessment intervals of 1 to 2 years (1,2,34,35). Because functional status was assessed at such widely spaced intervals, these studies underestimated not only the occurrence of disability (15) but also the likelihood of recovery.

A great strength of our study was the high follow-up rate, with successful completion of 97.5% of the monthly telephone interviews. The availability of data from monthly assessments allowed us to evaluate a diverse array of disability outcomes, including disability that persisted beyond 1 month. With few exceptions (1,15,25), previous community-based studies have not attempted to distinguish short-term disability from persistent or chronic disability

Table 4. Disability Experiences Over 24 Months of Four Nondecedents in the Intermediate-Risk Group

Age	Sex	Pattern of Disability*	Number of Months Disabled	Number of Disability Episodes
83	Female	021000001110001000000000	6	3
80	Male	010111101000000000100000	7	4
80	Female	110000100000022010000010	7	5
84	Female	003000000020000040122210	8	4

Note: ADLs = Activities of Daily Living.
*The string of numbers represents the number of ADLs disabled in each of the 24 months, starting with Month 1 and ending with Month 24.

(36). These distinctions are likely to be important for several reasons. First, the etiology of short-term disability may differ from that of persistent or chronic disability (16). Second, the costs of care, both monetary and nonmonetary, depend greatly on the duration of disability. Third, short-term disability may confer a lower risk of subsequent morbidity and mortality than persistent or chronic disability. Finally, the likelihood of recovery may diminish as the duration of disability increases. While beyond the scope of the current study, additional research is needed to identify the factors, besides risk group, that predict the onset, progression, and recovery from short- and long-term disability.

We found that decedents were more likely than nondecedents to have developed any disability and severe disability, regardless of risk group. Nonetheless, death was not invariably preceded by disability. In fact, the majority of decedents in the low-risk group and about one third of those in the intermediate- and high-risk groups were not disabled in the month prior to death. In contrast, Guralnik and colleagues found that most decedents aged 75 years or older were disabled in the year prior to death (37). Because the number of decedents was small, our results should be considered preliminary. In future studies, as the number of decedents increase, we plan to more completely evaluate the trajectory of disability prior to death.

We recognize potential limits to the validity of our findings. First, although our disability assessment had excellent reliability, it is possible that some of the disability transitions represented measurement error rather than a true change in functional status. Second, while the omission of eating, toileting, and grooming from the monthly assessments likely had little effect on the quantity and patterns of disability or on the number and duration of disability episodes, it may have led us to underestimate the severity of disability. Third, by truncating episodes of disability that persisted beyond the end of the follow-up period, we underestimated the duration of disability among the nondecedents. These underestimates would likely be greater for the intermediate- and high-risk groups, which had rates of disability at 24 months of 15.1% and 23.6%, respectively, than for the low-risk group, which had a rate of disability at 24 months of only 2.2%.

In summary, our results provide strong evidence that disability among community-living older persons, particularly those who are physically frail, is a highly dynamic process with considerable diversity. While providing hope to older persons and to their families and providers that disability is often reversible, these results present great challenges to investigators who are striving to elucidate the causal pathways of disability, and to policy makers who are charged with planning for the health care needs of an aging society.

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