

## Transitions between States of Disability and Independence among Older Persons

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The objectives of this prospective cohort study, conducted in New Haven, Connecticut, from 1998 to 2004, were to describe disability states experienced by older persons, to evaluate the rate of transitions between states and the duration of disability episodes, and to determine whether these findings differ on the basis of physical frailty—a condition of low physical capacity and vulnerability to adverse functional outcomes. Participants included 754 persons aged 70 years or older who were initially independent in four key activities of daily living: bathing, dressing, walking, or transferring. Disability was assessed during monthly telephone interviews for a median of 60 months, and participants were classified each month according to the following four states: no disability, mild disability (one or two activities), severe disability (three or four activities), and death. Transitions between states of disability and independence were common, with a majority of both frail and nonfrail participants experiencing at least one transition. The rate of transitions varied greatly among individuals. Nonfrail participants had lower rates of transition from less to more disability, higher rates of transition from more to less disability, and slightly shorter durations of disability. To fully understand the disabling process, investigators and clinicians must consider the episodic and recurrent nature of disability.

activities of daily living; aged; aged, 80 and over; prospective studies; recovery of function

Abbreviation: ADL, activity of daily living.

Disability in activities of daily living (ADLs) is common among community-dwelling older persons and is associated with adverse health outcomes and high health-care costs (1, 2). As the population ages, disability is becoming an increasingly important public health problem. Recent evidence has demonstrated that disability is a dynamic process with multiple recurrent episodes (3–8). While the likelihood of recovery from a single episode of disability is very high, older persons who have recovered independent function are at high risk of recurrent disability (3, 9). The disabling process can be conceptualized as a series of transitions between states of disability and independence. While prior studies of disability have evaluated multiple transitions over time (6, 7, 10–14), relatively little is known about the frequency and patterns of these transitions for individual persons. In addition, because prior studies have largely used assessment intervals of 12 months or longer, they have likely missed clinically meaningful transitions

between disability states (9, 15). Our recent finding that the duration of recovery of independent function is highly dependent on the duration of the preceding disability episode (16) highlights the need to determine the effect of a prior history of disability on future disability and to allow for the possibility of multiple disability episodes in models of the disabling process.

In this study, we describe a multistate representation of ADLs disability with four states: no disability, mild disability, severe disability, and death. We used data from a unique cohort of community-dwelling older persons who have had monthly assessments of ADLs function for a median of 60 months. Our objectives were to determine 1) the number of transitions among these four states per year, the number of disability episodes per year, and the proportion of time spent in each nondecendent state; 2) the rate of each type of transition and the duration of each type of disability episode; and 3) whether these findings differ on the basis of physical frailty.

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## MATERIALS AND METHODS

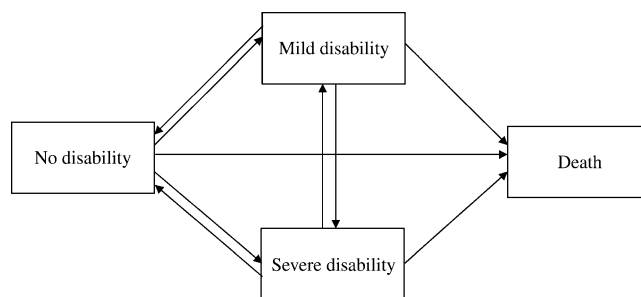
### Study population

The study population was drawn from members of an ongoing longitudinal study of 754 community-dwelling persons, aged 70 years or older, who were initially nondisabled in four key ADLs—bathing, dressing, walking inside the house, and transferring from a chair. The assembly of the cohort has been described in detail elsewhere (17). Potential participants were members of a large health plan in greater New Haven, Connecticut, and were excluded if they had a life expectancy of less than 12 months, planned to move out of the New Haven area, or were unable to speak English. Participants with significant cognitive impairment were excluded only if they had no available proxy (15). Persons who were physically frail were oversampled to ensure a sufficient number of participants at increased risk for disability (18, 19). Only 4.6 percent of the members contacted refused to complete the screening telephone interview, and 75.2 percent of the 1,002 eligible members agreed to participate in the study. The study protocol was approved by the Yale Human Investigation Committee, and all participants gave informed consent.

### Data collection

**Physical frailty assessment.** Physical frailty, hereafter referred to simply as frailty, is a clinical condition characterized by reduced physiologic capacity leading to increased vulnerability to adverse functional outcomes (20). Impaired mobility, represented by slow gait speed, is one of the most commonly reported components of the frailty syndrome (21). In the absence of a “gold standard,” operationalizing frailty as slow gait speed is justified by its high face validity (22), ease of objective measurement in both research and clinical settings (23, 24), and strong epidemiologic link to key consequences of frailty such as functional decline (19, 25, 26). We defined frail participants as those with a timed score of greater than 10 seconds (19) on the rapid gait test (i.e., walking back and forth over a 10-foot (3.048-m) course as quickly as possible). Evaluations of timed gait have been shown to be reliable with interrater reliability greater than 0.90 and 2-week test-retest reliability of 0.84 (by intraclass correlation coefficients) (26). Timed gait was evaluated during comprehensive in-home assessments performed by trained research nurses at baseline and every 18 months.

**Disability assessment.** During monthly telephone interviews, participants were assessed for disability in the four ADLs tasks. Interviewers used standard questions (19, 27) that have been described in detail elsewhere (15). Participants who needed help with or were unable to complete a task were considered disabled in that ADL. Participants were not asked about eating, toileting, or grooming because disability in these three ADLs is uncommon among community-dwelling older persons (18, 19, 28), particularly without concurrent disability in bathing, dressing, walking, or transferring (28, 29). The reliability of our disability



**FIGURE 1.** A multistate representation of disability. Boxes represent the four states, and arrows represent the possible transitions between states.

assessment was substantial (30) ( $\kappa = 0.75$ ) for reassessments within 48 hours and excellent ( $\kappa = 1.0$ ) for reassessments performed the same day. Although we did not formally evaluate the validity of our disability assessment, prior studies comparing self-reported function with directly observed function in these ADLs have demonstrated the high validity of self-report (31, 32). A designated proxy (17) completed the interviews for participants who had significant cognitive impairment, as defined elsewhere (15). The accuracy of proxy reports, compared with reports of cognitively intact participants, was found to be excellent, with  $\kappa = 1.0$  (15).

Follow-up interviews were included through February 2004, for a maximum follow-up of 71 months. A total of 182 participants (24 percent) died after a median follow-up of 35 months, and 31 (4.0 percent) dropped out of the study after a median follow-up of 22 months. Eight percent (3,305 of 40,327) of the monthly telephone interviews were completed by proxy.

### Multistate representation of disability

Our multistate representation of disability (figure 1) includes four states defined a priori: 1) no disability, able to perform all four ADLs without personal assistance; 2) mild disability (i.e., in one or two ADLs); 3) severe disability (i.e., in three or four ADLs) (33); and 4) death. Transitions occurred in both directions among the no-disability, mild-disability, and severe-disability states and in one direction from each of these three states to death. An episode of disability was defined as a period of consecutive months of reported disability that was preceded by independence and followed by recovery of independence, death, or completion of follow-up. For example, a non-disabled participant who experienced 2 months of severe disability and a month of mild disability and then recovered independence would have had three transitions and one episode of disability. Episodes of disability were classified as mild if the participant experienced only mild disability during the episode, as severe if the participant experienced only severe disability, or as mixed if the participant experienced both mild and severe disability.

## Statistical analysis

All analyses are stratified by physical frailty. Because of the complexity of the disabling process, we have chosen to evaluate other potential determinants of functional transitions in subsequent analyses and will not consider them further here.

**Disability transitions and episodes per year and the percentage of overall time in each state.** For each participant, we calculated the number of transitions per year, the number of episodes of disability per year, and the percentage of time spent in each state. The Wilcoxon rank-sum test was used to compare the nonfrail and frail groups. In these analyses, the assignment of frailty was based on each participant's baseline assessment.

**Rates of transitions and duration of episodes.** We calculated standardized rates of each transition exiting a state per 1,000 person-months in that state. We stratified each participant's time by 18-month study periods (to correspond with the frailty assessments) and then calculated the rates and variances for each stratum for frail and nonfrail participants using the sample variance formula proposed by Stukel et al. (34), which produces an unbiased estimate of the variance conditional on the known individual follow-up times. Using the total study population as the standard, we calculated standardized summary rates and variances for the nonfrail and frail groups with the method described by Glynn et al. (35) using the negative binomial distribution to account for departures from the assumption of randomness of recurrent events required by the Poisson distribution. Box and whisker plots (36) were used to depict the distributions of duration for disability episodes, classified by type of disability and the way in which the episode ended. Because participants could experience multiple episodes of disability and because frailty status could change over time, we used bootstrapping with sampling by individual to calculate a probability distribution for the differences in episode durations between nonfrail and frail participants. In these analyses, frailty status was updated every 18 months for each participant on the basis of the results of the comprehensive assessments.

**Handling of missing data for ADLs disability.** Data were available for 99.1 percent of the 40,697 monthly telephone interviews (excluding interviews after dropout); 146 participants (19 percent) had a total of 213 gaps in which their monthly ADLs data were missing. The distribution of missing data did not differ by frailty status. For 162 (76 percent) of these gaps, the disability state reported in the month preceding the gap was the same as that in the month following the gap; of these gaps, 151 were 1–2 months in duration, nine were 3–7 months, and two were longer. The two participants with the longest gaps were censored at the beginning of their first gap. We assumed that the remainder of these participants stayed in the same state throughout the gap and imputed the missing data accordingly. The disability state changed over the course of the remaining 51 gaps, representing 42 participants. For the 50 gaps of 1–3 months, we assumed that the participant made a single transition in the middle of the gap. The remaining participant was censored at the beginning of a 5-month gap. Our method is a variation on the “last and next” imputation method

recommended by Engels and Diehr (37) for longitudinal data, modified to account for our noncontinuous measure of disability. There were no substantial differences between transition rates calculated using this straightforward imputation strategy and rates calculated using two alternative strategies for handling the missing data: 1) excluding the 146 participants with missing data and 2) censoring participants ( $n = 12$ ) after any gap of 3 or more months and using the previously described imputation methods for gaps of 1–2 months. Because of the small amount of intermittent missing data (<1 percent), more complex strategies such as multiple imputation were not warranted (38).

All analyses were performed using SAS version 8.02 (39) software. All  $p$  values are two tailed.

## RESULTS

Overall, participants had a mean age of 78.4 (standard deviation: 5.3) years; 64 percent were women, and 90 percent were White. As expected, participants who were frail were older and had less education, more chronic conditions, and worse cognition than participants who were nonfrail (table 1). In addition, participants who were frail were more likely than those who were nonfrail to be female, non-White, and living alone. The median durations of follow-up were 57 and 63.5 months for the frail and nonfrail participants, respectively.

### Disability transitions and episodes per year and the percentage of overall time in each state

Of the participants, 268 (36 percent) remained independent and alive through the completion of follow-up, and therefore they made no transitions during a median follow-up of 64 months (figure 2). Nonfrail participants were more likely than frail participants to remain independent (47 vs. 20 percent,  $p < 0.001$ ). Among those with at least one transition between states, the median number of transitions was three (range: 1–25) for the nonfrail participants and six (range: 1–30) for the frail participants ( $p < 0.001$ ). Nonfrail participants spent more time with no disability and less time in disabled states than did frail participants (figure 3). Nonetheless, among both nonfrail and frail participants, the majority of time was spent in the nondisabled state.

### Rates of transitions and duration of episodes

In most cases, the absolute number of transitions was lower for the nonfrail participants (table 2). Compared with participants who were frail, those who were nonfrail had significantly lower rates of transitions to states of increased disability (i.e., no disability to mild disability, no disability to severe disability, and mild disability to severe disability) and higher rates of transitions from disability (either mild or severe) to no disability. Rates of transition to death among nonfrail and frail participants were comparable for participants who were nondisabled but were over two times as high for the nonfrail among participants with mild or severe disability, although this latter finding was statistically significant only among those with severe disability.

**TABLE 1. Baseline characteristics of participants by frailty, New Haven, Connecticut, 1998–2004\***

Characteristic	Nonfrail (n = 432)	Frail (n = 322)	p value†
Age (years) (mean (SD‡))	76.9 (4.7)	80.4 (5.4)	<0.001
Female (no. (%))	260 (60)	227 (70)	0.003
White (no. (%))	399 (92)	283 (88)	0.04
Education (years) (mean (SD))	12.5 (2.8)	11.3 (2.9)	<0.001
Living alone (no. (%))	148 (34)	150 (47)	<0.001
Chronic conditions§ (no.) (mean (SD))	1.5 (1.1)	2.0 (1.2)	<0.001
MMSE‡ score¶ (mean (SD))	27.1 (2.3)	26.3 (2.6)	<0.001

\* Participants were classified as frail if they had a timed score of greater than 10 seconds on the rapid gait test (i.e., walking back and forth over a 10-foot (3.048-m) course as quickly as possible).

† p value for the comparison of the nonfrail and frail participants, using chi-squared tests for categorical variables and the Wilcoxon rank-sum test for continuous variables.

‡ SD, standard deviation; MMSE, Folstein's Mini-Mental State Examination.

§ Nine self-reported, physician-diagnosed chronic conditions, namely, hypertension, myocardial infarction, congestive heart failure, stroke, diabetes, arthritis, hip fracture, lung disease, and cancer (other than minor skin cancers).

¶ Scores range from 0 to 30, with higher scores representing better cognitive status.

For the most common type of disability episode (mild disability ending in recovery), nonfrail participants had significantly shorter durations (figure 4), although the difference was clinically small and due primarily to a small number of long episodes (as reflected by the identical median and intraquartile ranges for the two groups). There were no significant differences in the durations of the mild episodes ending in death or completion of follow-up between nonfrail and frail participants.

Severe disability episodes ending in recovery were very short, lasting only 1 month, for more than 75 percent of episodes for both nonfrail and frail participants. Although the difference in episode duration between nonfrail and frail participants was statistically significant, it was clinically small. Severe disability episodes ending in death lasted significantly longer for the frail participants compared with the nonfrail participants.

The 186 participants experienced 244 episodes of mixed disability. The patterns of disability within these episodes varied widely for both the nonfrail and frail participants. However, the three most common patterns in both groups, accounting for 43 percent of all patterns, were severe to mild to no disability (30 percent of episodes among nonfrail and 21 percent among frail participants), mild to severe to death (17 and 9 percent), and mild to severe to mild to no disability (11 and 10 percent). Mixed disability episodes were, by definition, at least 2 months in duration (with at least 1 month each of mild and severe disability). The durations of mixed disability episodes did not differ significantly between nonfrail and frail participants.

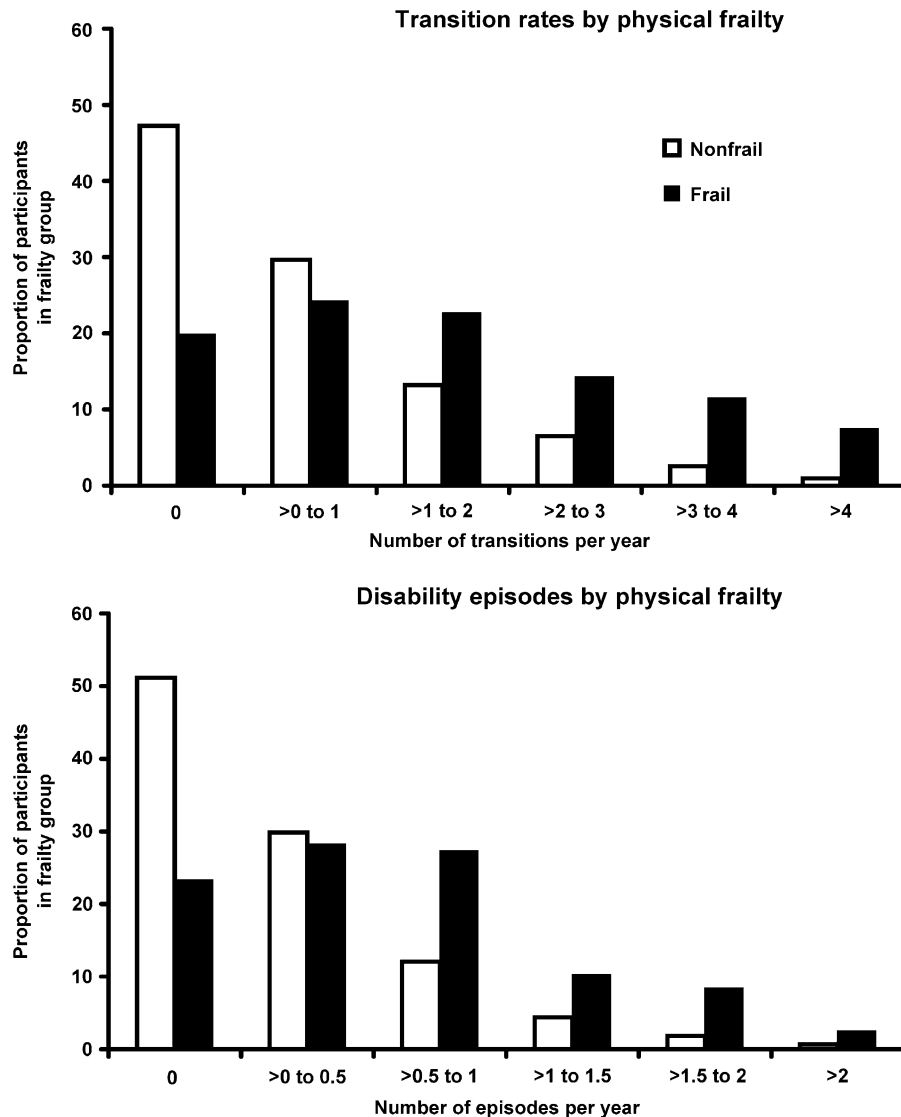
## DISCUSSION

In this study, we have described transitions among states of disability in a cohort of 754 older persons followed

monthly for nearly 6 years. Almost half of nonfrail participants and 20 percent of frail participants remained independent throughout the follow-up period and, therefore, made no transitions. Among participants with at least one transition, the median numbers of transitions were three and six for the nonfrail and frail participants, respectively. The range in number of transitions was very large, suggesting substantial variation among individuals for risk of disability transitions, even within subgroups classified by frailty. While both nonfrail and frail participants spent the majority of time in the nondisabled state, frail participants had more disability episodes and spent more time in disabled states.

These findings confirm the dynamic nature of the disabling process as suggested in prior studies (3–8). Because of the availability of monthly data for almost 6 years, we were able to demonstrate that brief (i.e., 1–2 months) disability episodes represent the majority of episodes among both nonfrail and frail older persons. These brief episodes would often be missed by studies using assessment intervals of 6 months or longer (15). Prior evidence indicates that these brief disability episodes are clinically important, in that they herald the development of subsequent disability and death (9).

The individual patterns of disability were highly variable, with some participants experiencing no disability, some experiencing prolonged or permanent disability, some experiencing a single discrete episode of disability, and some experiencing recurrent episodes of disability. Within individual episodes, we identified many different patterns of disability severity. Some participants, for example, had an abrupt onset of severe disability following a fracture. Others progressed gradually from independence to mild disability to severe disability without a clear causal event (40). These two patterns are consistent with the description of catastrophic versus progressive disability provided by Ferrucci

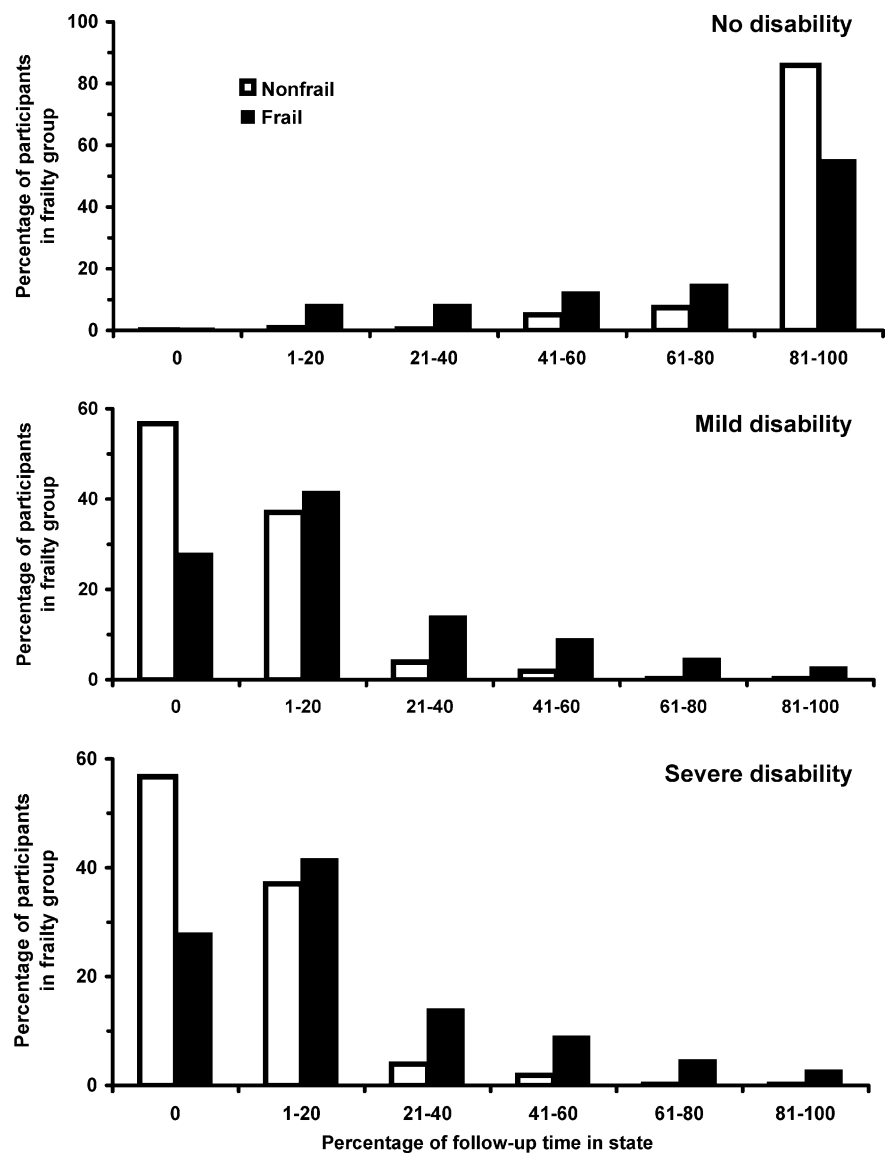


**FIGURE 2.** Distributions of disability transition and episode rates by frailty, New Haven, Connecticut, 1998–2004.  $p < 0.001$  for comparisons of nonfrail and frail groups.

et al. (33). This spectrum of patterns likely reflects the underlying complexity of the disabling process. Disability, like other geriatric syndromes, is thought to result from the interaction of predisposing factors and precipitating events (41–44). Our previous research has demonstrated that the type of precipitating event (acute illness requiring hospitalization vs. nonhospital events) and the initial severity of the resulting disability are important predictors of the time to recovery, while predisposing factors associated with disability risk are strongly associated with the duration of recovery (16). Adding to this complexity, the predisposing factors and precipitating events are most likely interrelated, such that a change in one predisposing factor may alter other predisposing factors or the risk for potential precipitating events. For example, a fall without resulting injury could

cause fear of falling, resulting in decreased social and physical activity, which might in turn lead to decreased strength and increased risk of disability, depression, or subsequent falls. The detailed description of individuals' patterns of disability provided in this study can serve as a basis for further investigation of the interplay among these predisposing factors and precipitating events.

Frail participants, relative to those who were nonfrail, had much higher rates of transitions from nondisabled to disabled states and somewhat lower rates of transitions to states representing improved functional status. This finding provides support for the postulate of Campbell and Buchner (45) that a key consequence of frailty is unstable disability, in which persons experience substantial fluctuations in function in the setting of minor external events. Although



**FIGURE 3.** The percentage of time spent in each nondecedent state by baseline frailty, New Haven, Connecticut, 1998–2004.  $p < 0.001$  for all comparisons of nonfrail and frail groups.

disability transition rates among all participants differed by frailty, transition rates also varied considerably within each of the nonfrail and frail groups, respectively. In subsequent analyses, we plan to evaluate other potential determinants of risk for disability transitions, such as self-efficacy, age, and cognitive impairment (among others), and to determine the effect of prior disability history on the rate of future disability transitions.

Participants who were frail had lower rates of transitions from disabled states to death than did those who were nonfrail. These findings suggest that the mechanism of death may differ on the basis of frailty, potentially through differences in the events that precipitate disability. For example, nonfrail persons might require a major insult, such as a severe

stroke, to precipitate disability. In contrast, frail persons may develop disability in response to the progression of a chronic disease such as arthritis. Consistent with our findings, those of Covinsky et al. (46) revealed that, on average, frail older persons experience a slowly progressive decline in functional status with only slight acceleration in decline as death approaches. On an individual level, however, we identified substantial variation in trajectories to death even among frail participants, ranging from death without reporting disability in the previous month to death after several years of continuous disability. Lunney et al. (47) have described the existence of four basic functional trajectories at the end of life: sudden death without preceding functional decline, terminal illness with a rapid period of functional decline

TABLE 2. Number and rates of transitions by frailty, New Haven, Connecticut, 1998–2004\*

Transition	Nonfrail†			Frail‡			p value§
	No.	Rate of transition per 1,000 person-months	95% confidence interval	No.	Rate of transition per 1,000 person-months	95% confidence interval	
No disability to							
Mild disability	306	13.6	11.3, 16.4	720	58.4	50.8, 67.2	<0.001
Severe disability	58	2.6	1.7, 4.0	146	11.8	9.1, 15.3	<0.001
Death	24	1.1	0.5, 2.2	22	1.8	0.8, 3.9	0.36
Mild disability to							
No disability	273	385	340, 435	661	194	174, 216	<0.001
Severe disability	34	47.0	31.8, 69.3	266	78.1	67.5, 90.3	0.02
Death	10	13.7	5.5, 34.2	23	6.8	3.5, 13.1	0.22
Severe disability to							
No disability	23	192	110, 333	54	40.0	26.3, 60.9	<0.001
Mild disability	37	275	183, 412	253	183	156, 215	0.07
Death	26	124	83, 185	75	54.1	39.3, 74.4	0.002

\* Frailty status was updated every 18 months during the comprehensive assessments.

† Nonfrail participants contributed 23,221 person-months to the study: 22,323 in no disability, 720 in mild disability, and 178 in severe disability.

‡ Frail participants contributed 17,312 person-months to the study: 12,491 in no disability, 3,412 in mild disability, and 1,409 in severe disability.

§ p values for the comparison of rates between nonfrail and frail participants, accounting for recurrent transitions and adjusting for time in the study.

prior to death, organ failure with fluctuating function, and frailty with a steady overall decline with minor fluctuations. We observed all of these patterns within both our frail and nonfrail groups.

The duration of disability episodes tended to be longer among frail participants compared with nonfrail participants, although these differences were less pronounced than those observed in transition rates. These findings indicate that the greater time spent in disabled states by frail versus nonfrail participants is due primarily to an increased frequency of disability episodes and only secondarily to longer durations of each episode. In epidemiologic terms, the higher prevalence of disability among frail persons results primarily from an increased incidence rather than an increased duration of disability.

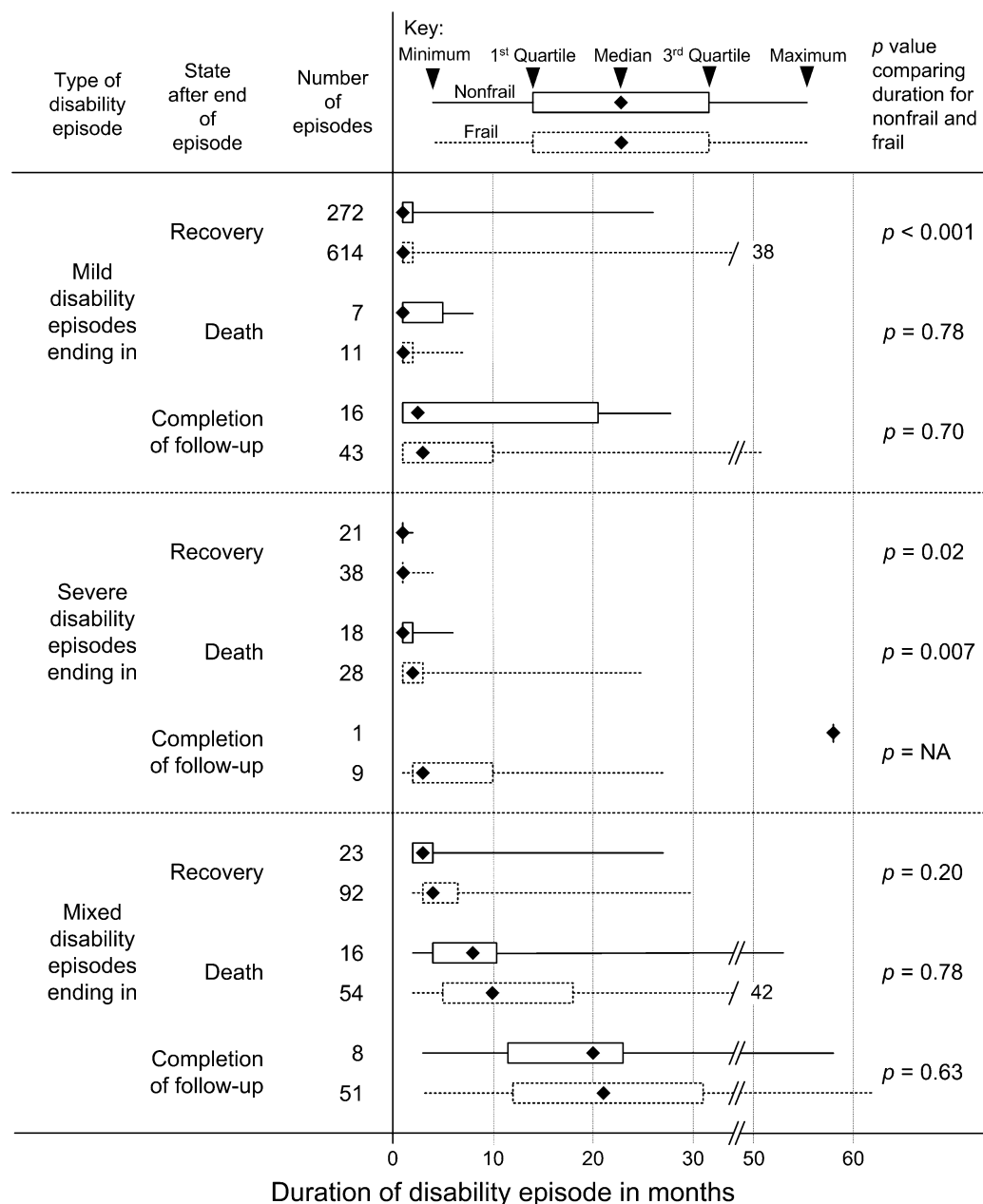
While previous longitudinal studies of older persons have tended to show an increase in disability over time (6, 48), our results indicate that many older persons experience recurrent, relatively brief episodes of disability followed by a return of independence. In planning for the care needs of disabled older persons, progressive decline in function and increase in need for assistance are not inevitable. From a policy perspective, flexible systems are warranted that can provide the additional services older persons need during episodes of disability. Furthermore, among older persons with a history of disability, interventions are needed to decrease the frequency and duration of future disability episodes.

The episodic nature of disability also has important implications for how epidemiologists think about active life expectancy, usually defined as the expected duration of functional well-being (27). Although current methods for calculating active life expectancy incorporate transitions into

and out of states of disability (49, 50), the usual metrics include the expected durations of disability-free, disabled, and total life, without consideration of how the disability is distributed. Different patterns of disability (e.g., six 1-month episodes of disability distributed over 2 years vs. 18 months of independence followed by 6 months of disability) may have very different implications for health-care utilization, caregiver burden, and other important outcomes, such as quality of life.

The internal validity of our study is enhanced by the high participation and follow-up rates. In addition, the rates of measurement error are likely low, as we used disability and frailty measures demonstrated to be valid and reliable. When the cohort was assembled, only currently nondisabled participants were included. Because disability is more common among frail persons, the prior disability history likely differed by frailty group and may be a potential confounding factor in these analyses. In addition, since frail participants spend more time in the disabled state, they might be more likely to be misclassified as nondisabled on enrollment. Our long follow-up and frequent assessments likely minimize the effects of any initial measurement error, particularly in the setting of multiple transitions. We did not adjust our analyses for age or other factors that differed between the frail and nonfrail participants, and our study does not address the causal relations among age, frailty, and disability. While both frailty and older age are associated with disability, it is likely that physiologic changes with aging contribute to the development of frailty, which then increases the risk of disability.

Several other aspects of these analyses deserve comment. First, our participants were initially nondisabled, potentially limiting the generalizability of our results. This effect is



**FIGURE 4.** Durations of disability episodes for nonfrail and frail participants, New Haven, Connecticut, 1998–2004. Disability episodes are classified by type of disability and how the episode ended. No  $p$  value is given for severe disability episodes ongoing at completion of follow-up because there was only a single episode among the nonfrail. Frailty status was updated every 18 months during the comprehensive assessments. NA, not applicable.

counterbalanced by our oversampling of frail participants. In addition, because our participants were members of a single health plan in a small urban area, our results may not be generalizable to older persons in other settings. However, our population did reflect the demographic characteristics of persons aged 65 years or older in New Haven County, characteristics which are comparable to those of older persons in the United States as a whole (51). Second, because we assessed only four ADLs, we may have

underestimated the rate of severe disability. Any underestimate, however, is likely to be modest since disability in the three excluded ADLs is uncommon (18, 19, 28). Third, because the amount of intermittent missing ADLs data was exceedingly small, we used a simple imputation method rather than multiple imputation (38). Several sensitivity analyses had minimal effects on the results, suggesting that our selection of an imputation method had little effect on our conclusions. Fourth, 8 percent of our monthly interviews were completed



by proxies. Although we demonstrated a high reliability for our proxy reports, previous research on the use of proxies suggests that proxies tend to overestimate functional deficits, although this is less true for basic ADLs than other, potentially more subjective measures such as instrumental ADLs or affective function (52–54). Our results did not change appreciably when proxy responses were excluded (data not shown). Finally, although our disability assessment was highly reliable, some transitions could have been due to measurement error rather than true changes in function.

In conclusion, multiple transitions among disability states are common among older persons, particularly those who are frail. In addition, the number of transitions per year varies widely among older persons, even within groups classified on the basis of frailty. Compared with persons who were not frail, frail older persons have higher rates of transitions to states of greater disability, lower rates of transitions to states of lesser or no disability, and lower rates of transitions from severe disability to death. To fully understand the disabling process, investigators and clinicians must consider the episodic and recurrent nature of disability. In future research, we plan to identify the potential determinants of variability in transition rates, including prior history of disability, precipitating events, and other physical, medical, and psychosocial factors that facilitate or impede transitions between the different disability states.

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