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Progressive versus Catastrophic Disability: A Longitudinal View of the Disablement Process

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Background. There is little epidemiologic data on the development of disability over time in older persons. This study uses prospective data from cohorts followed annually for 6 to 7 years to identify persons who developed severe disability and to characterize the time course of their disabling process and subsequent mortality.

Methods. Incidence rates of severe disability, defined as need for help in three or more activities of daily living (ADLs), were estimated for 6,640 persons who had not reported severe disability at baseline and at the first four annual follow-up visits. Among persons developing severe disability, those who reported no need for help in ADLs in previous interviews were defined as cases of catastrophic disability, and those who had previously reported some disability in ADLs were defined as cases of progressive disability.

Results. Overall, 212 subjects developed progressive and 227 developed catastrophic disability. The rates of progressive disability and catastrophic disability were 11.3 and 12.1 cases per 1,000 person-years, respectively. For both types of disability, incidence rates increased exponentially with age, but the increase was steeper for progressive disability. At ages 70–74, less than 25% of severe disability was progressive, while over age 85 progressive disability represented more than half of severe disability. Incidence rates of total and both types of severe disability were similar in men and women. Mortality after severe disability onset was extremely high. Survival time was unrelated to age at disability onset and type of disability but was significantly longer in women than in men (median 3.44 vs 2.12 years; $p < .0001$).

Conclusion. Tracking the development of disability provides new and important insights into the disability experience in older men and women that are potentially relevant in planning preventive, intervention, and long-term care strategies.

A LARGE portion of the geriatric literature is dedicated to studies of disability in the older population. Prevalence (1,2) and incidence (3–5) rates of disability have been reported for large samples representative of the general population. Many predictors of disability have been identified, including demographic characteristics, specific chronic conditions, and health behaviors. In most cases, disability has been considered as a simple, static condition, whereas the development of disability as an ongoing, dynamic process has received little attention (6). For example, little information is available on gender and age differences in the course of disability over time. This is an important issue, since length of the disabling process and survival time after developing disability are critical elements in assessing the impact of disability and the need for health and social services in selected subgroups of the population.

The most important causes of disability in young to middle-aged persons are congenital or perinatal conditions, trauma, and acute or rapidly progressive diseases (7). For almost all of these conditions the typical time course of the disabling process is rapid, and is assumed to be a sequela of the underlying cause. Conversely, disability in older age is often portrayed as the end stage of a progressive breakdown of the homeostatic equilibrium (8,9) that takes place in persons affected by multiple diseases (10), although it may be accelerated by acute medical conditions (8,9,11). The term "frailty," which has recently been defined in several ways (12,13), is an attempt to summarize this complex causal chain in a unique notion (14). However, it is also well known that some older persons become disabled suddenly, as a consequence of a catastrophic medical event such as a stroke, without showing any previous sign of functional decline. Thus, the time required for severe disability to develop is quite variable; it likely covers a wide range of times in the older population, but its distribution is completely unknown.

Certain aspects of the time course of disability can be inferred from the results of a limited number of studies (4,15,16), but the dynamics of the process in itself is not well understood (6); no research has used data on incident disability and change in disability status detected longitudinally over multiple evaluations to track the entire process. This prospective study uses data from a large, population-based sample of older persons who were assessed annually to describe the temporal characteristics of the process leading to severe disability and to understand how these characteristics are related to age, gender, and subsequent mortality. We hypothesized that rapid disability onset would be more common in the younger segment of the elderly population and would be followed by higher mortality rates than disability of the same magnitude but with gradual onset.

METHODS

Study Population

This study uses data from three communities of the Estab-

lished Populations for Epidemiologic Studies of the Elderly (EPESE), a longitudinal study of persons age 65 years and older, funded by the Epidemiology, Demography, and Biometry Program of the National Institute on Aging. The EPESE design and data collection methods have been described in detail elsewhere (2,17). Between 1981 and 1983, a survey was conducted on the entire elderly population living in East Boston (Massachusetts) and in two Iowa counties, and on a stratified random sample of the New Haven (Connecticut) population. More than 10,000 participants, representing more than 80% of the eligible population, were interviewed. Follow-up data from these cohorts were collected annually by telephone or in-person interviews. Seven follow-up interviews were conducted in Iowa and New Haven. In East Boston the data collection ended with the sixth follow-up interview.

Information on level of functional disability was collected by self-report in all interviews. Participants were asked if they needed help from another person or were unable to perform each of the following activities of daily living (ADLs): walking across a small room, bathing, dressing, eating, transferring from bed to chair, and using the toilet.

Outcome Measures

The first part of the analyses described here focuses on incidence of severe disability, and the second part on subsequent mortality. Subjects were defined as severely disabled if they reported need for help with or inability to perform three or more ADLs.

Persons known to be free of severe disability for a period of four years were followed for two to three additional years to detect incident cases of severe disability. In total, 7,771 subjects were found alive and reinterviewed at the fourth annual follow-up, the starting point for identifying incident cases of severe disability in this study. To define a population at risk for developing severe disability, 513 persons who had reported need for help in three or more ADLs on any interview between baseline and the fourth follow-up were excluded from the analysis. Also excluded were 594 subjects in whom, in any interview, the sum of missing responses to ADL questions plus the number of items for which the subjects reported need for help was three or more. These participants were not included in the study because severe disability could not be ruled out. Incident cases of severe disability were identified over the next two (East Boston) or three (Iowa and New Haven) follow-up interviews. The first occurrence of severe disability was considered in these analyses.

Persons developing severe disability anytime after the fourth follow-up were classified into two groups, according to their patterns of responses to ADL questions over time. If a participant reported no need for help in ADLs in the two interviews prior to the development of severe disability, the event was defined as catastrophic disability. If a participant reported any need for help in ADLs in the interview prior to the development of severe disability, the participant was classified as having progressive disability. Twenty-four subjects who had reported disability in one ADL two years before but no need for help in the interview immediately before the development of severe disability were excluded from the analysis. Thus, the population considered in this analysis consists of 6,640 persons.

Subjects who developed severe disability were followed for mortality through obituaries, interviews with proxies, and the National Death Index, for up to 5.5 years after the onset of severe disability.

Data Analysis

Crude incidence rates of total severe disability, progressive severe disability, and catastrophic severe disability are reported as number of events per 1,000 person-years. In computing these rates, person-years were calculated as time between the fourth follow-up interview and the onset of severe disability, death, loss to follow-up, or the end of the study period, whichever came first. Cox proportional hazards regression models were used to estimate relative risks (RR) and 95% confidence intervals (CI) for the association of age and gender with the two different types of severe disability. When the event considered was progressive disability, subjects developing catastrophic disability were censored at disability onset. Likewise, in the analysis of catastrophic disability, subjects with progressive disability were censored. In these analyses, persons were classified in five age groups (69–74, 75–79, 80–84, 85–89, 90+), according to their age at the time of the fourth follow-up interview. A polychotomous logistic regression model with a three-level outcome was used to compare the relative risks associated with age and gender of developing progressive disability and catastrophic disability versus no disability.

In the survival analysis, which was limited to subjects who had developed severe disability, person-years were calculated as time between the onset of severe disability and death or the end of 1992, whichever came first. Survivorship was analyzed by the Kaplan-Meier product limit method and Cox proportional hazard regression models. In these analyses, type of severe disability (progressive and catastrophic), age at the onset of severe disability (<85 vs ≥ 85), and gender were considered as covariates. Time of severe disability onset was considered as the midpoint between the last follow-up interview free of severe disability and the interview in which severe disability was first detected. Median survival time post severe disability onset was estimated using the Kaplan-Meier product limit method.

All proportional hazard regression models were community-stratified.

RESULTS

Of the 6,640 persons who were alive and free of severe disability at the beginning of the observation period, 181, 137, and 121 persons developed severe disability one, two, and three years later, respectively. Crude incidence rates of severe disability for the total population, according to age and gender, and by community, are reported in Table 1. The risk of developing severe disability during the three-year observation period was similar in both men and women, and progressively higher in the older age groups. Across the entire age range, each five-year increase in age was associated with approximately a doubling of the incidence rate of severe disability. In the three communities, age-specific incidence rates of severe disability, stratified by gender, were remark-

ably similar (Figure 1). After adjusting for age, gender and community were not significant predictors of incident severe disability (women vs men, RR: 1.1 — 95% CI: 0.8–1.4; Iowa vs East Boston, RR: 0.7 — 95% CI: 0.6–1.1; New Haven vs East Boston, RR: 1.1 — 95% CI: 0.8–1.6).

In Table 2, progressive and catastrophic severe disability are considered separately as two mutually exclusive outcomes. Over the observation period, 212 subjects developed severe disability after they had reported a lesser degree of disability in the previous years (progressive disability), and 227 developed severe disability with no previous report of any need for help with ADLs (catastrophic disability).

Overall incidence rates of progressive and catastrophic disability were virtually the same (11.3 vs 12.1 per 1,000 person-years, respectively; Table 2). An exponential increase in these two types of disability was seen with increasing age, with the rate of increase steeper for the progressive disability group. Age-adjusted incidence rates were similar in men and women.

Table 2 shows the results of two proportional hazard models which assess the relative risk associated with age and gender of developing progressive disability vs no disability, and catastrophic disability vs no disability. Compared with the reference group (69 to 74 years old), subjects between 75 and 79 years of age were 1.8 times more likely to develop both progressive and catastrophic disability. After age 80, relative risks for both types of disability increased with increasing age, but the increment in the magnitude of the relative risk at each higher age was larger for progressive than for catastrophic disability. Compared with the reference group (69–74 years), those aged 90 years or more had a

Table 1. Incidence Rates of Severe Disability (3 or more ADLs) in 6,640 Persons Aged 69 Years and Older by Gender, Age, and Community

Strata	Subjects at Risk	Person-years	Incident Cases of Severe Disability	Incidence Rate/1,000 Person-years
Total population	6640	18766	439	23.4
Men				
69–74 yr	953	2727	23	8.4
75–79	710	2016	32	15.9
80–84	437	1186	34	28.7
85–89	212	567	27	47.6
90 +	112	258	24	92.8
Women				
69–74 yr	1378	3976	30	7.6
75–79	1270	3664	53	14.5
80–94	867	2481	79	31.8
85–89	481	1317	75	56.9
90+	220	572	62	108.4
Community				
East Boston	2288	5423	107	19.7
Iowa	2664	8377	197	23.5
New Haven	1688	4965	135	27.2

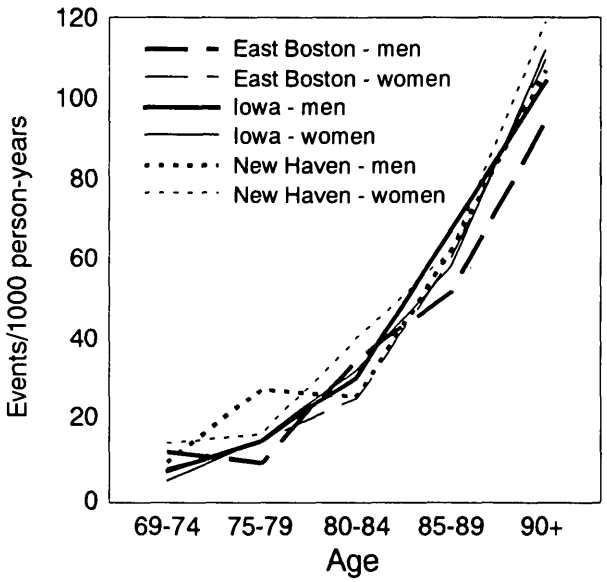

Figure 1. Incidence rates (per 1,000 person-years) of severe disability according to age group, stratified by community and gender.

Table 2. Incidence Rates of Progressive and Catastrophic Disability and Results of Proportional Hazard Models Relating Age and Gender to Risk of Progressive Disability and to Risk of Catastrophic Disability

Strata	Subjects at Risk	Incidence Rate of Progressive Disability/ 1,000 Person-years	Incidence Rate of Catastrophic Disability/ 1,000 Person-years	Relative Risk* of Developing Progressive Disability	Relative Risk* of Developing Catastrophic Disability
Total population	6640	11.3	12.1		
Age					
69–74 yr	2331	3.0	4.9	Reference —	Reference —
75–79	1980	5.6	9.3	1.8 (1.0–3.2)	1.8 (1.2–2.8)
80–84	1304	13.9	16.9	4.5 (2.7–7.5)	3.3 (2.1–5.0)
85–89	693	29.2	24.9	9.2 (5.5–15.3)	4.6 (2.9–7.2)
90+	332	65.0	38.5	20.1 (12.0–33.7)	6.9 (4.3–11.4)
Gender					
Men	2266	9.9	10.8	Reference —	Reference —
Women	4052	12.1	12.8	1.0 (0.8–1.4)	1.1 (0.8–1.4)

*Compared to persons who did not develop severe disability, adjusted for age. Risk estimates are based on 212 persons who developed progressive disability and 227 persons who developed catastrophic disability

relative risk of developing progressive disability three times higher than the relative risk of developing catastrophic disability. Women were no more likely than men to develop either progressive or catastrophic disability.

Among those who developed severe disability, the proportions with progressive and catastrophic disability are shown for age- and sex-specific subgroups in Figure 2. With increasing age, progressive disability comprises a larger proportion of the total disability for both men and women.

To obtain age-specific relative risks of progressive and catastrophic disability that are directly comparable, we fitted the same data with a single polychotomous logistic regression model. The results of this analysis are shown in Figure 3. The age-associated increases in the relative risks for progressive and catastrophic disability begin to diverge after 80 years of age. In the age groups 85–89 and 90+, the difference between the two coefficients reached statistical significance.

To examine the relationship between disability type (progressive vs catastrophic) and the risk of mortality, we performed subsequent analyses limited to the 439 participants who developed severe disability. Survivorship of this group from time of severe disability onset to the end of 1992 was analyzed using the Kaplan-Meier product limit method and plotting stepped survival curves stratified by type of disability, gender, and two age groups (<85 vs ≥85).

Overall, mortality in this population was extremely high. For example, more than 80% of those who became severely disabled between the fourth and the fifth follow-up interview died within 5 years. This value is likely an underestimate of the true mortality rate, as persons who both developed severe disability and died before the next interview could not be detected and are not included in these analyses.

The median survival time was unrelated to age at disability onset (age <85 vs 85+: 2.73 and 2.95 years) and was significantly longer in women than in men (women vs men: 3.44 and 2.12 years; $p < .0001$) in all those who developed severe disability.

These relationships are evident through the 5-year follow-up (Figure 4), with the exception of the 83 younger women who had developed catastrophic disability. In the first two years, mortality in this group of women was higher than mortality in the older women with the same type of disability, and closely followed the survival curve for younger men. However, after the first two years, the mortality rate declined and the survival curve became similar to that of the older women.

The independent effects of type of disability, age at onset of severe disability, and gender on mortality among the severely disabled were tested using a single Cox proportional hazard regression model. Female gender was significantly associated with lower mortality (RR for women vs men: 0.6; 95% CI: 0.4–0.7). There were no statistically significant associations with mortality for age, or for disability type (RR for progressive vs catastrophic: 1.1; 95% CI: 0.9–1.4). Figure 5 shows the age-adjusted survival function obtained from this model stratified by gender and type of disability. Both the strong gender effect and the lack of a "type of disability" effect are clearly evident.

DISCUSSION

Most of the literature has approached disability in the elderly as a static condition rather than as a dynamic process. This view ignores the fact that, depending on the basic underlying causes and on other personal and environmental cofactors, disability may begin abruptly, progress slowly, remain stable, and may even diminish over time. The average survival time after disability onset is highly variable, and

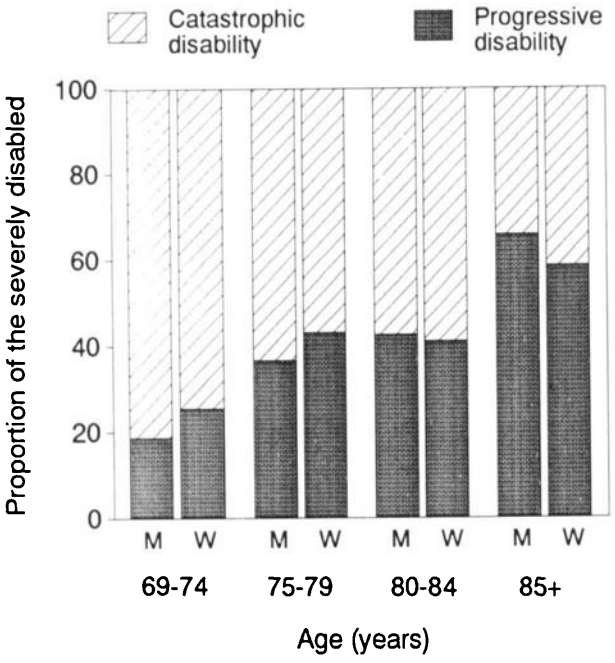

Figure 2. Proportion of persons with catastrophic and progressive disability among those who developed severe disability during the follow-up period, according to age group and gender (M = Men, W = Women).

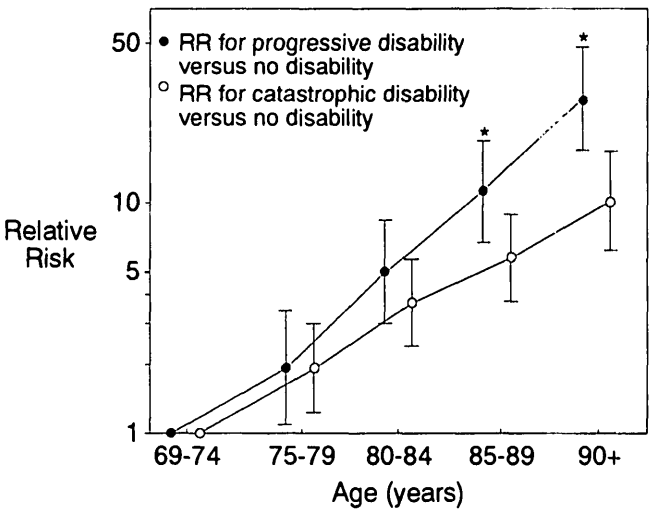

Figure 3. Logistic model relating age to risk of developing progressive disability and catastrophic disability vs no disability in 6,640 subjects free of severe disability at the beginning of the observation period. All relative risks are from a single polychotomous logistic regression model and are adjusted for gender. Age 69–74 is considered as the reference group. *$p <$ .01 for the comparison of age strata-specific relative risks of developing progressive disability and catastrophic disability vs no disability.

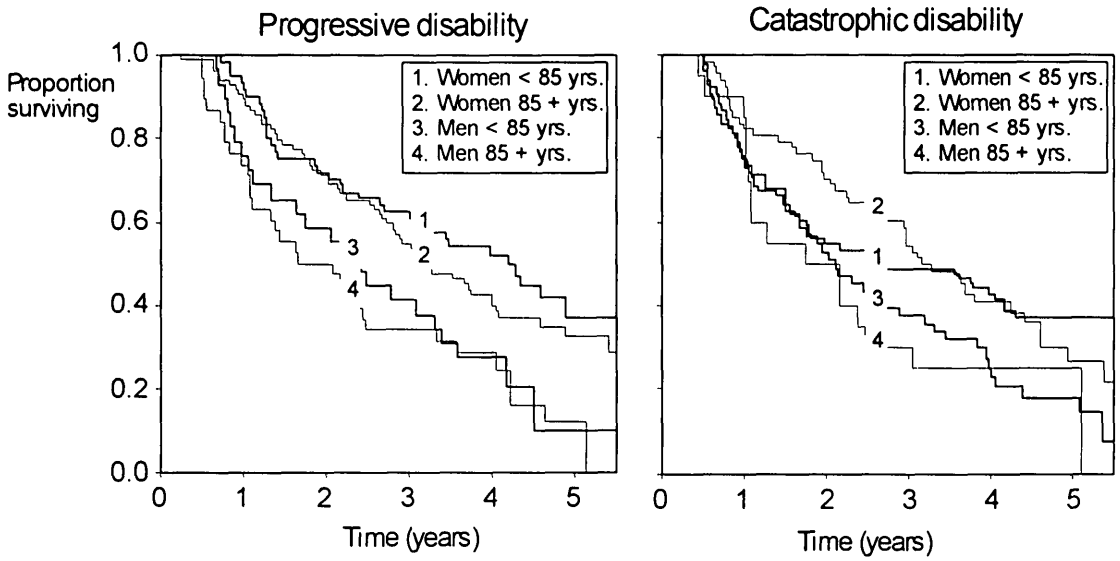

Figure 4. Kaplan-Meier survival functions of subjects with progressive and catastrophic disability, stratified by gender and age group. Survival time is calculated from time at disability onset, which was considered as the midpoint between the last interview without severe disability and the first interview in which severe disability was detected.

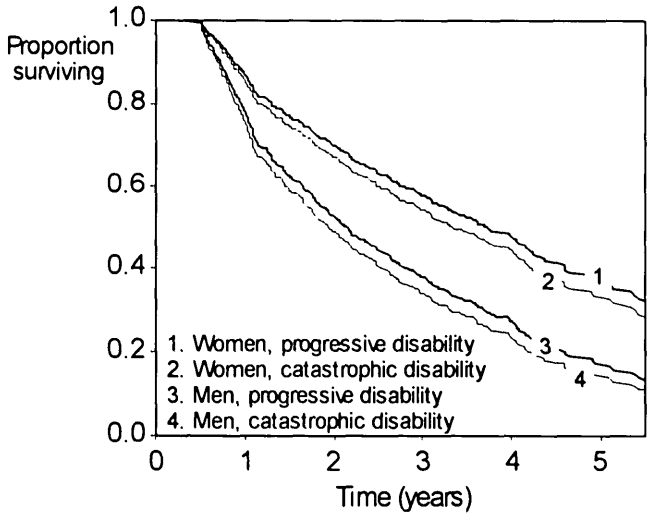

Figure 5. Survival function of 439 older persons with severe disability, according to gender and type of disability. The curves are from a Cox proportional hazard model and are age-adjusted.

it is not clear which factors determine length of survival (18–21). The onset and progression of disability, and survivorship with disability, delineate the lifetime course of disability. Complex and heterogeneous patterns are encountered in the older population, and treating disability as a simple outcome may be misleading.

In this study, the time course of disability was constructed using prospective data, and two main periods in the process of disablement were distinguished: development of severe disability, and survival with severe disability. The time at which an older person reported severe disability above a specific threshold was used to identify the point of intersection between these two periods. Finally, we made a distinction between subjects who developed severe disability in less than one year and subjects who had developed severe disability over a longer period, defining their process of disablement as catastrophic and progressive disability, respectively.

The percent of subjects who developed severe disability as a catastrophic event was similar to the percent of subjects who developed severe disability more progressively. Overall, older age was associated with increased risk of both types of disability. However, confirming our hypothesis, the characteristics of the disabling process were different at different ages. Among persons who developed severe disability, onset at later ages was more likely to be associated with a longer disabling process, and onset at a younger age was more likely to be associated with freedom from disability in ADLs during the previous years. In about 60% of the cases aged 85 years and older, development of severe disability was the final stage of a process of functional decline that had started more than one year before, while in the age group 69–75 years, less than 25% of those who developed severe disability reported any disability in ADLs during the previous year. These results suggest that the development of severe disability follows different pathways in different age groups. A plausible interpretation is that younger persons are less likely to show progressive disability because the effect of minor pathologic events on functional status is counterbalanced by compensatory strategies which may be physiological, behavioral, or social (8). In these persons severe disability is more often the "catastrophic" result of a major event (i.e., a stroke), or of an event which causes the breakdown of critical compensatory mechanisms (9). The same sequence of pathologic events that a younger person can compensate for may not be "counteracted" by compensatory mechanisms in very old persons, due to underlying frailty (12–14). Consequently, each event is followed by a significant change in functional status, and disability develops "progressively," step by step. In these subjects the decline in physical function may be very slow, and signs of

functional deterioration may be objectively detectable long before the development of disability in ADLs (22).

The differential characteristics of the developmental course of disability associated with age may be extremely relevant in designing and targeting effective preventive strategies in different age groups. In vulnerable older people with moderate impairments and disabilities, interventions aimed at slowing down the impending decline in function may be more effective than primary prevention, in which traditional risk factors are modified. Indeed, inconsistencies between studies assessing traditional risk factors in the elderly may be explained by the presence in the study population of these subjects (23). In this subset of the older population, decline in physical function may act as a strong competing risk factor for multiple outcomes.

This study also found that the time course of the disabling process was remarkably similar in men and women. There were no substantial differences between genders in both the age-specific incidence rates of overall severe disability and the proportion of persons who developed progressive and catastrophic disability. This result contrasts with previous suggestions that decline in health status associated with age is attributable to different chronic conditions in men and women. According to this view, progressive and non-life-threatening chronic conditions more frequently affect women, while men are more likely to develop atherosclerotic cardiovascular disease that manifests clinically as acute events such as strokes and myocardial infarctions (24). However, while morbidity may be different in men and women, Ettinger and colleagues (25) have recently reported that causes of disability are almost the same in older men and women.

Overall, after severe disability onset, mortality rates were very high. More than 80% of those who were followed for at least five years died during this period. Women with severe disability had longer survival than men but, surprisingly, age and characteristics of the disablement process were not associated with survivorship. Therefore, this study did not confirm our original hypothesis that the rapid onset of disability would lead to higher mortality than progressive onset disability. The findings of similar incidence of severe disability but longer survival of women with severe disability are compatible with a large body of evidence showing higher prevalence of disability in women compared to men at ages over 75 years (5,26–28). However, this study adds an additional perspective to the interpretation of this phenomenon because it shows very clearly that older women do not spend more years living with disability because it develops more slowly and progressively than in men, but that they survive longer after the onset of severe disability. This hypothesis has been suggested by other investigators (4,28). However, there were limitations in their ability to assess this issue, since they could not estimate time at disability onset with reasonable precision.

The observed differences in survival between men and women with severe disability remain to be explained. It is likely that the underlying causes of disability and the relationship between disease severity and disability severity may be different in men and in women. Further research using these cohorts will assess diseases predicting severe disability, and disease occurrence and cause of death after the onset of severe disability. Further research is also needed to evaluate whether men systematically underreport disability as compared to women, so that men reporting disability are in fact more frail and at higher risk of death.

The lack of an effect of age and type of disability on the risk of dying in this group of severely disabled older persons is also of scientific interest. It is important to consider that the population at risk in this study included subjects aged 69 years and older and that the operational definition of disability used here identifies a rather severe state. At this end stage of the functional spectrum and in this age group, it is quite possible that differences in age and the path by which individuals reached their disability state became relatively inconsequential. The prognosis *quoad vitam* is probably more strongly affected by the direct consequences of the disability itself, such as immobilization, malnutrition, social isolation, and others. Considering the lack of an age gradient in mortality risk, it is surprising that a differential mortality according to gender is still evident in this group.

The high mortality rate in those with disabilities confirms the results of many other studies (18–21). Mortality rates in persons with disability in three or more ADLs were comparable or higher than mortality rates reported for patients with severe medical conditions, such as myocardial infarction, stroke, hip fracture, and severe septicemia (29–32). However, it should be pointed out that, even for subjects with catastrophic disability, the comparison of our results with data from the literature may be problematic because of age differences and because those with severe disability represent the most severe of these clinical events.

The disappearance of the prognostic effect of age for mortality at this severity of disability is a relatively new finding. Other reports have found an association between age and mortality even in disabled subjects (18–21,33). However, most of these studies used a less severe definition for disability.

An important strength of this study is that it used annually collected data from a prospective study on large representative populations of elderly persons followed for up to seven years. It thus avoids recall bias that would be present if the onset of disability were assessed retrospectively. The study design permitted the characterization of functional status for four years prior to its baseline, which allowed for the identification of a large population at risk of incident disability. Using subsequent follow-up information on this population, we could identify sufficient cases of incident severe disability to do a meaningful analysis. Furthermore, mortality data on those persons who developed severe disability were available for up to 5.5 years. We are not aware of any other cohort in which these analyses would be possible.

Specific limitations directly related to the design of this analysis must be considered. Among those at risk of developing severe disability, we could not identify persons who developed severe disability and died before the next follow-up visit. Therefore, both incidence rates of severe disability and mortality rates of subjects developing severe disability are likely to be underestimated in this study. Since we did not have any information on these subjects, we assumed that they were randomly distributed between those with some

previous disability (progressive), and those with no previous disability (catastrophic). Whether and how much this assumption influenced our results is unknown.

There were 543 subjects who were excluded from the population at risk because the number of missing values in the items assessing disability would not allow severe disability to be ruled out. Distribution according to age and gender, disability in ADLs (considering only non-missing items), as well as survivorship after the fourth follow-up were similar in this group compared to those in the eligible study population. Thus, we have no specific reason to believe that the results of our study would be different if we included this group in the study population.

Results of this study are generalizable only to subjects aged 69 years or older who develop disability in three or more ADLs over their lifetime. From a public health perspective, this is a very important group of the older population (34–38). In fact, persons with these characteristics usually need substantial medical care (35), formal and informal care in the community (36,39), and are among the most likely candidates for nursing home admission (40,41).

In conclusion, this research offers a new concept by which to approach the study of disability. Our understanding of disability in the older population may be substantially enhanced by considering the time course of disability development and distinguishing between catastrophic and progressive disability. Approaches to prevention, therapeutic options, and decisions on the use of long-term care may all be illuminated by considering the dynamic aspects of the development of disability, especially as further research determines the role that modifiable risk factors play in the disablement process. In this study the analysis was restricted to the effect of age and gender, basic demographic indicators. However, the difference by age in the time characteristics of the disablement process, and the differential mortality by gender in those severely disabled, suggest that we have more to learn about this issue and help us to begin formulating hypotheses about the processes underlying the development of severe disability. Further research is needed to understand how other demographic and psychosocial characteristics, specific diseases, and other risk factors influence the course of disability onset.

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