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Morbidity and Disability in Older Persons in the Years Prior to Death

ABSTRACT

Background: A large proportion of the disease and disability which affects older persons occurs in the years just prior to death. Little prospective evidence is available which quantifies the burden of morbidity and disability during these years.

Methods: In three community-based cohorts of persons age 65 and older, chronic conditions and disability were evaluated for the three years prior to death in 531 persons who had three annual assessments and then died within one year of the third assessment. Number of chronic conditions, prevalence of disability in activities of daily living (ADLs), and prevalence of disability on a modified Rosow-Breslau scale were determined for these decedents and compared to 8821 members of the cohorts known to have survived.

Results: Prevalence rates of disease and disability increased during the follow-up for both decedents and survivors, with decedents generally having higher rates than survivors. Disability rates prior to death, but not the number of diseases, increased with increasing age at death. The odds ratio for disability in ADLs at any of the three assessments for decedents versus survivors ranged from 3.0 to 4.2 in the three communities. In each community the odds ratio for ADL disability was higher in women decedents versus survivors than in men decedents versus survivors.

Conclusions: These results have important implications for disability levels in future older populations in which death is projected to occur at increasingly higher ages. (*Am J Public Health* 1991;81:443–447)

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Introduction

Prior to death, there is a decline in health status which may be quite variable. For the individual with a severe stroke who remains in a nursing home for several years, the state of poor health prior to death may be prolonged; for the person with metastatic cancer dying six months after diagnosis, duration of disability is moderate; and for the previously healthy individual who suffers sudden death, the state of poor health is virtually nonexistent. Just as the duration of poor health prior to death may be quite variable, its severity may also vary considerably. Increases in morbidity and disability prior to death have tremendous impact on individuals, their families, and the health care delivery system. With 71 percent of all deaths in the United States occurring among people age 65 and older,[1] it is of value to describe the systematic decreases in health status prior to death in this population.

The rising costs of caring for the older population have lead to a great deal of interest in the utilization and cost of health care in the years prior to death.[2] A study using Medicare data showed that 28 percent of all Medicare costs were incurred by the 6 percent of enrollees who would die within the next 12 months.[3] A study using data from the province of Manitoba was able to capture nearly all health care utilization in the years prior to death and found substantial increases in several measures of utilization with increasing proximity to death.[4]

Limitations are inherent in the use of health care utilization data to measure health status prior to death. Direct measures of disease and disability in older persons provide a more accurate description. There are a limited number of studies which examine disease or disability prior to death using either retrospective reporting of proxies[5,6] or prospective study designs.[7,8] In the present study, three representative populations of older persons were prospectively evaluated using self-report of common chronic diseases and two scales of physical functioning. The objectives of this analysis were to quantify the prevalence rates of disease and disability as death approached, compare these prevalence rates among decedents to rates in surviving members of the cohort, and examine how this process varies by gender and age at death. It was further hypothesized that disease and disability rates would increase to a greater extent in decedents than in survivors during the period of observation.

Methods

Study Populations

The data for these analyses are from the Established Populations for Epidemiologic Studies of the Elderly (EPESE),

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TABLE 1—Number of EPESE Participants Surviving to Follow-up 3 and Dying between Follow-ups 2 and 3 by Site, Age Group, and Sex

Site and Age Group (years)	Survived to Follow-up 3		Died between Follow-ups 2 & 3	
	Men	Women	Men	Women
East Boston				
65–74	814	1333	46	37
75–84	314	583	30	47
85+	79	145	17	27
Total	1207	2061	93	111
Iowa				
65–74	746	1089	32	23
75–84	363	787	43	27
85+	80	181	12	21
Total	1189	2057	87	71
New Haven				
65–74	569	806	37	29
75–84	271	483	30	40
85+	49	129	16	17
Total	889	1418	83	86
Total All Sites	3285	5536	263	268

longitudinal studies of persons aged 65 and older. Participants included in these analyses were enumerated and interviewed in three communities in 1982 and early 1983. Details of study design and sampling strategies have been reported elsewhere.[9,10] Briefly, in East Boston, Massachusetts, and Iowa and Washington Counties, Iowa, full community surveys were conducted. A baseline response rate of 84 percent yielded 3,812 participants in East Boston, and in Iowa an 80 percent response rate yielded 3,673 participants. The New Haven target population was a stratified cluster sample of 3,420 eligible persons age 65 and older, drawn from three types of community dwellings: public elderly housing, where age and income are restricted; private elderly housing, where age is restricted; and private apartments and houses. There was oversampling of men and those living in elderly housing. A baseline response rate of 82 percent yielded 2,812 participants.

For the sake of clarity in understanding change in functional status and disease prior to death, these analyses were limited to a subset of participants for whom interview information was available for three consecutive years. The subjects of these analyses are those respondents from the three sites who participated in the baseline and first and second annual follow-up interviews and whose vital status was known for the next year of follow-up. Participants who died any time before the second annual follow-up were excluded from these analyses. Ascertainment of vital status at the end of the third follow-up year was nearly 100 percent at all sites.

Data Collection

The baseline interview was conducted in participants' homes and the first and second annual follow-up interviews were conducted by telephone or, if this was not possible, in person. A proxy interview was conducted for those unable to participate in the interview. Chronic conditions were assessed by asking respondents at baseline if they had ever been told by a doctor that they had a heart attack, stroke, cancer, diabetes, or hip fracture. At each follow-up interview, respondents were asked if they had been told by a doctor since the last interview that they had any of these conditions. Disability in activities of daily living (ADLs) was defined as self- or proxy-report of needing help from a person or special equipment in performing one or more of the following activities: walking across a small room, bathing, grooming, dressing, eating, transferring from bed to chair, or using the toilet.[11,12] Disability on a modified Rosow-Breslau scale of physical functioning was defined as the need for help in performing one or more of the following tasks: walking up and down stairs to the second floor, walking one-half mile, and doing heavy housework.[13] ADLs and Rosow-Breslau items were assessed at baseline and each annual follow-up.

Analytic Methods

Mean number of self-reported chronic conditions and prevalence of disability at baseline and at the first and second follow-ups were calculated separately for those dying in the one year period between follow-up 2 and follow-up 3 and for those surviving to follow-up three. The number of chronic conditions at each follow-up was calculated by determining the lifetime prevalence of each condition, taking into account baseline report as well as annual follow-up report of the occurrence of the condition in the previous year or years. Therefore, the number of chronic conditions for an individual could only stay the same or increase during the follow-up period. Individual reports of disability at each assessment were independent of other assessments.

Multiple logistic regression models were used to assess the odds of being disabled in any of the first three interviews for those dying between the second and third follow-ups compared to those surviving to follow-up 3.

Results

Table 1 shows the number of study participants who survived to follow-up 3 and who died between follow-ups 2 and 3 according to community, age group, and sex. There were 531 decedents and 8821 survivors in the communities by this definition. Those dying prior to follow-up 2 are not included in these numbers or in subsequent analyses.

In Figures 1, 2, and 3, the mean number of chronic conditions, the percent disabled in ADLs, and the percent disabled in Rosow-Breslau items and are shown for those dying between follow-ups 2 and 3 and those surviving to follow-up 3. Results are shown for baseline, follow-up 1 and follow-up 2 and are presented separately for each site, sex, and age group. For those dying between follow-up 2 and 3, the baseline data reflect morbidity and disability status from two to three years prior to death, the follow-up 1 data reflect status between one and two years prior to death, and the follow-up 2 data reflect status between zero and one year prior to death.

For nearly every site, sex, and age subgroup, the mean number of conditions and the proportion disabled was higher in those destined to die than in survivors. In most subgroups, these differences are evident even at baseline, which is two to three years prior to decedents' deaths. In general, mean number of conditions and disability prevalence rates increased as death approached. For those surviving to follow-up 3, there was also, for most subgroups, an increase in chronic conditions and disability from the baseline through the second follow-up interview. For some subgroups, the slope of the increase in de-

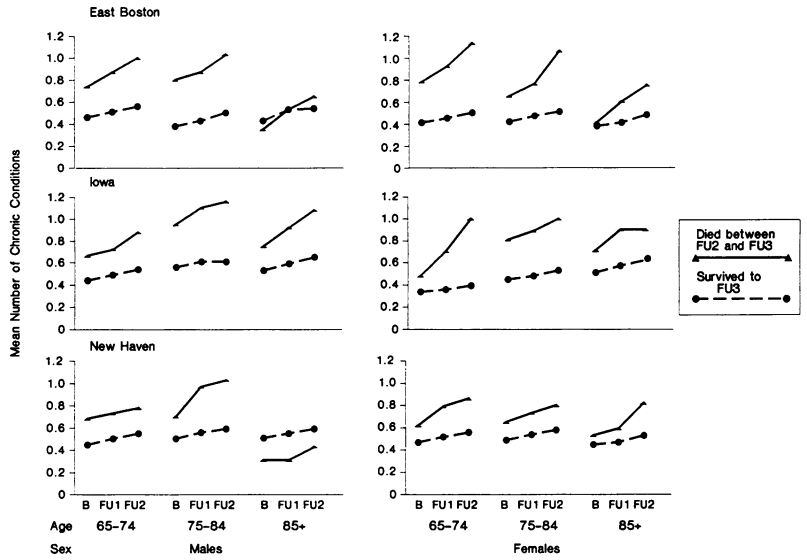

FIGURE 1—Mean Number of Chronic Conditions at Baseline, Follow-up 1 and Follow-up 2 According to Survival Status between Follow-up 2 and 3, Age Group and Sex; EPESE

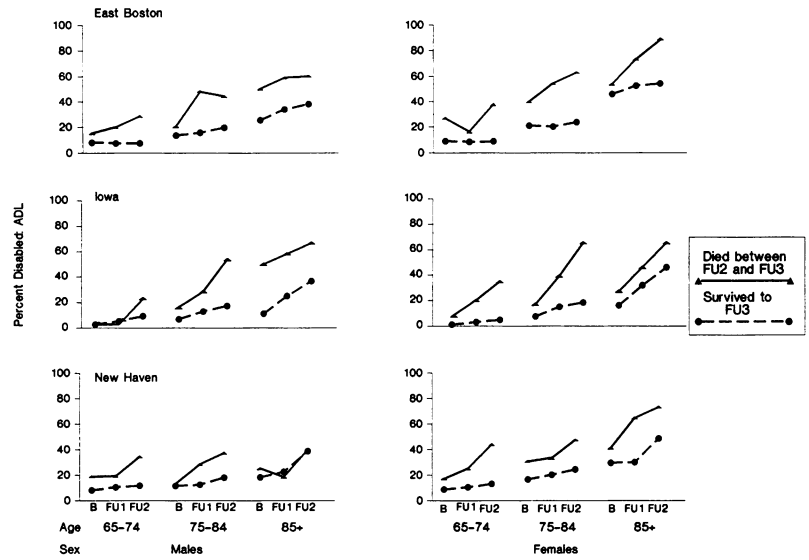

FIGURE 2—Percent Disabled in One or More Activities of Daily Living at Baseline, Follow-up 1 and Follow-up 2 According to Survival Status between Follow-up 2 and 3, Age Group and Sex; EPESE

cedents was clearly steeper than for the survivors, although this was not the case in all subgroups. In general, smaller differences were seen between decedents and survivors in the age group 85 years and older than for the two younger age groups.

Disability rates as measured by ADLs generally showed a substantial increase as death approached and were higher with increased age at death. In decedents aged 65–74 and 75–84 years at baseline, only about one-fourth or less report ADL disability at baseline, which was from two to three years prior to their deaths. At follow-up 2, within one year of death, the 65–74-year-old group had, in general, an ADL disability prevalence rate of 40 percent or less. In the 75–84-year-old group of decedents, up to two-thirds were disabled in ADLs in the year prior to death. Decedents aged 85 and older at baseline had the highest rates of ADL disability in the year prior to death (between 60 and 90 percent), with the exception of New Haven men.

Disability rates as assessed by the Rosow-Breslau items were higher in both decedents and survivors than corresponding rates of ADL disability. In the year prior to death, prevalence rates of disability, as measured by the Rosow-Breslau scale, were over 60 percent in nearly all subgroups, with those 85 and older having prevalence rates in excess of 80 percent. An increase in Rosow-Breslau disability rates with increased age at death was evident in most subgroups. Unlike disability measured by both instruments used here, mean number of chronic conditions prior to death did not show a consistent increase with age at death.

Table 2 demonstrates the magnitude of the differences in disability in ADLs in the baseline and first two follow-up interviews between those dying and those surviving. Odds ratios are presented for disability in any of these interviews for decedents compared to survivors. Overall, decedents were about three to four times as likely as survivors to report an ADL disability in either the baseline or first two follow-ups, after adjusting for age and sex. In men, decedents were 2.4 to 3.7 times as likely as survivors to report ADL disability. In women, the odds of disability in decedents was 3.7 to 5.2 times that of survivors. In each site, the odds ratio for disability for women who died versus survived was higher than the odds ratio for disability for men who died versus survived. The odds ratios for disability in decedents versus survivors by age group reveal no consistent trends with age across the three communities.

Discussion

Although the prevalence rates of disease and disability increase with age, there is no *a priori* reason to believe that within older populations those dying at a younger age should have less disability prior to death than those dying at older ages. These data reveal that those dying at the oldest ages generally have more disability, but not disease, prior to death than those dying at younger ages. As expected, the rates of disease and disability rise as death approaches, and those destined to die

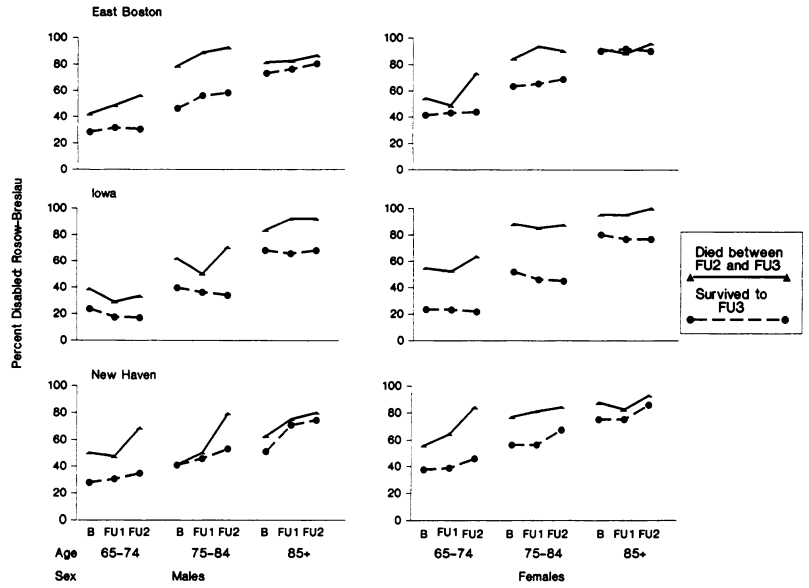

FIGURE 3—Percent Disabled in One or More Rosow-Breslau Items at Baseline, Follow-up 1 and Follow-up 2 According to Survival Status between Follow-up 2 and 3, Age Group and Sex; EPESE

have higher disease and disability rates than those of the same sex and age who survive.

In the conceptualization of these analyses, it was speculated that it might be possible to elucidate an even more refined relationship of morbidity and disability with death than we were able to demonstrate here. Consistent patterns were sought for differences in morbidity and disability during the three years of observation in decedents compared to survivors. Alternative patterns were postulated, including both groups starting out at the same disease or disability level and then diverging, the two groups starting out at different levels but remaining parallel, and the two groups starting out at different levels but still diverging during the years of observation. None of these patterns were observed in any consistent manner (Figures 1–3). This may be the result of methodologic shortcomings of this study or may reflect true variability in these relationships among different age groups, men and women, and the communities under study. A summary measure of ADL disability, that is, having any ADL disability in the three years prior to death, was employed to further investigate differences in sex and age relationships comparing decedents and survivors (Table 2). The odds of disability in decedents versus survivors showed no clear trend with age, but in each community the odds ratios for disability comparing decedents to survivors were higher in women than men.

A number of methodologic limitations must be considered in the interpretation of these results. The results in Figures 1–3 summarize percent disabled and mean number of conditions in a subgroup at a particular point in time, but changes for particular individuals as they approach death could differ considerably from these summary measures. It has been documented that change in functioning over time in individuals can be quite variable, with some reporting improvement, some reporting decline, and some reporting no change.[12,14] Research is now underway to analyze the multiple patterns of change which result from the repeated measures obtained in these longitudinal studies. These populations were all community-dwelling at baseline, although follow-up was completed for those entering an institution in subsequent years. Because rates of institutionalization increase dramatically with age, it is likely that the age gradient seen in disease and disability prior to death would be even steeper if all those in nursing homes three years prior to the deaths were included in the study. Although the cohorts under study are large, the number of deaths per year is not great and stratifying these deaths by age group and sex results in small sample sizes for certain subgroups. Larger numbers of deaths would have resulted in more accurate estimates of disease and disability prior to death and led to smoother curves for decedents in Figures 1, 2, and 3. The measures available to define morbidity and disability were fairly crude. The list of five chronic diseases was not comprehensive, being limited to those conditions queried at each interview. Disability status as estimated by both scales used here was dichotomized for ease of understanding and presentation. More refined scales, or perhaps the use of other measures which may be more sensitive to change over time, could lead to a finer understanding of the relationships investigated in this study. Finally, in comparing decedents to survivors there may be a "ceiling effect" which obscures the magnitude of differences in these two groups. This is seen, for instance, for the Rosow-Breslau scale for those aged 85 and older, in whom

TABLE 2—Odds Ratios (95% confidence intervals) for Reporting Disability in Activities of Daily Living at Any Interview (Baseline, Follow-up 1, or Follow-up 2) for Those Dying between Follow-up 2 and Follow-up 3 Compared to Those Surviving to Follow-up 3

	East Boston	Iowa	New Haven
Total Population*	4.0 (2.9, 5.6)	4.2 (3.0, 6.1)	3.0 (2.1, 4.2)
Men**	3.6 (2.2, 5.8)	3.7 (2.3, 6.0)	2.4 (1.5, 3.9)
Women**	4.4 (2.8, 6.9)	5.2 (3.0, 9.0)	3.7 (2.3, 6.1)
Age 65–74***	3.7 (2.3, 5.9)	3.3 (1.8, 6.1)	3.3 (1.9, 5.5)
75–84***	4.4 (2.5, 7.5)	5.5 (3.2, 9.5)	3.3 (2.4, 4.6)
85+***	4.4 (1.6, 11.8)	3.7 (1.5, 9.0)	1.9 (0.8, 4.2)

*Adjusted for sex and age.
**Adjusted for age.
***Adjusted for sex and age within 10 year age group.

the level of disability in survivors is so high that there may be little room for the decedents to appear more disabled (Figure 3).

There have been few prospective studies which have evaluated changes in disease and functional status prior to death. A number of studies have addressed terminal drop or terminal decline, but nearly all have focused on psychosocial or cognitive factors.[7] In a study which assessed declines in a number of domains, Palmore and Cleveland examined both terminal decline (defined as a steady, linear decrease prior to death) and terminal drop (defined as an accelerated decrease as death approaches) in 178 decedents in the Duke Longitudinal Study of Aging.[7] In a multivariate model, they found significant associations of both age and number of months prior to death with physical functioning. These results are in agreement with the findings presented here, as they can be interpreted to mean that, controlling for age at exam, there is decreasing physical functioning with increasing proximity to death, and, controlling for proximity to death, there is decreasing physical functioning with increasing age. They found no evidence of terminal drop.

Deeg and colleagues analyzed data for 88 residents of a home for the elderly in the Netherlands for whom four assessments were available in the year prior to death.[8] Declines were observed in physical, cognitive, and social functioning and morale as death was approached, and decedents had poorer scores in these domains than survivors. Model fitting revealed statistical evidence of an accelerated decline, or terminal drop, in physical functioning during this last year of life. In contrast to the present study, no age differences were found in physical functioning prior to death when comparing those younger than age 80 and those aged 80 and older. In another small study, there was no clear age gradient in the proportion of those judged clinically to be fully functional at 12 months, 6 months and 1 week before death.[15] These results suggest that there may be no age gradient in disability in the final year of life, but that this gradient may be present in the several years prior to death, as shown in this study. More research is necessary to answer this question definitively.

The current study has important implications for the older population now and in the future. Irrespective of the age at which an older individual dies, it is likely that a large proportion of the total years spent in the disabled state will be contributed by the years just prior to death. As the total population ages, preventive interventions, whether initiated at young or older ages, must have the ultimate goal of not only increasing longevity but of reducing disability. Any prevention efforts, at whatever age, to reduce total number of disabled person-years must address the issue of morbidity and disability prior to death, making this an important area for continued investigation. This study revealed that women decedents had proportionately higher rates of disability prior to death than men when compared to same-sex survivors, even after controlling for differences in age at death. This is important in an aging population in which, at each higher age, the female:male ratio increases and in which women have higher overall rates of disability than men.

Finally, the findings that the highest disability rates prior to death were found to be associated with death at the oldest ages can have grave implications for the total population burden of morbidity and disability in future years. If, as projected, life expectancy continues to increase,[16] the proportion of persons dying at the oldest ages will also increase. The total number of person-years of disability prior to death would thus increase, assuming age-specific rates of disability prior to death remain unchanged. Increased disability prior to death in future older populations, in which a large proportion of deaths will occur at the oldest ages, could make the quest for an overall compression of morbidity in the older population difficult, if not impossible. □

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