Patterns of Functional Decline at the End of Life

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Context Clinicians have observed various patterns of functional decline at the end of life, but few empirical data have tested these patterns in large populations.

Objective To determine if functional decline differs among 4 types of illness trajectories: sudden death, cancer death, death from organ failure, and frailty.

Design, Setting, and Participants Cohort analysis of data from 4 US regions in the prospective, longitudinal Established Populations for Epidemiologic Studies of the Elderly (EPESE) study. Of the 14456 participants aged 65 years or older who provided interviews at baseline (1981-1987), 4871 died during the first 6 years of follow-up; 4190 (86%) of these provided interviews within 1 year before dying. These decedents were evenly distributed in 12 cohorts based on the number of months between the final interview and death.

Main Outcome Measures Self- or proxy-reported physical function (performance of 7 activities of daily living [ADLs]) within 1 year prior to death; predicted ADL dependency prior to death.

Results Mean function declined across the 12 cohorts, simulating individual decline in the final year of life. Sudden death decedents were highly functional even in the last month before death (mean [95% confidence interval {CI}] numbers of ADL dependencies: 0.69 [0.19-1.19] at 12 months before death vs 1.22 [0.59-1.85] at the final month of life, $P=.20$); cancer decedents were highly functional early in their final year but markedly more disabled 3 months prior to death (0.77 [0.30-1.24] vs 4.09 [3.37-4.81], $P<.001$); organ failure decedents experienced a fluctuating pattern of decline, with substantially poorer function during the last 3 months before death (2.10 [1.49-2.70] vs 3.66 [2.94-4.38], $P<.001$); and frail decedents were relatively more disabled in the final year and especially dependent during the last month (2.92 [2.24-3.60] vs 5.84 [5.33-6.35], $P<.001$). After controlling for age, sex, race, education, marital status, interval between final interview and death, and other demographic differences, frail decedents were more than 8 times more likely than sudden death decedents to be ADL dependent (OR, 8.32 [95% CI, 6.46-10.73); cancer decedents, one and a half times more likely (OR, 1.57 [95% CI, 1.25-1.96]); and organ failure decedents, 3 times more likely (OR, 3.00 [95% CI, 2.39-3.77]).

Conclusions Trajectories of functional decline at the end of life are quite variable. Differentiating among expected trajectories and related needs would help shape tailored strategies and better programs of care prior to death.

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CLINICAL OBSERVATION SUPports the existence of differences in functional decline before dying. Although these differences may have important implications for the organization and delivery of care at the end of life, little empirical work examines such patterns across large populations.

In 1968, Glaser and Strauss[1] described 3 different trajectories of dying: abrupt, surprise deaths; expected deaths (both short-term and lingering); and entry-reentry deaths, where individuals slowly decline but return home between stays in the hospital. More recently, these ideas have been expressed as a set of functional trajectories[2-4] in which short-term expected deaths (terminal illness) are portrayed separately from lingering expected deaths (frailty). The 4 theoretical trajectory groups in FIGURE 1 were operationalized in an analysis of Medicare claims data and had distinctly different patterns of demographic characteristics, care delivery, and Medicare expenditures.[2] However, to our knowledge, no study has evaluated whether patients in these 4 groups actually differ in the slope of decline in physical function before death.

Earlier research documented that those who are dying experience a steeper decline in functional status than do same-age survivors.[5-7] Functional decline before death differs by age[6] and, among the chronically ill, medical conditions influence the pattern of functional disability.[8-15] A recent study found a sharper terminal decline in function in the last months of life for cancer decedents compared with those dying from other chronic illnesses.[16] The current study extends this work with more in-depth analysis of the role of different diseases and conditions related to dying in older age.

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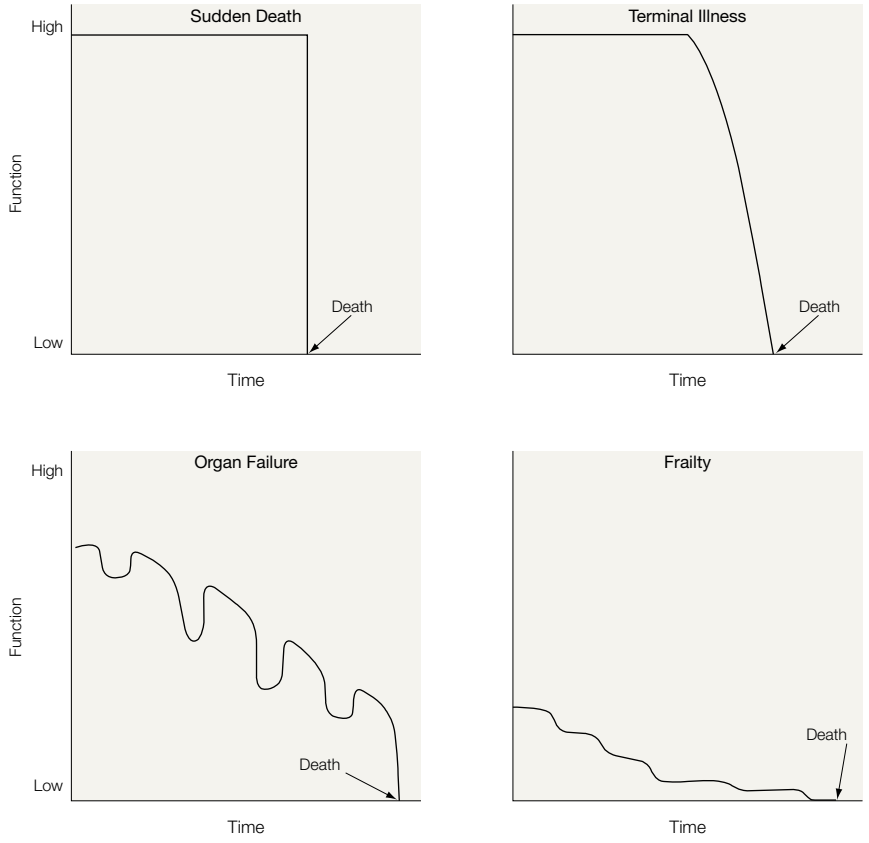
Figure 1. Theoretical Trajectories of Dying



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METHODS

Study Cohort

We analyzed data from 4 areas from the Established Populations for Epidemiologic Studies of the Elderly (EPESE) study: East Boston, Mass; Washington and Iowa counties, Iowa; New Haven, Conn; and 5 contiguous rural counties of north central North Carolina. The EPESE followed community-based cohorts of persons aged 65 years or older with baseline in-person interviews conducted between 1981 and 1987 followed by 6 to 10 annual in-person or telephone follow-up interviews. Others have described the design and data collection methods in detail.[17,18] Of the 14 456 EPESE participants who were interviewed at baseline, 4871 died during the first 6 years of the follow-up period and a date of death is available for 4865. The group of 4190 decedents (86%) who happened to be interviewed within 1 year before death constitutes the sample population for these analyses. Those 4190 did not differ from the remaining decedents in age at death or any other demographic characteristics.

Each interview included self-reported or proxy-reported physical function. At baseline, 99% of decedents participated directly in the interview process. Proxies provided data for the last follow-up interview of 26% of the decedents, who were too cognitively or physically impaired to participate directly at that point. Interviewers asked if participants needed help or were unable to perform each of the following 7 activities of daily living (ADLs): walking across a small room, bathing, grooming, dressing, eating, transferring from bed to chair, and using the toilet. In addition, questions ascertained their ability to walk a half mile; stoop, kneel, or crouch; climb a flight of stairs; and do heavy housework, such as washing floors. Each year, participants also reported on a variety of other health issues, such as the new diagnosis of a chronic illness (cancer, heart disease, or diabetes), or the occurrence of a hip fracture, stroke, hospitalization, or nursing home stay during the preceding year. We have death certificate data for 4865 of the 4871 decedents.

Analysis

The 4190 EPESE decedents who provided interview data during their final year of life were evenly distributed in 12 cohorts based on the number of months between the participant's final interview and death, with 6.6% to 8.2% interviewed in any particular month. Of particular interest, 315 were interviewed 12 months before death and 316 in the final month of life. We derived functional patterns from the mean number of ADL dependencies for each monthly cohort.

We also grouped decedents into categories corresponding to the 4 theoretical trajectories based on information from the death certificate and from interviews. Decedents with a diagnosis of cancer (*International Classification of Diseases, Ninth Revision [ICD-9]* codes 140.0-239.9) noted as the immediate or underlying cause of death on their death certificate constituted the cancer group. Decedents with congestive heart failure (*ICD-9* codes 428.0-428.9) or chronic lung disease (*ICD-9* codes 490.0-496.9) in any diagnosis field on the death certificate made up the organ failure group. Those decedents who had reported a nursing home stay during any follow-up interview comprised the frailty group. The sudden death group consisted of those who died with no diagnosis of cancer or organ failure on the death certificate, with no nursing home stay, and who had reported no history of the following at any point during the study: cancer, heart disease, diabetes, hip fracture, or stroke. Remaining (unclassified) decedents formed the "other" group.

Table 1. Decedent Group Characteristics*

Characteristic	Sudden Death (a)	Cancer (b)	Organ Failure (c)	Frailty (d)	Other (e)	All
No.	649	897	817	837	990	4190
Age, mean (SD), y	80.4 (7.8)[b,c,d,e]	78.7 (6.9)[a,c,d]	82.3 (7.7)[a,b,d,e]	85.1 (7.2)[a,b,c,e]	79.2 (7.0)[a,c,d]	81.1 (7.6)
Women, No. (%)	321 (49.5)[d]	424 (47.3)[d]	441 (54.0)[n]	514 (61.4)[b,c,e]	501 (50.6)[d]	2201 (52.5)
Nonwhite, No. (%)	157 (24.3)[c,d]	178 (19.9)	122 (15.0)[a,e]	134 (16.1)[a,e]	243 (24.6)[c,d]	834 (20.0)
Education, mean (SD), y	7.9 (3.9)[b,c,d,e]	9.1 (4.3)[a,e]	8.6 (3.8)[a,b]	8.7 (3.9)[a]	8.2 (3.9)[a]	8.6 (3.9)
Currently married, No. (%)	262 (44.1)[d]	412 (50.3)[c,d]	322 (42.2)[b,d]	257 (34.1)[a,b,c,e]	446 (47.7)[d]	1699 (44.0)
No. of reported medical conditions, mean (SD)†	0[b,c,d,e]	1.05 (0.91)[a,e]	1.04 (0.94)[a,e]	1.08 (0.96)[a,e]	1.45 (0.66)[a,b,c,d]	0.99 (0.92)

*Each superscript letter represents a significant difference ($P<.05$) with the group bearing that label, with a Bonferroni correction for multiple comparisons.
†Self report of cancer, heart disease, diabetes, history of hip fracture, or stroke.

Because comorbidity is common among elderly patients, we expected overlap among the cancer, organ failure, and frailty decedents (the only groups with the potential for overlap). Therefore, we forced unique decedent group membership by sequentially identifying each category and removing those decedents from the pool before identifying the next category. We chose the hierarchy of cancer>organ failure>frailty, based on the expectation that cancer would be the dominant illness when it is listed as the immediate or underlying cause of death. We found that all demographic characteristics and patterns of functional decline attributed to a decedent group were consistent regardless of whether the groups were independently identified with overlap allowed or sequentially defined, and, when sequentially defined, regardless of which order was used to define and remove the decedent groups. The characteristics of these trajectory groups were notably consistent regardless of the specific way in which they were defined.

We compared descriptive characteristics among the groups using analysis of variance with a Bonferroni correction for multiple comparisons. In addition to describing the demographic characteristics of the categorized decedents and plotting the decline in physical function as the cohort interval approached the date of death, we developed a logistic regression model to examine the importance of decedent group membership in predicting the likelihood of being disabled before dying, adjusting for the effects of age, sex, race, education, marital status, and the amount of time between the final interview and death. We defined disability as requiring assistance with or being unable to perform any ADL. The group expected to be least disabled (men who died suddenly at ages 65-74 years) was chosen as the reference group. As with the descriptive analyses, the regression model was found to be consistent across each different decedent classification approach. Results reported here are for decedent classification in the following order: sudden death, cancer, organ failure, frailty, and other.

RESULTS

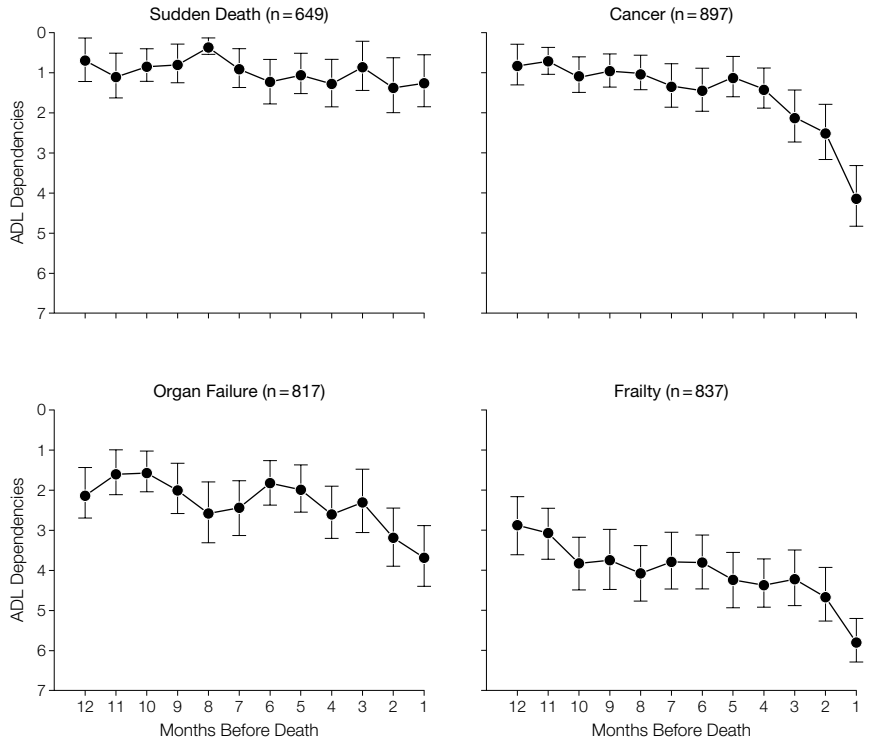
Compared with participants in EPESE who survived the first 6 years of the follow-up period, those who died were significantly older at baseline (77.0 vs 72.6 years, $P<.001$) and more likely to be men (47% vs 33%, $P<.001$) and single (56% vs 49%, $P<.001$). At baseline, decedents also reported a higher number of the following previous medical conditions: history of cancer, heart disease, diabetes, hip fracture, or stroke (0.76 vs 0.44, $P<.001$). Years of education and percentage of nonwhite race did not differ between decedents and survivors.

Among the 4190 decedents who happened to have interviews during the final year of life, the decedent group sizes were as follows when sequentially identified: sudden death (n=649 [15%]), cancer (n=897 [21%]), organ failure (n=817 [20%]), frail (n=837 [20%]), and other (n=990 [24%]). When allowed, overlap existed primarily among the organ failure and frailty groups (n=320 [8%]) and the cancer and frailty groups (n=202 [5%]).

Among the decedent groups, cancer decedents were the youngest group (TABLE 1). Death from cancer peaked before age 80 years, and 79% were younger than 85 years when they died. Organ failure decedents were also significantly older, whereas members of the sudden death and unclassified groups were younger than the mean age. Those classified as frail were the oldest. Of these, 77% were aged 80 years or older, and the distribution among age groups increased steadily with each incremental increase in age. Frail decedents were most likely to be women and least likely to be currently married. The unclassified or "other" decedents had the most coexisting medical conditions.

For all decedents, mean function declined across the 12-month–based subgroups in a pattern that could be expected to represent mean individual decline in the final year of life. With decedents grouped into 3 age categories (65-74 years, 75-84 years, and ≥85 years), the overall level of dependency was greater with increasing age, but the trajectory of ADL dependence followed a similar slope of decline for each age group. Similarly, sex differences existed in the amount of disability but not in the slope of decline in the last year of life. As has been well documented by others,[19,20] women in this study were consistently more disabled than their male counterparts. No differences in functional disability prior to death associated with race or level of education were significant.

Figure 2. Dependent Activities of Daily Living (ADLs) for Each Month Cohort, by Trajectory Group



Error bars indicate 95% confidence intervals.

FIGURE 2 shows patterns of observed ADL disability for each of the 4 trajectory-based groups. Those in the sudden death group were substantially more independent and these cohorts did not decline in function as death approached. The mean (95% confidence interval [CI]) number of ADL disabilities for those interviewed in the final month of life (1.22 [0.59-1.85]) was not significantly different from that for those interviewed 12 months before death (0.69 [0.19-1.19]) ($P=.20$). Cancer decedents also experienced better functional status early in the final year, but those interviewed during the 3 months before death were markedly more disabled. Individual variation in functional ability during any 1-year period fits with the clinical pattern of disease exacerbations associated with congestive heart failure and chronic obstructive pulmonary disease. However, this study examined only mean group disability and this also declined erratically for the organ failure decedents. Decedents in the frailty group were relatively more disabled throughout the last year of life. Like the cancer group, both the organ failure and frailty groups demonstrated a substantial decline in function during the last 3 months of life. For all 3 of these groups, those interviewed in the final month of life were significantly more disabled than those interviewed 12 months before death (cancer: 4.09 [3.37-4.81] vs 0.77 [0.30-1.24]; organ failure: 3.66 [2.94-4.38] vs 2.10 [1.49-2.70]; frailty: 5.84 [5.33-6.35] vs 2.92 [2.24-3.60]; $P<.001$ for all).

The decedents who met none of the classification criteria (ie, the "other" group) showed a pattern of modest and gradual decline in independence during the final year of life. Those interviewed 12 months before death reported dependence in 1.23 (95% CI, 0.77-1.69) of 7 activities; those interviewed in the final month of life reported a mean of 2.27 (95% CI, 1.58-2.96) dependencies. Of these unclassified decedents, 395 (40%) had ischemic heart disease noted as the underlying cause of death, whereas this rate of ischemic heart disease was 27% across the full decedent pool. The pattern of modest, gradual functional decline in the unclassified group closely matched the pattern of decline we found when we evaluated all ischemic heart disease decedents (n=1140) as a single decedent group. Among decedents who had had ischemic heart disease noted in any field on the death certificate, those interviewed 12 months before death reported dependence in 0.74 (95% CI, 0.35-1.13) of 7 activities; those interviewed in the last month of life reported a mean of 2.38 (95% CI, 1.28-2.98) dependencies.

In the multiple logistic regression model of ADL dependency, assignment to a trajectory category continued to be a very strong predictor of disability even after controlling for age, sex, race, education, marital status, and the interval between the final interview and death (TABLE 2). Not surprisingly, decedents aged 85 years or older were 4 times more likely to require assistance as those aged 65 through 74 years. Women were more than one and a half times more likely to be dependent than were men. Yet, after controlling for these and other demographic differences, those assigned to the frailty group were more than 8 times more likely to be ADL dependent than those who died suddenly.

COMMENT

The empirical trajectories of functional decline for the 4 categories of decedents differed markedly and were very similar to the previously published theoretical model. The scheme is clinically intuitive and the possible existence of these different pathways to death has important implications for health care delivery. Only short-term expected deaths, such as may occur with cancer decedents, are likely to have a predictable terminal period that meets the public expectation of dying and the health care requirements for hospice

care. Those who experience entry-reentry deaths or lingering deaths may also need the supportive services offered by hospice care, but hospice reimbursement requires the certainty of a limited lifespan. Additional data about functional trajectories of dying will better inform both health care practice and delivery of service at the end of life.

Prospective, longitudinal data collected from a population-based sample at high risk of death provides an important opportunity to learn from retrospectively examining lives before both predictable and unpredictable death. The ideal data set would require frequent measures (at least quarterly) on all high-risk individuals for many years, thereby generating multiple data points in the year before each death. Unfortunately, such research is prohibitively expensive to conduct with large, population-based samples. On the other hand, with a large number of annual follow-up interviews and a sufficient sample size, the EPESE study allowed an alternative approach: analyses from multiple subgroups of the sample, each of which had data collected at a similar time point in the final year of life. Though limited to group analyses, this viewpoint permits a useful examination of functional decline from prospectively collected data.

This study and our previous analysis of Medicare claims data[2] demonstrate the importance of recognizing differences in the trajectories or clinical course that people can experience in the last phase of life. However, these studies also highlight the conceptual and operational challenges associated with attempts to create distinct categories from a complex event such as death, especially among elderly individuals. Defining frailty is a particular challenge. In this study, after first removing cancer and organ-failure decedents, we classified 20% of the decedents as frail using evidence of a nursing home stay as the defining criterion. Using a similar procedure in our previous analyses, we classified 47% as frail with the criterion of a Medicare claim listing 1 condition from a previously published list of conditions commonly associated with slowly declining health.[21] As a proxy for frailty, nursing home utilization has some face validity, but it undoubtedly underestimates the frail population and tends to present a circular argument when ADLs serve as the outcome measure. Unfortunately, diagnoses on death certificates do not currently offer a reasonable alternative approach for the identification of frail elderly decedents.

Table 2. Multiple Logistic Regression Model Predicting ADL Dependency*

Effect	No. (%)	OR (95% CI)
Decedent group		
Sudden death	649 (16)	Reference
Cancer	897 (21)	1.57 (1.25-1.96)
Organ failure	817 (20)	3.00 (2.39-3.77)
Frailty	837 (20)	8.32 (6.46-10.73)
Other	990 (23)	1.84 (1.47-2.29)
Age group, y		
65-74	949 (23)	Reference
75-84	1846 (44)	1.62 (1.35-1.95)
≥85	1395 (33)	4.15 (3.36-5.14)
Women	2201 (53)	1.66 (1.41-1.95)
White	3338 (80)	0.75 (0.62-0.90)
Finished high school	1150 (28)	0.79 (0.67-0.93)
Currently married	1699 (44)	1.23 (1.04-1.46)

Abbreviations: ADL, activities of daily living; CI, confidence interval; OR, odds ratio.
*ADL dependency defined as requiring assistance with or being unable to perform any activity of daily living; model adjusted for number of months between functional assessment and death. The model correctly predicted disability for 75% of the decedents who had a predicted probability >0.5 from the model (C = 0.758).

These findings encourage further exploration of the possibility of a fifth conceptually distinct trajectory of dying: one in which individuals experience a steady decline in function but at a moderately high level of performance. This trajectory arose in the unclassified group and also among all decedents with ischemic heart disease as the underlying cause of death. A better understanding of the importance of this type of decline and the role of heart disease in functional decline at the end of life will require more comprehensive clinical data than are available in the EPESE study.

Even with these limitations, this empirical validation of the existence of different trajectories of dying is an important first step in getting beyond the "one-size-fits-all" model for end-of-life care and research. The public image of dying and most scientific evidence for care at the end of life come from studies of those diagnosed with a terminal illness. Yet that is not the experience facing most individuals in the United States, only 23% of whom die from cancer.[22] Many more will die from acute complications of an otherwise chronic condition, most likely without a discrete terminal illness phase.[3,23] Good end-of-life care must allow for this unpredictable timing of death. In addition to supporting those with a clearly terminal illness, we must find ways to better assist those for whom a serious chronic illness or multiple chronic problems present an ongoing threat of sudden exacerbation and death. End-of-life care must also serve those who become increasingly frail, even without a life-threatening illness. Because of a steadily diminishing reserve capacity to cope with inevitable but unpredictable acute health challenges, these frail elderly persons may also die without a clear terminal period. Given the variable trajectories of dependency, our data support the idea that each group requires a different clinical approach and different types of health services.

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Philosophy asks the simple question, What is it all about?
Alfred North Whitehead (1861-1947)