

# Trajectories of Health for Older Adults Over Time: Accounting Fully for Death

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The process of healthy aging can best be described by plotting the trajectory of health-related variables over time. Unfortunately, graphs including data only from survivors may be misleading because they may confuse patterns of mortality with patterns of change in health. Two approaches for creating graphs that account for death in such situations are 1) to incorporate a category or value for death into the longitudinal health variable and 2) to measure time in years before death or some other event. The first approach has been applied to self-rated health (excellent to poor) and the 36-Item Short-Form Health Survey (SF-36). It allows for

flexible and interpretable analyses and may be appropriate for other variables as well. The second approach also accounts fully for death, but the questions it can address are limited. Both approaches are useful and should be used at a minimum for supporting analyses in longitudinal studies in which persons die during observation.

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The study of healthy aging is essentially the study of how health-related variables, such as cognition, change over time for persons with different characteristics. One of the best ways to demonstrate this change is a graph, such as a plot of average cognitive ability over time for men and women. Unfortunately, if some people die during the study, their longitudinal health variable (which we refer to generically as “health”) is “missing” after their death. The usual analytic approach is to perform a complete case analysis or an available data analysis, both of which restrict study to the healthiest subgroup of the study sample and may give an overly optimistic picture of the trajectory. Our goal is to develop a graph of health over time that accounts appropriately for death. In this paper, we demonstrate how omission of the deaths gives incorrect results and explain and illustrate two approaches for including deaths in longitudinal graphs.

There are 3 components of a longitudinal analysis: a longitudinal variable (health) measured frequently (every year), a measure of time, and an independent variable ( $x$ ) whose association with health over time is of interest. Time could be a calendar year, years since recruitment, or age at the time of the measurement. Alternatively, time could be measured in relation to some event, such as years before death or before and after stroke or myocardial infarction. Finally, we would usually be interested in how persons differ by some factor, such as treatment or control status or sex, indicated by the variable  $x$ . **Figure 1** shows a generic health analysis based only on available data and shows the mean of health over time for two groups.

Although the two lines in **Figure 1** appear to be parallel, the upper line increased by 7.77 points in 9 years and the lower line increased by 8.98 points in 9 years. One might predict that the two lines would cross at some future date. This is a foolish conclusion, since the health-related variable in this case is age and  $x$  denotes age 75 years or older at baseline versus age 65 to 75 years at baseline. The “finding” implies that younger persons age faster than older persons and will eventually catch up in age. Fortu-

nately, the truth is known in this situation: Both groups age 1 year per year. The discrepancy occurs because the oldest people are most likely to die. The mean age of persons alive at each point does not increase 1 full year per year. In this case, one has mistaken a pattern of dying for a pattern of change in health. This particular mistake would never be made, but similar mistakes could easily be made when the true model is not known, which is usually the case. We suggest some ways of graphing data that account fully for death and avoid such problems.

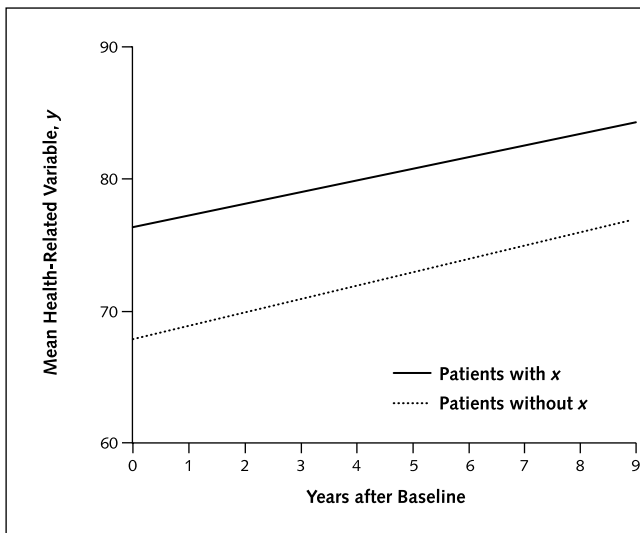
## METHODS

We explored incorporating deaths into 2 components of the longitudinal analysis: health and time. We operationalized the approaches and illustrated them using data from the Cardiovascular Health Study.

The Cardiovascular Health Study is a population-based longitudinal study of 5888 adults 65 years of age and older at baseline (1). Participating investigators and institutions from the study are listed in the Appendix (available at [www.annals.org](http://www.annals.org)). Participants were recruited from a random sample of the Medicare eligibility lists in four U.S. counties. Extensive baseline data were collected for all participants. After baseline, participants had an annual clinic visit and provided additional information by mail and telephone. Two cohorts were followed, one cohort ( $n = 5201$ ) with 10 years of follow-up and the second cohort (all African Americans,  $n = 687$ ) with 7 years of follow-up to date. Data collection began in 1990 and follow-up was almost complete for all surviving participants in 2000 (2). At baseline, the mean age was 73 years (range, 65 to 100 years), 58% were women, and 84% were white.

The Cardiovascular Health Study has longitudinal data on many older adults, with 9 years of follow-up and very little loss to follow-up. Many participants died (30% in the first 9 years), but there were relatively few missing data. We imputed values for the missing data (except those missing because of death), explained in detail elsewhere (3,

Figure 1. Mean of health over time.



The variable *x* denotes age  $\geq 75$  years at baseline versus age 65 to 75 years at baseline.

4). In the current paper, we refer to excellent, very good, or good health as being “healthy” and fair or poor health, or dead, as “not healthy.”

**RESULTS**

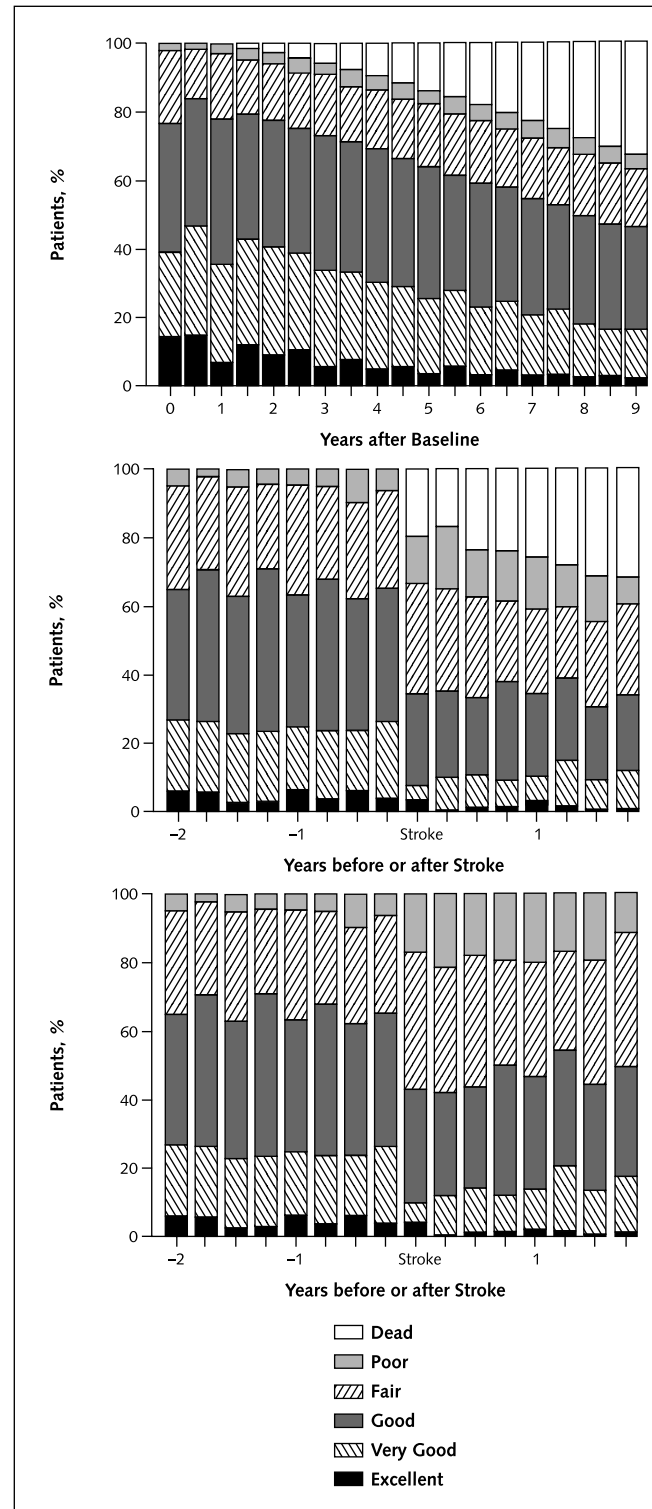
A few measures, such as the Quality of Well-Being scale (5) and the Health Utilities Index (6), were constructed so that death has a value of 0, but most health-related variables do not have a value for death. We consider adding a category or value for death, which results in a new variable that has a value for death, is a monotone transformation of the original variable, is interpretable, and is on a ratio scale.

Diehr and colleagues (7, 8) have considered the ubiquitous measure “How is your health: excellent, very good, good, fair, or poor?” When this measure is used longitudinally, it seems logical to add a sixth category, dead. One approach to exploring the trends in health over time is to calculate transition probabilities among the 6 health states (9). By using such probabilities, the health of a hypothetical cohort of men in poor health at age 70 years was projected to improve until about age 76 years, after which it declined (10). Another approach is to graph the frequencies of the 6 categories over time. The top panel of Figure 2 shows the percentage of Cardiovascular Health Study participants in each health state by time from baseline. All persons were alive at baseline, but over time a substantial percentage of the original cohort died. Tracing the top of the “good” layer shows the regular decrease in the percentage of persons who are healthy (the percentage in excellent, very good, or good health) over time.

Such stacked bar graphs can be used with different measures of time, such as time before and after a stroke, as shown in the middle panel of Figure 2. The percentage of

persons who are healthy is flat in the 2 years before the stroke, decreases by about 30 percentage points at the time of the stroke, and does not indicate recovery (the percent-

Figure 2. Persons' health in the first 9 years of the Cardiovascular Health Study (top), in the 2 years before or after stroke (middle), and before or after stroke with no deaths (bottom).



**Table. Three Ways of Recoding Self-Rated Health To Include Death\***

Method	Ordinal	Healthy (Yes or No)	Probability That a Person Is Healthy 2 Years Later
Interpretation of mean	Unclear	Percentage of persons who are healthy	Percentage of persons expected to be healthy
Abbreviation	—	PCTH	EPCTH
Excellent	5	100	95
Very good	4	100	90
Good	3	100	80
Fair	2	0	30
Poor	1	0	15
Dead	0	0	0

\* The measure of self-rated health was the question, “How is your health: excellent, very good, good, fair, or poor?” EPCTH = percentage of persons expected to be healthy 2 years later; PCTH = percentage of persons who are healthy.

age does not increase after the stroke). This decrease is caused, in part, by the deaths. A qualitatively different picture emerges in the bottom panel of **Figure 2**, which does not include the deaths and indicates a smaller decrease at the time of the stroke, followed by some recovery. This panel may be misleading because it does not represent the trajectory of health for all persons experiencing a stroke.

The stacked bar graphs show the distribution of all 6 health states over time but are inconvenient for analysis because it is difficult to compare the trajectories of different groups. Diehr and colleagues (7) considered two ways of assigning values to the 6 levels (**Table**). The second column shows how the 6 states could be transformed to create an ordinal variable. This variable could be used in nonparametric analyses but is unsatisfying to plot over time because its mean is not interpretable. The third column transforms the 6 categories into a binary variable that takes on the value of 100 if the person is “healthy” and 0 if the person is “not healthy.” “Dead” is coded as 0. The mean of this variable is the percentage who were healthy, or PCTH. This value is completely interpretable, but it may lose information in going from 6 categories to 2. Furthermore, it may seem inappropriate to group fair or poor health with death.

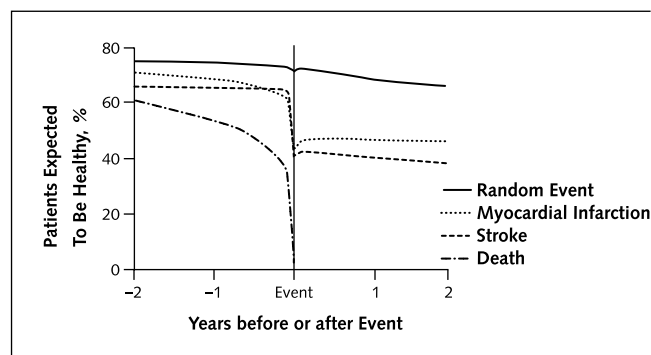
The fourth column of the **Table** gives coding for a new variable that overcomes both these shortcomings: the estimated percentage probability of persons being healthy 2 years later, or the expected percentage of healthy persons (EPCTH). Under this transformation, “excellent” is coded as 95 because 95% of older adults who are in excellent health are healthy 2 years later, “poor” is coded as 15 because only 15% are healthy 2 years later, and “dead” is coded as 0. These probabilities were developed from several data sets, including the Cardiovascular Health Study, and were nearly the same if a 1-year time horizon was used (8). The mean of EPCTH is the percentage of persons expected to be healthy 2 years later. Mean EPCTH is consistently lower than PCTH because it refers to health 2 years in the future and health declines on average for older adults. If

mean PCTH is plotted versus time, the area under the curve is the mean number of years spent in the “healthy” state, or the years of healthy life. The interpretation of the area under the EPCTH curve is the expected years of healthy life beginning 2 years in the future (8).

Mean PCTH and EPCTH can be examined before and after a stroke, and the trajectories can be compared for different types of events. **Figure 3** shows the smoothed trajectories before and after death, stroke, myocardial infarction, and a random event for a comparison group, which was constructed in a manner similar to that of a figure published elsewhere (3). The trajectories are very different: The random event group declines only a little over time, the myocardial infarction shows previous decline and some recovery, the strokes show no previous decline and no recovery, and the deaths have the lowest initial value and the steepest decline in the 2 years before the event.

The PCTH and EPCTH transformations may be appropriate for disability measures, as well as health status. For example, the Cardiovascular Health Study measured activities of daily living each year and assessed which of 6 activities could be performed without limitations (4). We defined “healthy” as having no activities of daily living disabilities, rather than being in excellent, very good, or good health. The PCTH from activities of daily living could be calculated by coding persons with no disabilities as “disability-free,” 100, and those with some disabilities as “not disability-free,” 0. Dead persons would be coded as 0. The mean of PCTH for a group is the percentage of persons who are disability-free. The EPCTH is the estimated probability of persons being disability-free 1 year later, conditional on the activities of daily living. In the Cardiovascular Health Study, participants with no disabilities had an 88% chance of being disability-free 1 year later and would be coded as 88, persons with one disability would be coded as 42, persons with two disabilities would be coded as 21, persons with three disabilities would be coded as 14, and persons with four to six disabilities would be coded as

**Figure 3. Expected percentage of persons who are healthy before or after an event.**



Adapted from Diehr et al. (3).

7. Dead persons would be coded as 0. The area under the PCTH curve over time is the years without disability, sometimes called disability-adjusted life-years. Similarly, the area under the EPCTH curve is expected disability-adjusted life-years starting 1 year in the future. The relation of such summary measures to preference-based quantities is discussed elsewhere (8). The transformed variable can be graphed and can also be used as a dependent variable in regression analyses.

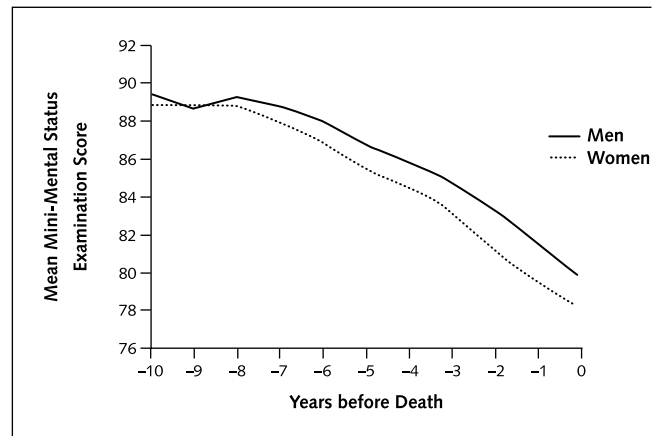
The PCTH and EPCTH can also be calculated for continuous measures of health, such as the 36-Item Short-Form Health Survey (SF-36) physical component score, by using logistic regression (8). Such a regression could include other variables, such as age and sex, to improve the estimate, although this has not been done. In that study of veterans, for a subgroup of patients who died within 2.5 years of baseline, the average physical component score from the available data decreased by only 3.5 points in 2 years, which is a surprisingly small change (11). The EPCTH, which accounted for death, decreased from 35% to 8% in 2 years, which was a more reasonable picture of the change in physical health for people who were dying.

The modified Mini-Mental State Examination, which takes values from 0 to 100, does not have a code for death, although it might be transformed by one of the methods previously mentioned. Death can be incorporated into the time variable by measuring time backward from the date of death (4). **Figure 4** shows the mean Mini-Mental State Examination scores, which decreased in the years before death for both men and women. The mean Mini-Mental State Examination score before any other event could be treated in the same way, since a person must be alive before having an event. Another approach is a regression model to predict the Mini-Mental State Examination score as a function of age and age at death (4). These approaches are reasonable if the research goal is to examine the trajectory of health before death (or another event, such as stroke). It uses data only for persons with an event, which requires that the number of events be large. The approach is descriptive but not predictive because the date of death must be known to determine a person's place on the curve.

## DISCUSSION

We gave examples of graphs that were misleading because they did not fully account for death. Such graphs may seem to show the expected trajectory of health but, in fact, refer to a different and healthier subset at each time point—those persons who are still alive. Such information is sometimes of interest, but it should always be clearly stated that the graphs do not refer to a prospective cohort and cannot be used to describe the future for an individual. Problems of differential mortality in drawing longitudinal conclusions from cross-sectional data are well understood (12), but similar problems with the use of longitudinal data may be less familiar.

**Figure 4.** Mini-Mental Status Examination score by years from death.



The first approach, incorporating death in the health-related variable, allows for extremely flexible analyses. The means of the new variables PCTH and EPCTH are interpretable and both are on a ratio scale, which makes them at least as desirable as the original variables on which they are based (8). Related graphical approaches have been used by other studies (13–16). Once the graph exists, regression analyses and tests of hypotheses can be used to test features of the graphs. Such analyses need to account for correlated data if persons contribute more than one observation. When these transformed variables are used, it is advisable to impute values for data missing for other reasons than death, since values for the dead will always be known, and death might have too much influence (11). Other outcome variables could probably be transformed to include a reasonable value for death. The primary requirement is that death can be considered “not healthy” on the construct underlying the variable of interest.

The second graphical approach, measuring time before some event (such as death), also completely accounts for death and is useful for descriptive studies of the health-related variable before an event, in situations where the number of events is large.

The Cardiovascular Health Study data are unusual in having little loss to follow-up, which allowed us to estimate the missing data from data before and after the missing assessment (3, 4). In data sets with fewer deaths and more loss to follow-up, death may not be the most important threat to validity, and methods presented in this paper may not be as salient.

## CONCLUSION

Patterns of death can bias the observed patterns of health-related variables over time, providing results that are too optimistic. The transformation of health-related variables to include death or running time backwards from an event should be considered at least for supporting analyses

or sensitivity analysis in longitudinal studies of healthy aging in which deaths occur.

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