

Three Year Functional Trajectories Among Old Age Survivors and Decedents: Dying Eliminates a Racial Disparity

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BACKGROUND: Long-term trajectories of disability comparing decedents and survivors and differences by race have not been assessed.

OBJECTIVE: To examine self-reported difficulty in walking a quarter mile and the need for assistance with activities of daily living (ADL) beginning 3 years before death among decedents and age- and gender-matched survivors.

DESIGN: A case-control sample drawn from the Health, Aging and Body Composition Study (Health ABC). Data were collected between 1997 and 2015.

PARTICIPANTS: Of the 1991 participants who died by the end of the study, 1410 were interviewed for 3 years prior to death, including an interview 6 months before dying. Of these, 1379 decedents were successfully matched by age and gender with 1379 survivors and tracked over the same 3-year period.

MAIN MEASURES: Self-reported difficulty walking a quarter mile and the ability to perform activities of daily living without assistance (bathing, dressing, transferring).

KEY RESULTS: Decedents (mean age at death, 84) increased in mobility disability from 44.1% 3 years before death to 69.4% 6 months before death and in ADL disability from 32.9% to 58.4%. Among survivors, mobility disability increased from 31.4% to 40.7% and ADL disability from 17.4% to 31.4%. The proportion of decedents and survivors with mobility disability differed significantly in adjusted models at all assessment points ($p < 0.0001$). African-American survivors were significantly more disabled than White survivors at all points ($p < 0.0001$), but trajectories of disability among decedents did not differ by race in the last 18 months of life ($p = 0.35$).

CONCLUSIONS: Trajectories of self-reported disability differ between survivors and decedents. Older adults who died were more disabled 3 years before death and also had a greater risk of increasing disability over each subsequent 6-month assessment. The gap in disability between African Americans and Whites was erased in the final 1 to 1.5 years before death.

KEY WORDS: racial disparities; end of life; disability mobility; functional decline.

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Substantial research demonstrates that physical disability is an important predictor of mortality.^{1–4} We also know that African American older adults are more likely to experience disability than Whites.^{5–7} Yet despite substantial research examining trajectories of disability before death,^{8–11} it is unclear how disability trajectories among decedents and survivors differ in old age and if they are influenced by race.

An early study examined 10,187 decedents with 2 years of Health Interview Survey assessments (1986–1994). In this sample, African Americans were younger at death than Whites (mean age, 71.3 vs. 73.9 respectively), but were more disabled even with adjustment for age and education. The authors concluded that the “Black health disadvantage embrace[s] both ends of the life course,”¹² noting that African Americans face greater risk of infant mortality and preterm birth as well as disparities in risk of death in old age. The Black-White disparity persisted even with adjustment for education in this early analysis. By contrast, analyses using the Health and Retirement Survey (HRS) from 2000 to 2010 did not find differences in the 2 years before death among White, African American, and Hispanic decedents (mean age at death for all race groups, 79). After adjustment for socioeconomic factors, the prevalence of disability in the activities of daily living (ADL) increased from 26% to 54% among Whites, from 29% to 58% among African Americans, and from 30% to 58% among Hispanics.¹¹ Gender was more important than race in predicting disability in the 2 years before death. The prevalence of disability increased from 21% to 47% among men but from 32% to 61% among women. An alternative use of the HRS modeled trajectories of disability among decedents over 15 years. Taking into account both age and time to death, this modeling effort found that 12% of decedents experienced early accumulating ADL disability over the 15 years before death. African Americans (along with Hispanics and women) were more likely to experience this disability trajectory.¹⁰

The different conclusions regarding race differences in disability before death are likely due to differences in definitions of disability, length of follow-up, ages at death, and the decades in which the cohorts were followed. Another limitation is their restriction to decedents. We compared disability trajectories of both survivors and decedents, by race, over the same period and within the same cohort to take a closer look at the effects of dying on racial differences in disability. Specifically, we sought to determine if approaching the end of life narrows racial disparities.

METHODS

Sample

We derived our sample from the Health, Aging and Body Composition (Health ABC) panel study. Participants were originally recruited in 1997–1998 to investigate changes in body composition and mobility decline. Participants were recruited by mail from a random sample of White Medicare beneficiaries and all African American community residents in Pittsburgh and Memphis who met the age criteria. At baseline, the 3075 participants were aged 70–79 and met the following additional eligibility criteria: no self-reported difficulty walking one-quarter of a mile or walking up ten steps, no difficulty performing mobility-related activities of daily living (ADLs), no life-threatening cancers with active treatment within the past 3 years, and no plans to move from the study area for the next 3 years. At baseline, the cohort was 48.4% male and 41.6% African American. The institutional review boards at the University of Pittsburgh, University of Tennessee Health Science Center, and University of California at San Francisco approved the study protocol, and written informed consent was obtained from all participants. Background on the cohort is available at <https://healthabc.nia.nih.gov>.

Matching Decedents and Survivors

We identified deceased subjects at each assessment period, eliminating participants who died before the start of year 4 (whose early death prevented them from having 3 years of follow-up). Each decedent was matched by age and gender with one survivor at the assessment interval when he or she died. A survivor, by definition, was alive 6 months after the matched decedent's death, but could die, be lost to follow-up, or be used as a survivor again in matching to a death that occurred later in cohort follow-up. (In fact, only one participant was matched more than once.) We randomly chose one subject when there were multiple survivors that could be matched to a decedent. We identified 1379 matched pairs or dyads of decedents and survivors for an analytic sample of 2758 subjects. Each participant was interviewed every 6 months over the 3-year period. Survivors and decedents were compared across the 3 years, going back in time from the assessment

6 months before the death of the decedent to assessments 36 months earlier, over six different assessments.

Measures

The primary outcome was a dichotomous self-report of mobility disability, subjects' self-reported ability to walk a quarter mile (difficulty, no difficulty). At 6-month intervals throughout the study, participants were asked if they had any difficulty walking a quarter mile (about 2 or 3 blocks). A secondary analysis addressed disability in the activities of daily living (bathing, dressing, or transferring from bed to chair). Questions about these activities were asked less regularly, so these analyses had higher rates of missing data.

Analyses

We identified decedent interviews that fell into a window defined by 90 days on either side of the date of death minus 6, 12, 18, 24, 30, and 36 months. Among decedents, 9% were missing mobility data 6 months before death, but that proportion increased to as much as 22–24% in earlier assessments. The proportion of missing data for survivors was more stable across assessments, varying from 11 to 15%. Given the likelihood of illness, hospitalization, or long-term care residence in this population, we did not assume that data were missing at random. We accordingly conducted two sets of analyses, one limited to people with valid values and one in which we imputed values. For the latter, we assigned disabled status to all intervals in which mobility information was missing. Results from models limited to valid data and using imputed values were similar. We present results using data without imputation, except for the analysis of volatility (which relied on temporarily sequential pairs of assessments).

We used a generalized linear mixed-effects logistic model to compare trajectories of self-reported mobility disability between decedents and survivors controlling for time and interactions between time and survival status as well as race. To examine volatility within disability trajectories we examined each pair of assessment intervals and noted the number of participants who switched between reports of no difficulty and difficulty. We counted the total number of transitions and also the number of increases and decreases in disability. Using a Poisson model, which included vital status and race, we examined correlates of the number of reported transitions. Statistical analyses were conducted using SAS version 9.3 (SAS institute, Cary, NC). Significance was set at 0.05 for two-sided hypothesis testing. Summary statistics were reported as mean (SD) and frequency count (%).

RESULTS

Characteristics of the decedents and survivors are shown in Table 1. By design, age and gender were matched across survivors and decedents. The mean age of death in the

Table 1 Decedent and Survivor Characteristics

	Decedents (n = 1379)		Survivors (n = 1379)	
	African Am (n = 562)	White (n = 817)	African Am (n = 532)	White (n = 847)
Female n (%)	303 (54)	344 (42)	287 (54)	360 (43)
Mean age at study entry (SD)	74 (2.8)	74 (2.8)	74 (2.9)	74 (2.9)
High School graduate, n (%)	301 (54)	713 (87)	323 (61)	760 (90)
Household income <\$25 K, % (n)	293 (45.7)	411 (46.2)	284 (48.6)	464 (49.7)
Self-reported comorbidity*				
Lung disease, n (%)	93 (17)	187 (23)	53 (10)	127 (15)
Diabetes, n (%)	210 (37)	184 (23)	177 (33)	176 (21)
Congestive heart failure, n (%)	110 (20)	173 (21)	26 (5)	58 (7)
Cancer, n (%)	192 (34)	372 (46)	84 (16)	196 (23)

*As of death or censoring

decedent group was 84. Decedents and survivors were similar in the proportion African Americans (40.1% among decedents, 38.6% among survivors). Among African-Americans, decedents were less likely to report high school education than survivors (54% vs. 61%). Decedents were significantly more likely to report lung disease, congestive heart failure, and cancer in the 3-year follow-back period relative to survivors but did not differ in the prevalence of diabetes.

Prevalence of Mobility Disability in Survivors and Decedents

Reports of no difficulty walking a quarter mile were more prevalent in the survivor group than among decedents at each interval during the 3-year period. At 3 years before death or censoring, 55.9% of the group that would later die reported no difficulty walking a quarter mile compared to 68.7% of survivors. At 6 months before death, only 30.6% of people who later died reported no difficulty compared to 59.2% among survivors. Over the six assessment periods, the gap between decedent and survivor trajectories widened, with the decedent group showing a steeper trajectory of disability ($p < 0.0001$). The increase in proportion of disability was 4.1%, on average, among decedents across each 6-month period compared to 1.4% among survivors.

Trajectories of mobility disability varied by race. As Fig. 1 demonstrates, White survivors were more likely to report no difficulty walking a quarter mile than African American survivors over the 3 years ($p < 0.0001$). In the generalized linear mixed-effects model, survival status and time were both significant predictors of self-reported disability ($p < 0.0001$). Interactions involving race were all significant: race and decedent status ($p < 0.0001$), race and month ($p = 0.01$), and race by decedent status by month ($p = 0.03$). However, among decedents, disability trajectories for the two racial groups converged. Though African American decedents were less likely to report absence of mobility disability from 36 to 24 months before death, trajectories did not differ beginning 18 months before death ($p = 0.35$).

Prevalence of ADL Disability Among Decedents and Survivors

ADL disability levels were lower, but varied between decedents and survivors and among the racial subgroups in a pattern similar to that of mobility disability. As Fig. 2 demonstrates, survivors were less likely to need help than decedents. Furthermore, White survivors were less likely than African American survivors to need help in ADLs. Because ADLs were assessed less regularly than mobility, data were missing from 19% of the sample at 6 months before death or censoring and 31% of the sample at 36 months. Nonetheless, the subsample with ADL data available was similar in vital status, age, gender, and race to the full analytic sample.

Volatility in Functional Status

Decedents and survivors differed in volatility, that is, switching between having difficulty walking a quarter mile and not having difficulty over the 6 assessment points. In counting the number of changes between disabled and non-disabled states across all pairs of intervals (which ranged from 0 to 5), 40.3% of survivors had no change compared to 46.9% of decedents ($p = 0.0005$). In a Poisson model examining vital

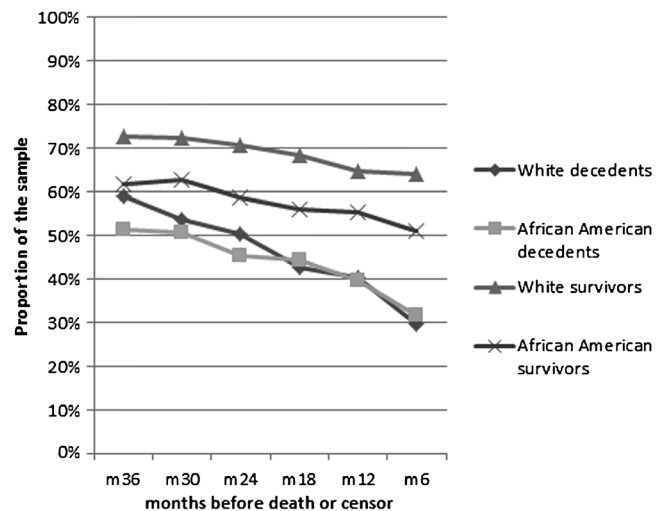


Figure 1 Ability to walk a quarter mile without difficulty by vital status and race

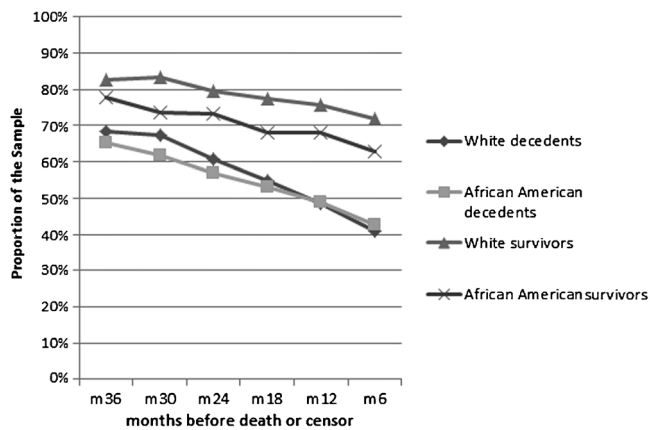


Figure 2 Ability to perform activities of daily living without assistance by vital status and race

status and race as correlates of the number of changes, African-American respondents showed greater volatility than Whites ($p = 0.0006$).

DISCUSSION

Analysis of the Health ABC cohort shows that trajectories of self-reported mobility disability differ between survivors and decedents. Older adults who died after 3 years of follow-up were more likely to have difficulty walking a quarter mile at the start of this period and also had a greater likelihood of disability over each subsequent 6-month assessment. Trajectories of decline for survivors were significantly different for African American versus White participants, but decedent trajectories for the two racial groups merged as death approached.

These findings are consistent with research identifying the role of disability in predicting mortality. Research suggests that disability, more than multi-morbidity, is predictive of mortality among older persons aged 80 years and older.¹³ Most investigators have examined the role of ADL disability in predicting death, but some have previously identified the direct contribution of mobility impairment, even in the absence of ADL disability.^{14, 15}

Mobility impairment is generally understood to be an antecedent of ADL disability.¹⁶ Although our ability to analyze ADL disability was limited by the study design, the data suggest that trajectories of ADL disability follow a similar pattern to mobility trajectories, but at a substantially lower level of disability. These findings provide additional support to the supposition that mobility impairment precedes ADL disability.

Our results confirm and extend the findings of an early investigation by Guralnik et al. in 1991.¹⁷ These investigators compared functional decline between the 531 persons who died between follow-ups 2 and 3 of the Established Populations for Epidemiologic Studies of the Elderly (EPSE) and the

8821 study participants known to have survived through year 3. They found that rates of disability increased during the 3 years of follow-up for both decedents and survivors, with decedents having higher rates throughout the period. They also found that disability rates increased with increasing age for both groups and were higher for both female decedents and survivors. Our gender- and age-matched sample controlled for those two covariates and allowed us to further elucidate differences in racial groups.

The attenuation of differences in the prevalence of mobility disability between African Americans and Whites as death approaches has not previously been reported. A large body of evidence demonstrates that older African Americans report more physical disability than Whites,^{6, 18} even after adjusting for age, sex, and socioeconomic status.^{19, 20} This disparity is also seen in performance-based measures.²¹ Attenuation of racial disparities in disability with the approach of death is consistent with previous work suggesting that part of the racial disparity can be explained by the number and severity of health conditions as well as access to medical care.^{5, 6, 22} Recent research suggests that racial and ethnic differences in disability are largely attenuated, though not eliminated, after adjusting for chronic conditions together with health behaviors and economic factors.^{23, 24}

The convergence of trajectories in disability in African American and White decedents but not survivors suggests that dying eliminates a health disparity. An earlier study found that functional health of African American women converged with White women after age 90, but African American men remained consistently more impaired than White men.²⁵ Our analysis, which controlled for both age and gender, showed a disparity remaining for survivors, suggesting that proximity to death rather than chronological age better explains the convergence. Results from our research are consistent with results from the analyses of the last 2 years before death in the Health and Retirement Survey¹¹ described earlier, but differ from other studies suggesting persistence of disparities at the end of life.^{10, 12}

The elimination of disparities among decedents but persistence among survivors in our study is notable because all participants came from the same cohort. They were recruited with the same entry criteria and received the same assessments on the same schedule. Decedents and survivors were matched on age and gender, and multivariate analyses allowed comparison of trajectories over 3 years. Notably, African American and White decedents did not differ in the prevalence of chronic conditions at the time of death. Thus, the number of chronic conditions and their disabling effects at the end of life appear to affect African Americans and Whites similarly. Otherwise said, for African Americans who reach late life, the approach of death reduces disparities in disability that are otherwise prominent throughout the lifespan.

While analyses using Health ABC offer the benefit of large samples, long follow-up, careful assessment of vital status, and a large number of older African Americans, the results from this research should be interpreted in light of limitations

in the study design. Clinical assessments were conducted annually, but it is possible that the medical status of the two groups differed. In this scenario, one group could have had more advanced disease, and thus a report of similar disability by race would mask a persisting disparity. However, we did not see evidence of differences in medical status. Another possibility is that the greater medical attention associated with participation in the study promoted more change in health behavior and access among African American participants than the White participants, who may have been receiving better medical care at baseline.⁷ Still, greater medical attention seems unlikely as the cause for reduced disparities, since disparities in disability persisted among survivors who had similar exposure to the research process.

The Health ABC cohort is a population-based sample of well-functioning older Americans drawn from two cities and observed from 1997 to 2015. Although not generalizable to the entire US population of older adults, these results are useful to formulate hypotheses to test in other cohorts. Use of other cohorts covering different periods of follow-up would allow researchers to determine whether disparities associated with the end of life were more pronounced in earlier decades, as suggested in the earlier analysis of the Health Interview Survey.¹² If so, these changes would reflect one welcome sign of progress in health equity. However, much work remains to be completed towards reducing health disparities, with a goal of eliminating them well in advance of death to ensure all individuals and families are able to benefit from not only longer, but also healthier lives.

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A very early decedent/survivor comparison (without the racial comparison) was presented at the Annual Assembly of the American Academy of Hospice and Palliative Care and the Hospice and Palliative Nurses Association in 2015.

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Compliance with Ethical Standards:

Conflict of Interest: The authors declare that they do not have a conflict of interest.

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