

# Is Death “The Great Equalizer”? The Social Stratification of Death Quality in the United States

By  
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Socioeconomic status (SES) gradients in mortality risk are well documented, although less is known about whether the quality of older adults' dying experiences is stratified by SES. I focus on six core components of a “good death”: pain and symptom management, acceptance, medical care that is concordant with one's preferences, dying at home, emotional preparation, and formal preparations for end-of-life care. Analyses are based on four data sets spanning the 1980s through 2010s, a period marked by rising economic inequalities: Changing Lives of Older Couples (1986–1994), Wisconsin Longitudinal Study (1993–2010), New Jersey End of Life study (2005–2007), and Wisconsin Study of Families and Loss (2010–2014). I find evidence of SES disparities in two outcomes only: pain and advance care planning (ACP), widely considered an important step toward a “good death.” Implications for health care policy and practice, against the backdrop of the Affordable Care Act implementation, are discussed.

*Keywords:* advance care planning; death; dying; inequality; pain; affordable care act

Death has been described as “the great equalizer” (Moodie 1853/2010), where all individuals “share a common destiny . . . the good and the bad, the clean and the unclean . . . will die” (Ecclesiastes 9:2–3, 12–13). Despite

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eloquent claims about the universality of death, empirical research shows conclusively that death is not an egalitarian transition. Socioeconomic advantage, whether defined by educational attainment, occupational status, income, or wealth, is associated with delayed mortality. These disparities have widened over the latter half of the twentieth and early twenty-first centuries (Olshansky et al. 2012), a pattern that mirrors growing socioeconomic disparities across diverse domains including health, family structure, and political attitudes, as documented elsewhere in this volume.

However, far less is known about whether such disparities exist regarding the *quality of death* in later life, or the extent to which the dying process is marked by pain versus comfort, awareness and acceptance versus denial, medical care that accords with rather than departs from one's wishes, and personal control versus acquiescence in end-of-life decision-making. Given mounting national attention to poor-quality, protracted, and futile end-of-life care, it is essential to understand whether the quality of death is stratified by socioeconomic resources, and whether these disparities have widened during the recent period of rising economic inequalities (Institute of Medicine 2014). I provide a brief historical overview of death and dying in the contemporary United States and suggest reasons why specific aspects of the dying process may be stratified by socioeconomic status. I analyze four data sets spanning the late 1980s through 2010s: the Changing Lives of Older Couples study (CLOC; 1986–1994), Wisconsin Longitudinal Study (WLS; 1993–2004), New Jersey End of Life study (NJEOL; 2005–2007), and Wisconsin Study of Families and Loss (WISTFL; 2010–2011) to reveal patterns of both stratification and universality in the end-of-life experiences of older adults. I focus on five attributes considered essential to a “good death” (i.e. pain, quality of care, emotional preparation, awareness, and site of death), and then investigate more fully the strategies that older adults use to take control over end-of-life medical decisions (i.e., advance care planning). These analyses highlight the complex ways that socioeconomic disadvantage may constrain autonomy and ultimately, the receipt of patient-centered care (Institute of Medicine 2014).

## Background

### *Mortality trends and differentials in later life*

Life expectancy has increased dramatically over the past six decades. In 1950, the average 65-year-old man and woman in the United States could expect to live another 12.6 and 14.4 years, respectively. By 2010, these figures increased to 17 and 18.5 years, respectively (Arias 2010). Despite aggregate-level trends of increased life expectancy, steep disparities exist where those with richer socioeconomic resources outlive those with fewer resources. These disparities have persisted and even widened in recent decades, as economic inequalities have intensified (Olshansky et al. 2012), although the magnitude of these disparities varies based on the specific cause of death and one's age, race, gender, and birth cohort (Phelan, Link, and Tehranifar 2010).

Socioeconomic disparities in late-life mortality are a contemporary phenomenon, reflecting the current cause of death structure in the United States. Roughly three-quarters of the 2.4 million deaths in the United States in 2010 were to persons ages 65 and older. The leading causes of death among older adults are chronic and progressive illnesses that can persist for months if not years prior to death, including heart disease, cancer, chronic lower respiratory diseases, stroke, Alzheimer’s disease, and diabetes (Federal Interagency Forum on Aging-Related Statistics 2012). Roughly 90 percent of older adults who die insured by Medicare have at least one of these conditions in the year prior to death. Thus, for the vast majority of older adults, death encompasses a prolonged period of disability, discomfort, and cognitive impairment; the receipt of personal care from a family member or paid caregiver; and the use of invasive life-sustaining technologies or intensive medication regimens (Shugarman et al. 2005). Dying older adults’ final days are typically spent in a hospital or nursing home, although survey data reveal that the vast majority of Americans would prefer to die at home (Federal Interagency Forum on Aging Related Statistics, 2012). Patients who are incapacitated and have not previously made plans for their own end-of-life care may receive unwanted and futile interventions such as feeding tubes or the withdrawal of treatments they may have desired (Institute of Medicine 2014). Difficult decisions about withholding or continuing treatment often fall upon distressed family members who may disagree with one another. The costs of end-of-life care are high, with Medicare payments averaging between \$24,000 and \$28,000 in the last year of life (Institute of Medicine 2014).

For dying older adults, prevention and cure are unrealistic goals; rather, the goal of patients and their families is to achieve an experience of “dying well” and ultimately a “good death” (Emanuel and Emanuel 1998). Philosophical writings and empirical studies generally converge upon several key components of “dying well” including pain and symptom management (including use of palliative care), communication about the course of one’s illness, the receipt of medical treatments consistent with one’s wishes, support for one’s existential and spiritual concerns, support for families and caregivers, and both emotional and practical preparedness for the impending death (Steinhauser et al. 2006).

A rapidly accumulating literature explores the components and correlates of death quality among older adults (George 2002), yet research on socioeconomic differentials is scarce. Lewis and colleagues (2011) conducted an extensive database search of articles published between 1996 and 2010, using paired terms capturing socioeconomic status (SES) (e.g., “class” “poverty,”) and end-of-life indicators (e.g., “dying,” “end of life care”). This search yielded only sixty-seven articles, thirty-three of which were focused on the United States. Nearly all of the thirty-three focused on racial differences, where SES indicators such as education were used as control variables only.

This dearth of research is due largely to data availability; most research on death quality focuses on small clinical samples of single-disease groups that do not allow for investigations of fine-grained SES differences (e.g., Melmed et al. 2002). Furthermore, most older adults at the end of life are retired, may rely on Social Security as their primary income source, or may have spent down most

their assets to pay for medical or nursing home care. As such, the handful of studies that do obtain information on SES may not necessarily capture the socioeconomic position that individuals occupied for most of their adult lives. In addition, research on end-of-life outcomes including site of death or use of hospice services often relies on administrative data such as death certificates or Medicare claims records, which include only minimal information on sociodemographic characteristics (Gruneir et al. 2007).

Other studies rely on area-level indicators of SES and explore associations between these aggregate-level indicators (e.g., percent poor in Metropolitan Statistical Area) and outcomes such as county-level availability of health services or average number of nursing home beds per thousand people, as measured by Area Resource File (ARF) data sets. For example, recent studies show that Medicare spending for care in the last year of life is higher for persons living in areas with the highest versus lower poverty rates (Nicholas et al. 2011) and in areas with the highest versus lowest median family incomes (Shugarman et al. 2005). However, studies using area-level SES indicators may be susceptible to the “ecological fallacy” and cannot assess conclusively whether the SES gradient in mortality extends to death quality. Additionally, outcomes such as Medicare expenditures do not necessarily represent a “good” or “bad” death, because they cannot distinguish whether high levels of service use at the end of life were desired by the patient and family. Recognizing these data limitations, researchers have called for a national minimum data set that can be used to assess end-of-life care and death quality within and across countries and have recommended key variables to be included in such resources. However, such data sources do not yet exist (Casarett, Teno, and Higginson 2006).

Furthermore, assessments of disparities in death quality over time are virtually absent from the literature. Policies, practices, and research targeting quality of dying issues are very recent developments. George (2002) conducted a database search on key words related to the end of life (e.g., “death and dying”), focusing primarily on MEDLINE, PsychInfo and Social Science Citation Index. The search was not restricted by date of publication, yet 90 percent of the roughly one thousand articles identified had been published after 1990.

### *Study aims*

I explore the extent to which SES indicators, including educational attainment, household income, assets, and home ownership, are associated with attributes considered essential to the quality of one’s death. I also explore whether SES and race affect one’s preparations for end-of-life care; specifically, whether one engages in advance care planning (ACP). ACP, which comprises having a living will, appointing a durable power of attorney for health care (DPAHC), and informally conveying one’s treatment preferences to significant others is an important precursor for having one’s treatment preferences heeded and for achieving a “good death” (Teno et al. 2007). Identifying disparities in ACP among contemporary cohorts of older adults may provide a harbinger for understanding disparities in death quality among future cohorts, because ACP is associated with less unwanted or futile care (Teno et al. 2007) and higher rates of hospice and palliative care use (Nicholas et al. 2011).

Specifically, I describe patterns from four data sets spanning the late 1980s through 2010s: CLOC (1986–1994), WLS (1993–2004), NJEOL (2005–2007), and WISTFL (2010–2014) to explore disparities in older adults’ end-of-life experiences and preparations. I focus on five subjective death quality appraisals (pain, problematic end-of-life care, place of death, mental awareness, and psychological preparation); evaluations are provided by recently bereaved spouses of older decedents. Assessments of ACP are provided by older adults, who are reporting on their own preparations. Each of these four data sets was designed for different purposes, and consequently each uses slightly different measures of SES and death quality attributes; however, the latter capture conceptually similar attributes such as pain and emotional preparation.

Fundamental cause theory (FCT) provides a guiding conceptual framework for exploring disparities in death quality and preparations. FCT posits that socioeconomically advantaged persons possess health-enhancing material and social resources including money, knowledge, power, prestige, and beneficial social connections. These resources are flexible, may be deployed across a variety of situations and settings, and thus have far-reaching effects on multiple aspects of health (Phelan, Link, and Tehranifar 2010). However, socioeconomic resources are protective only in situations where they can be used to gain an advantage. If these resources are not of potential use in a given situation, then “high SES should confer no advantage” (Phelan, Link, and Tehranifar 2010, S31). Consistent with this assumption, Phelan, Link, and Tehranifar (2010, S37) propose that policies or interventions that “automatically benefit individuals irrespective of their own resources or behaviors” should be effective in reducing inequalities.

Consistent with this perspective, one might predict that the dying experiences of older adults are relatively egalitarian. Three federal programs/policies that may equalize end-of-life experiences are Medicare, Medicaid, and the Patient Self-Determination Act (PSDA; 1990). Each of these policies benefits all older adults regardless of their economic standing. Medicare, a health insurance entitlement program enacted into law in 1965, insures persons ages 65 and older. Traditional Medicare includes Parts A and B, although beneficiaries can also purchase Part D, which covers prescription drugs. Part A covers inpatient hospital services, skilled nursing care, and some home health care. Part B provides coverage for physician and other outpatient services, outpatient hospital services, some medical equipment and supplies, and some home health services. In some cases, Part B services require a deductible or coinsurance. Medicare’s hospice benefit, implemented in 1983, covers palliative care and services for Medicare beneficiaries with a projected life expectancy of six months or less if the patient’s disease follows its “normal course,” as certified by a doctor. Persons opting to use the hospice benefit agree to give up treatments intended to cure and extend the life span, and instead receive benefits including health provider visits to one’s home, medical supplies, and short-term care in an inpatient hospice (Centers for Medicare & Medicaid Services [CMS] 2013).

Medicaid also is an important source for providing end-of-life medical care, although it was not initially designed as such. Medicaid is a state/federal jointly funded health insurance program primarily targeted toward low-income persons.

Many persons at the end of life are eligible for Medicaid because their health care needs deplete their financial resources to the point deemed “medically eligible” for such benefits. Unlike Medicare, however, Medicaid is partially operated at the state level, so individual states can determine which services (such as hospice care) are covered (CMS 2013).

The PSDA is a law mandating that all federally funded health care facilities give all patients an opportunity to complete an advance directive, which comprises a living will and durable power of attorney for health care (DPAHC). A living will is a legal document specifying the medical treatments a person would like to receive if incapacitated. A DPAHC permits a person appointed by the patient to make decisions about health care if the patient is incapable of doing so. However, living wills and DPAHC appointments have widely recognized limitations, so health care professionals urge patients to also convey their preferences and values to significant others via informal conversations (Institute of Medicine 2014).

Given universal access to these programs, we might expect that death quality is similar across the social strata. Conversely, disparities may emerge in more subtle ways to affect death quality, reflecting a range of processes including cultural differences in preferences for palliative (or pain-relief) services, literacy levels and access to the professionals who may assist one with their ACP, access to high quality end-of-life care sites in one’s geographic region, and both the psychological predisposition and means to make plans regarding one’s end-of-life care.

## Data

Analyses are based on four data sets spanning three decades: CLOC, WLS, NJEOL, and WISTFL.

*CLOC.* The CLOC is a prospective study of a two-stage area probability sample of 1,532 married individuals from the Detroit Standardized Metropolitan Statistical Area (SMSA). Respondents were noninstitutionalized English-speaking members of a married couple where the husband was age 65 or older. Approximately 65 percent of those contacted for an interview participated, consistent with response rates from other Detroit-area studies. Baseline face-to-face interviews were conducted in 1987 and 1988. After the baseline interviews were completed, the CLOC investigators monitored spousal loss by reading obituaries in three Detroit-area newspapers and by using monthly death record tapes provided by the State of Michigan. The National Death Index was used to confirm deaths and obtain causes of death. Women were oversampled at the baseline interview in order to maximize the number of participants who would become widowed during the study period. The data are weighted to adjust for unequal probabilities of selection and response rate. The average age is 70.

Of the 319 respondents who lost a spouse during the study period, 86 percent ( $n = 276$ ) participated in at least one of the three follow-up interviews conducted six months (wave 1), 18 months (wave 2), and 48 months (wave 3) after the

spouse's death. This analysis focuses on the 210 bereaved spouses who participated in the six-month interview, when questions were administered assessing subjective aspects of the late spouse's death.

*WLS.* The WLS is a random sample survey of 10,317 men and women who graduated from Wisconsin high schools in 1957. Participants were first surveyed during their senior year in high school and were reinterviewed at ages 36 (1975), 54 (1993), 65 (2004), and 72 (2011). Of the 9,025 living graduates in 2004, 7,265 (80.5 percent) participated in an interview. All sample members graduated high school; by contrast, 75 percent of Wisconsin youth graduated high school in the late 1950s. Nearly all study participants are white. Despite these limitations, the 2004 sample is broadly representative of white American men and women age 60 to 64 who have completed at least a high school education (U.S. Census Bureau 2003).

Topical modules were administered to random subsamples to reduce the interview length; the ACP module was administered to a random 70 percent subsample. The analytic sample for the death quality analysis is based on the 409 persons who lost a spouse in the 10 years prior to the 2004 interview, and completed questions assessing (retrospectively) their perceptions of their spouse's death. The analytic sample used to assess respondents' own ACP includes 4,971 persons who completed the end-of-life module. All measures used in this analysis are based on the 2004 data, unless noted otherwise.

*NJEOL.* The NJEOL is a study of noninstitutionalized adults ages 55 and older residing in New Jersey in 2005–2007. To be eligible for the study, individuals had to be either English- or Spanish-speaking, have no cognitive limitations, and have been diagnosed by a physician with a chronic health condition. Recruitment was conducted over the telephone from two large university hospitals and one comprehensive cancer center in New Jersey. The initial sampling frame consisted of 1,146 patients who were identified as potential study participants by the general internal medicine department at the study's main site; 575 met the criteria for inclusion in the initial sampling pool. Reasons for exclusion include invalid contact information, death after having been identified as a study candidate, severe cognitive and physical limitation precluding participation, and not meeting the study's age criteria.

The final sample includes 305 persons who consented to participate in a 1.5-hour face-to-face survey; this represents 53 percent of the eligible sampling frame. Reasons for nonparticipation included a reluctance to participate, frailty, and time constraints. The average participant is 69 years old, and roughly two-thirds are women. The analytic sample used to explore death quality focuses on the 234 persons who report that a significant other died within the past 10 years. The analytic sample used to explore individuals' own ACP draws on the full 305 participants. The sample is ethnically and racially diverse (57 percent non-Hispanic white, 27 percent non-Hispanic black, 16 percent Hispanic); thus, these data are also used to explore racial disparities in ACP. The average study participant is 69 years old.

*WISTFL.* WISTFL is a spin-off study of the WLS. Deaths to WLS sample members were regularly tracked using National Death Index and Social Security Death Index searches; follow-up interviews were subsequently conducted with one or two (where available) of the decedent's next of kin, to assess the conditions surrounding the death. Data collection on the WISTFL began in late 2010; to date, 743 interviews have been completed. The analyses presented here focus on the 198 bereaved spouses of recently deceased WLS participants; the average bereaved spouse is 72.2 years old.

## Measures

### *Dependent variables*

*Death quality.* Five aspects of death quality are considered. These attributes were measured in at least two of the four surveys and are considered integral aspects of death quality (Steinhauser et al. 2006). All responses were provided retrospectively by the surviving spouse. *Psychological preparation* refers to whether the surviving spouse and decedent had discussed how the spouse would manage after the death. *Pain* refers to whether the decedent experienced high or moderate levels of pain in the last week of life (versus slight or no pain). *Problematic care* refers to whether the decedent received care that was inconsistent with his/her wishes (WLS, NJEOL, WISTFL) or whether the surviving spouse believes that health care providers contributed in part to the death (CLOC). *Awareness* refers to whether the decedent was aware that he or she was dying (CLOC) or was capable of decision-making in the last week of life. *Death at home* refers to whether the decedent died at home versus in a nursing home or hospital. Each outcome is coded as a dichotomous measure.

*Advance care planning.* Three types of health-related end-of-life planning are considered: whether one has (1) a *living will*, (2) appointed a *DPAHC*, and (3) held *informal discussions* about end-of-life preparations. I also consider one aspect of financial planning: a *signed and witnessed will*. Actions to protect one's financial assets, such as the execution of a signed and witnessed will, may trigger health-related ACP in tandem—especially among persons with richer assets to protect. Affirmative responses are coded as 1. Each of the four types of planning is treated as a separate outcome in the WLS analysis; living wills and DPAHCs are combined in the NJEOL due to the small sample size and high levels of overlap in persons who did each type of planning; 90 percent of participants with a DPAHC also have a living will.

### *Independent variables*

The focal independent variables indicate SES including education, income, wealth/assets, and home ownership. *Education* refers to the highest level of schooling completed. *Total household income* refers to income received from all sources in the past year, in one's household.<sup>1</sup> *Home ownership* refers to whether



one currently owns a home. *Assets* or *net worth* are the total value of one’s savings, investments, properties (e.g., homes, business equity), and debts. Assets are assessed in the WLS and WISTFL only. The WLS project staff calculated a continuous measure of total net worth by summing these reports. Based on this continuous measure, I created five categorical indicators: no or negative assets (\$0 and lower), 25th percentile or below (\$1 to \$170,125), 25th to 50th percentile (\$170,125 to \$341,000), 50th to 75th percentile (\$341,000 to \$729,375), and 75th percentile or above (\$729,375 and above). The latter is the omitted group.

I control for demographic, health, and psychosocial characteristics that have been found elsewhere to be correlated with SES and both death quality and ACP (Carr 2003, 2012; Carr and Khodyakov 2007). Analyses predicting death quality include a limited set of controls, given the relatively small samples of bereaved spouses; controls are added for age, gender, race (in CLOC and NJEOL), number of children, survivor depressive symptoms, death suddenness, and decedent’s age and cause of death. Analyses predicting ACP in the WLS use a broader range of covariates including sex, marital status, parental status, self-rated health, hospitalizations in the year prior to interview, having a regular source of medical care, experiencing the recent death of a loved one described as “painful,” IQ, death avoidance attitudes, conscientiousness, and beliefs about doctor versus patient control over health decisions.

In analyses predicting ACP among members of the racially diverse NJEOL sample, the key independent variable is self-reported race/ethnicity (non-Hispanic white, non-Hispanic black, Hispanic). Analyses are adjusted for variables that correlate with both race/ethnicity and ACP (Carr 2011): sex, age, marital status, parental status, education, income, home ownership, Spanish language speaker, and self-rated health.

## Analytic Plan

The analysis has four steps. First, I summarize results from logistic regression models predicting each of the five death quality attributes. Second, I describe rates of ACP among sample members in the WLS and NJEOL. Third, I estimate logistic regression models to evaluate socioeconomic (WLS) and race/ethnic (NJEOL) differences in both financial and health-related end-of-life planning, net of sociodemographic controls. Finally, I use logistic regression models to evaluate whether socioeconomic (WLS) and racial (NJEOL) disparities in health-related planning are accounted for by disparities in estate planning, and whether these patterns differ for formal health preparations that require legal assistance (i.e., living will and DPAHC) versus informal health preparations (i.e., discussions) that do not.

## Results

### *Disparities in death quality*

Table 1 summarizes logistic regression results predicting attributes of recent spousal deaths, as reported by older widows and widowers in the CLOC, WLS,

TABLE 1  
Odds Ratios Predicting Selected Death Quality Attributes of Recent  
Spousal Deaths, by Socioeconomic Status, 1986–2011

	Education (Years)	Total Household Income (by Quartile)	Wealth/Assets (by Quartile)	Home Ownership (1 = Own)
Preparation for death				
Decedent discussed how spouse would manage after loss				
CLOC (1986–1994)	n.s.	n.s.	—	n.s.
WLS (1993–2004)	n.s.	n.s.	n.s.	n.s.
NJEOL (2006–2008)	1.09 <sup>°°</sup>	n.s.	—	n.s.
WISTFL (2010–2011)	n.s.	n.s.	n.s.	n.s.
Quality of care				
Decedent experienced moderate/high pain				
CLOC (1986–1994)	0.89 <sup>°°</sup>	n.s.	—	n.s.
WLS (1993–2004)	n.s.	n.s.	OR = 2.79 <sup>°°</sup> for no/nega- tive assets vs. top 25%	0.48 <sup>°°</sup>
NJEOL (2006–2008)	n.s.	n.s.	—	0.53 <sup>°°</sup>
WISTFL (2010–2011)	0.84 <sup>°°</sup>	n.s.	n.s.	n.s.
Decedent received problematic care or care inconsistent with wishes				
CLOC (1986–1994)	n.s.	n.s.	—	n.s.
WLS (1993–2004)	n.s.	n.s.	n.s.	n.s.
NJEOL (2006–2008)	n.s.	n.s.	—	n.s.
WISTFL (2010–2011)	n.s.	n.s.	n.s.	n.s.
Decedent was aware/capable of making decisions at end of life				
CLOC (1986–1994)	n.s.	n.s.	—	n.s.
NJEOL (1993–2004)	1.10 <sup>°°</sup>	n.s.	—	n.s.
Death occurred at home (vs. hospital/nursing home)				
CLOC (1986–1994)	n.s.	n.s.	—	n.s.
WLS (1993–2004)	n.s.	n.s.	n.s.	n.s.
NJEOL (2006–2008)	n.s.	n.s.	—	0.61 <sup>°°</sup>
WISTFL (2010–2011)	n.s.	n.s.	n.s.	n.s.

NOTE: Data sets included are Changing Lives of Older Couples (CLOC; 1986–1994); Wisconsin Longitudinal Study (WLS; 1993–2004); New Jersey End of Life study (NJEOL, 2006–2008); and Wisconsin Study of Families and Loss (WISTFL; 2010–2011). Summarized results are based on logistic regression models evaluating effect of socioeconomic status on each end-of-life attribute. n.s. signifies an association that is not statistically significant, while a dash (—) denotes a measure that was not available in a particular data set. OR = odds ratio. <sup>°</sup> $p < .05$ . <sup>°°</sup> $p < .01$ .

NJEOL, and WISTFL. In both unadjusted (not shown) and full adjusted models (presented here), few indicators of SES were significant correlates of death quality. Highly educated CLOC participants were more likely to report that they and their late spouse discussed how they would manage after the death, yet this effect was not significant in the other three data sets. Inconsistent patterns also were found for death awareness and site of death. Highly educated persons in the NJEOL were more likely to say that their significant other had decision-making capacity at the end of life, and home owners were less likely to report a home death, yet these patterns were not evidenced in the other three data sets.

Of the two outcomes capturing quality of care, pain was strongly related to SES although reports of problematic care were not. Among bereaved spouses in the CLOC, each year of education was associated with an 11 percent decrease in the likelihood that their spouse experienced severe pain at the end of life; a similar pattern was evidenced in the WISTFL (odds ratio [OR] = .84,  $p < .05$ ). Assets also were associated with reduced risk of severe pain; in both the WLS and NJEOL, home owners were only half as likely (OR = .48 and .53,  $p < .05$ , respectively) to say the decedent experienced significant pain. Similarly, in the WLS, persons who reported no or negative assets were nearly three times as likely as those in the top quartile of wealth to say the decedent experienced significant pain at the end of life.

Overall, these analyses provide only limited evidence that key aspects of death quality are shaped by SES, with one exception: pain in the last week of life. For each of the four data sets, spanning the 1980s through 2010s, decedents with fewer socioeconomic resources are more likely to be described by their surviving spouse as having moderate or severe pain at the end of life (after cause of death and death suddenness were controlled). Furthermore, the effects of education (CLOC, WISTFL) and home ownership (WLS, NJEOL) were highly consistent across studies, even though data collection took place across three decades and three different samples, suggesting that patterns have not changed markedly over time. One potential explanation for SES disparities in pain level may be that persons with fewer socioeconomic resources are less likely to engage in ACP (Carr 2012), which is associated with higher rates of hospice and palliative care (Nicholas et al. 2011; Silveira, Kim, and Langa 2010). Thus, the analyses now focus in-depth on SES (WLS) and race (NJEOL) disparities in rates of ACP.

### *Disparities in ACP*

*Overall trends in end-of-life planning.* A consistent SES gradient emerged in the WLS regarding both formal (living will, DPAHC) and informal (discussions) health care planning, and financial planning (i.e., has a will), while pronounced race differences emerged in the NJEOL sample. Bivariate analysis of the WLS data shows statistically significant differences ( $p < .001$ ) in all three types of planning, by educational attainment, home ownership status, and net worth, although the magnitude of the differences and explanatory power were greatest for the measure of net worth. Descriptive analysis of the NJEOL data shows stark racial and ethnic differences, with blacks and Latinos far less likely than whites to engage in all forms of planning (results not shown).

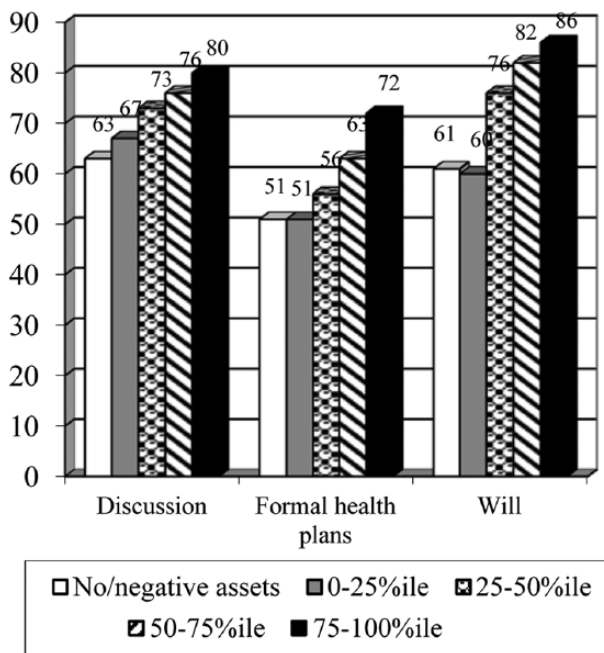
Slightly more than half of WLS participants and nearly three-quarters of white NJEOL participants have used legal tools to convey their end-of-life treatment preferences. These figures are higher than national averages, which range from 35 to 50 percent (Institute of Medicine 2014) but are consistent with other studies of older, well-educated adults (Silveira et al. 2010). These high rates of preparation among whites in both surveys are in stark contrast to the levels reported by blacks and Latinos in the NJEOL sample. Whereas 85 percent of NJEOL whites have discussed their end-of-life preferences, only 59 percent of blacks and one-third of Latinos have done so. Similarly, two-thirds of NJEOL whites have a living will, compared to one in four blacks and one in ten Hispanics. DPAHC appointments are even less common; 59 percent of whites but only one-quarter of blacks and 4 percent of Latinos have done so.

Disparities in ACP can be best understood by examining the specific combinations of preparations made. I next examined whether one made no preparations, health only, financial only, or both. Whereas health-related planning could plausibly be done at a federally funded health care facility, and thus is within the reach of all, financial planning or two-pronged planning (i.e., both health and financial) is more frequently done with the assistance of lawyers or financial advisors. The overwhelming majority of Hispanics (86 percent) and a slight majority of blacks (57 percent) have made no preparations, whereas the majority of whites in both samples have done both financial and health-related planning. Blacks are most likely to do health planning only, whereas whites are most likely to do financial planning alone. These results provide suggestive evidence of racial differences in the site of planning, that is, whether it occurs at a hospital or with a legal/financial professional.

Finally, bivariate analyses of the WLS show clear gradients in ACP across all SES indicators, where home owners, more highly educated persons, and persons with richer assets are more likely than renters, less highly educated persons, and those with fewer assets to engage in planning. Gradients are steeper for assets than for the other SES indicators. Regardless of the SES indicator used, the gradients are also steepest for formal health planning and estate planning, and flatter for discussions, which can be done with family members and do not require professionals' involvement or high levels of literacy. Gradients for net worth and educational attainment are plotted in Figures 1a and 1b, respectively.

*Socioeconomic disparities in end-of-life planning: Evidence from the WLS.* Logistic regression results predicting the odds of having a living will, DPAHC, discussions, and will are presented in Figure 2. Assets have a linear, positive association with the odds of planning; the likelihood of engaging in each of the four preparations increases for each successive quartile. For the outcome of will, however, persons in the 50th to 75th percentile do not differ significantly from those in the top quartile. Persons with no or negative assets also are less likely than persons in the highest quartile to engage in each type of planning, with relative odds ranging from 0.36 for a signed and witnessed will to 0.58 for DPAHC appointments.

FIGURE 1A  
 Proportion Engaging in Specific End-of-Life Preparations, by Net Worth Quartile,  
 Wisconsin Longitudinal Study (2004)

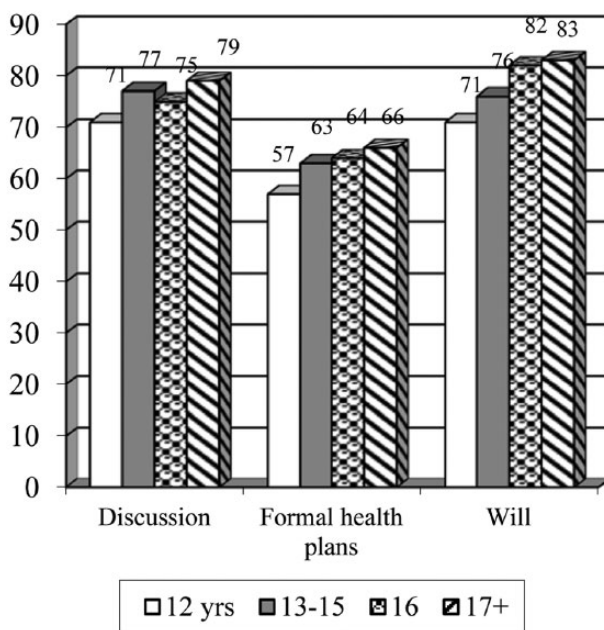


NOTE: Formal health plans include having either (or both) a living will and DPAHC. All subgroup differences are statistically significant at the  $p < .001$  level.

The remaining SES indicators are inconsistent predictors, however. College graduates and persons with postsecondary education have 1.35 and 1.40 the odds of completing a will, relative to high school graduates, although college education is not associated with any of the three health-related preparations. Home owners are 1.75 times as likely as non-home owners to have a will, although ownership does not predict health-related preparations. These weak effects do not reflect high zero-order correlations among the SES measures (range of .18 to .30); in supplementary analyses, I assessed the effects of each SES indicator separately and detected weak and inconsistent associations.

*Racial disparities in end-of-life planning: Evidence from the NJEOL.* Race differences in end-of-life planning, net of sociodemographic and health factors, are plotted in Figure 3. Model 1 controls for all sociodemographic and health characteristics described above, while model 2 further incorporates home ownership. Even after adjusting for factors widely considered to be the main obstacles to planning among ethnic minorities, large and significant gaps remain. The inclusion of home ownership accounts for a slight attenuation in the racial gap for

FIGURE 1B  
 Proportion Engaging in Specific End-of-Life Preparations, by Educational Attainment,  
 Wisconsin Longitudinal Study (2004)

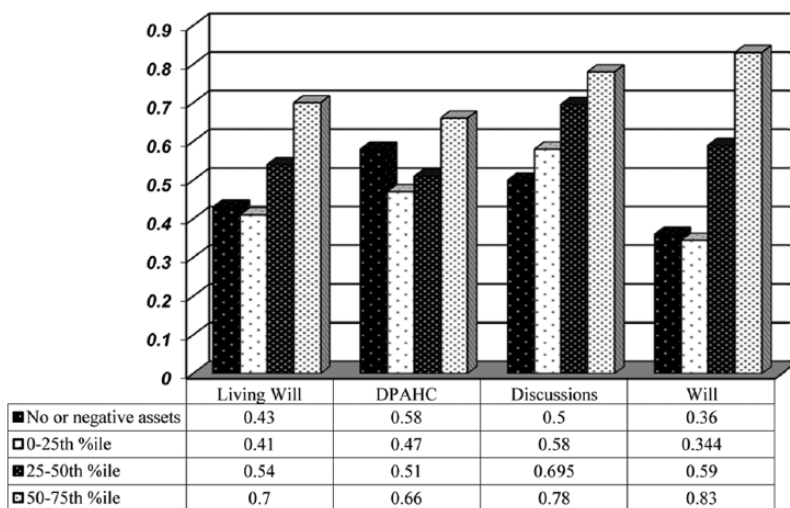


NOTE: Formal health plans include having either (or both) a living will and DPAHC. All subgroup differences are statistically significant at the  $p < .001$  level.

formal health planning and estate planning but does not account for gaps in discussions. In the fully adjusted models, blacks are less than half as likely as whites to have done formal health planning, and a quarter as likely to have had discussions or written a will. The Hispanic-white gap is even more pronounced, with Hispanics having just 0.13 to 0.16 the odds of whites of engaging in any of the three forms of planning. (All effects are statistically significant at the  $p < .05$  level.)

*Disparities in health-related planning: Assessing the role of estate planning.* The results presented thus far show that persons with fewer assets are less likely than wealthier persons to engage in all types of end-of-life planning, while blacks and Hispanics are less likely than whites to do so. Given that formal health-related planning (i.e., living wills and DPAHC appointments) may be completed in a bundle of documents when one completes a will, I next examine whether socioeconomic and race disparities in health-related planning operate via the completion of a will. Results presented in Table 2 show that the effects of low net worth on the odds of engaging in each type of health-related preparation

FIGURE 2  
Relative Odds of End-of-Life Planning by Net Worth Quartile, Wisconsin Longitudinal Study, 2004 (N = 4,917)

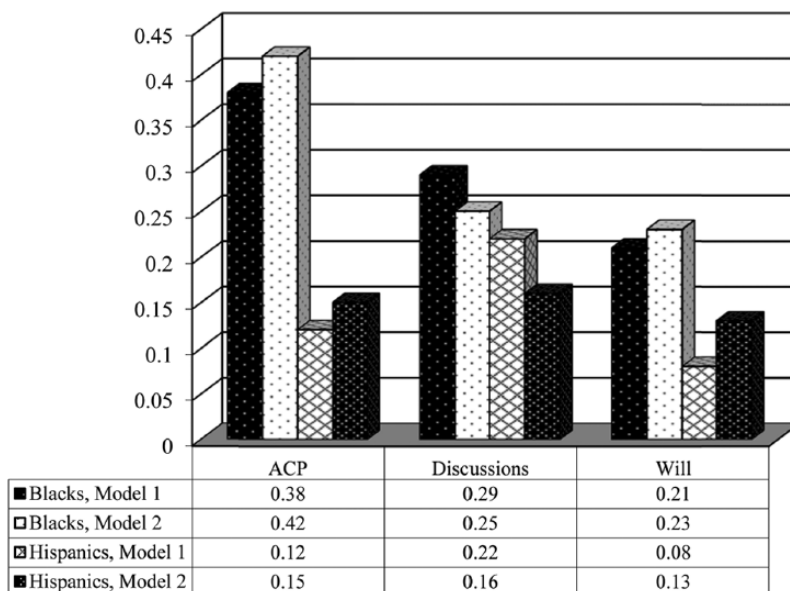


NOTE: Reference category is 75th to 100th percentile. All effects are statistically significant at the  $p < .001$  level, except the effect of 50th to 75th percentile on will (n.s.). All models are adjusted for education, home ownership, major occupational group (longest job), sex, marital status, parental status, self-rated health, hospitalizations in past year, has regular source of medical care, experiences with significant others’ painful deaths, IQ, death avoidance, conscientiousness, and beliefs about physician versus patient control over medical decisions.

attenuate considerably after adjusting for whether one has a will, and the model fit improves substantially. However, these patterns are most pronounced for the two legal aspects of health-related planning; the amount of variance explained for the living will and DPAHC outcomes nearly triples, from 0.093 to 0.26, and 0.078 to 0.20, respectively. By contrast, the model fit improvement is modest (.10 to .14) for discussions, as evidenced by the pseudo  $R$ -squared.

The attenuation in effects is pronounced for the lowest net worth categories, yet trivial for the 25th to 75th quartiles. For living will and DPAHC appointments, the gap between the lowest two assets categories and the highest assets category (75th to 100th percentile) declines by nearly 30 percent after controlling for whether one has a will. However, the declines are much smaller for the higher net worth categories and in the model predicting informal discussions. Furthermore, having a will has large and significant effects on the two legal aspects of planning (OR = 7.78 for living will and 5.43 for DPHAC appointments) but a more modest effect on informal discussions (OR = 2.45), which do not require legal assistance.

FIGURE 3  
Relative Odds of End-of-Life Planning by Race/Ethnicity, New Jersey End of Life Study,  
2007 ( $N = 297$ )



NOTE: Non-Hispanic white is the reference category. ACP (advance care planning) refers to whether one has executed either a living will or a DPAHC appointment. All effects are statistically significant at the  $p < .01$  level. Model 1 controls for age, sex, self-rated health, marital status, parental status, education, income, and Spanish language. Model 2 includes all controls in model 1 and home ownership.

Generally similar patterns are evidenced for racial differences, shown in Table 3. Binary logistic regression models are estimated for two outcomes: any formal health-related planning (living will or DPAHC) and informal planning (i.e., discussions). Model 1 is adjusted for demographic, health, and socioeconomic characteristics; and model 2 further incorporates a dichotomous indicator of whether one has a will. Model 1 in the left-hand panel shows that blacks and Latinos have 42 and 15 percent the odds of whites of doing formal health planning, yet these racial disparities are no longer statistically significant once will completion is controlled. Model 2 shows nonsignificant effects of race on ACP, although persons who have a signed and witnessed will are 19 times as likely as those who have not done estate planning to do formal health planning. The full attenuation of the race effect likely reflects vast racial differences in how and where end-of-life preparations are made. Fully 83 percent of white NJEOL sample members who have done health planning have also done estate planning; by contrast, just 28 percent of black and 11 percent of Hispanic respondents who have done health planning have also done estate planning.



TABLE 2  
 Binary Logistic Regression Models Predicting Odds of Health-Related End-of-Life Planning, by Asset Level,  
 Wisconsin Longitudinal Study, 1957–2004 (N = 4,971)

	Living Will			DPAHC			Discussions		
	Model 1	Model 2	% Δ	Model 1	Model 2	% Δ	Model 1	Model 2	% Δ
No or negative assets (2004)	0.428****	0.553****	29	0.576****	0.746	29	0.496****	0.574***	15.7
Assets: 0 to 25th percentile	0.405****	0.525****	29	0.467****	0.594****	27	0.580****	0.680****	16
Assets: 25th to 50th percentile	0.535****	0.576****	7	0.505****	0.537****	6.3	0.695****	0.740****	6.5
Assets: 50th to 75th percentile	0.703****	0.708****	<1	0.658****	0.661****	<1	0.784**	0.794**	<1
Owens home	1.21	0.945		1.23	1.00		1.06	0.933	
Has a signed and witnessed will		7.78****			5.43****			2.45****	
$\chi^2$ ; <i>df</i>	316.24; 28	933.64; 29		264.98; 28	700.5; 29		323.56; 28	441.52; 29	
Pseudo R <sup>2</sup> (Nagelkerke)	.093	.256		.078	.196		.104	.14	

NOTES: Odds ratios (ORs) are presented. The omitted category for each model includes persons who have not engaged in each type of end-of-life planning. DPAHC refers to a durable power of attorney for health care appointment. Model 1 is adjusted for all demographic, health, SES, and psychological variables (shown in Table 2). Model 2 further adjusts for whether one has a signed and witnessed will. % Δ refers to the change in the ORs between models 1 and 2. For example, a decline in OR from 0.428 to 0.553 is a 29 percent change in the OR where 0.29 =  $([0.553 - 0.428]/0.428)$ . \*\**p* < .05. \*\*\**p* < .01. \*\*\*\**p* < .001.

TABLE 3  
 Binary Logistic Regression Models Predicting Odds of Formal and Informal Health-Related End-of-Life Planning, by Race/Ethnicity, New Jersey End of Life Study, 2005 ( $N = 297$ )

	ACP (Either Living Will or DPAHC)		Discussions	
	Model 1	Model 2	Model 1	Model 2
Black	0.42**	0.81	0.250***	0.35**
Hispanic	0.15***	0.32	0.16***	0.25**
Owens home	1.9°	1.01	0.49	0.299**
Has signed and witnessed will		18.9****		5.04****
$\chi^2$ : $df$	67.8; 13	119.1; 14	60.3; 13	73.9; 14
Pseudo $R^2$ (Nagelkerke)	.32	.51	.31	.37

NOTE: Odds ratios are presented. The reference category is non-Hispanic whites. Model 1 adjusts for age, sex, self-rated health, marital status, parental status, education, income and Spanish language use. Model 2 includes all controls for model 1 and a dummy variable indicating whether one has a signed and witnessed will.

° $p < .10$ . \*\* $p < .05$ . \*\*\* $p < .01$ . \*\*\*\* $p < .001$ .

Very different patterns emerged for end-of-life discussions, a preparation that does not necessarily require professional assistance or familiarity with legal documents. Model 1 shows that blacks and Latinos have 25 and 16 percent the odds of whites of discussing end-of-life issues; these racial gaps attenuate modestly yet remain large and statistically significant even after estate planning is controlled. Furthermore, the direct effect of estate planning on informal discussions is considerably smaller than for formal preparations; those who have a will are five times as likely as those who do not to discuss end-of-life issues (compared to a factor of 20 differences for the prior outcome).

Consistent with these effects, estate planning explains a greater amount of variance in formal than informal preparations in the NJEOL. The pseudo- $R^2$  values for the two baseline models are virtually identical (.32 and .31), yet the inclusion of the estate planning measure increases the pseudo- $R^2$  value to .51 in the case of formal versus just .37 in the case of informal planning. The results from both data sets suggest one plausible explanation for why persons with no or low net worth and ethnic minorities are less likely than wealthier persons and whites, respectively, to make formal health-related preparations: they are less motivated to complete a will and, thus, less likely to complete the health-related legal documents in tandem.

## Discussion

Steep socioeconomic disparities in mortality rates have persisted and widened throughout the twentieth and early twenty-first centuries (Olshansky et al. 2012).

However, far less is known about whether the quality of one's death also is stratified by SES. This article was an effort to evaluate whether a range of SES indicators affect five aspects of death quality, and whether SES and race affect ACP, considered an important prerequisite for dying well. In general, I found limited evidence that SES affects death quality, as appraised retrospectively by recently bereaved spouses of older decedents, with one exception: pain. By contrast, SES and race were powerful predictors of health-related end-of-life preparations, yet these effects largely reflect disparities in financial or estate planning, a common precursor of health-related planning.

Four key findings emerged from the study. First, persons with lower levels of education or assets and non-home owners are more likely to describe their deceased spouses' death as moderately or severely painful. Second, wealth is a consistent predictor of health-related end-of-life preparations, yet this effect is partially accounted for by poorer persons' lower rates of estate planning. Third, the pronounced racial disparity in formal health-related planning is accounted for by blacks' and Hispanics' much lower rates of estate planning relative to whites. Fourth, although estate planning accounts either fully or partly for disparities in formal ACP, it does not account for disparities in informal end-of-life discussions, a behavior for which one need not enlist the help of legal or financial professionals.

The weak effects of SES on four of the five death quality indicators is surprising, yet it is consistent with one of the broad themes of FCT (Phelan, Link, and Tehranifar 2010); socioeconomic resources may be protective only in situations where they can be used to gain an advantage. If these resources are not of potential use in a given situation, then “high SES should confer no advantage” (Phelan, Link, and Tehranifar 2010, S31). Furthermore, policies or interventions that “automatically benefit individuals irrespective of their own resources or behaviors” should be effective in reducing health inequalities (Phelan, Link, and Tehranifar 2010, S37). All older adults receive Medicare and are eligible for the hospice benefit, both of which defray a sizable proportion of end-of-life care costs, including some nursing home care; this may partly account for why no consistent SES differences emerged with respect to perceived quality of care and site of death.

Furthermore, other subjective aspects of death, such as preparing emotionally for the death, may not be stratified by class because many beliefs surrounding “good death” are universal. As such, the majority of older adults, regardless of SES, may strive for similar interpersonal and psychological experiences at the end of life. For instance, Steinhauser and colleagues (2000) found that more than 90 percent (and as many as 99 percent) of patients and bereaved family members rated preparations such as naming a decision-maker, having personal affairs in order, and saying goodbye to important people as “very important” at the end of life. Thus, those aspects of the dying experience that reflect core values of what constitutes a “good death” do not and in the future may not vary widely by SES, given the near-universality of such preferences. However, as the ACP analyses show, not all individuals have the means to take appropriate steps to ensure that their values will effectively inform their medical treatments at the end of life.

The ACP analyses (of the WLS) show that financially disadvantaged older adults are less likely than their more advantaged counterparts to use living wills,

DPAHCs, discussions, and wills. However, while one-third of the gap in DPAHC and living will rates between the low/negative and top assets categories were explained by estate planning, less than 10 percent of the gap between the top two assets categories in ACP were explained by estate planning.

Similar, but even more pronounced, racial disparities emerged (in the NJEOL). Blacks and Latinos were significantly less likely than whites to have done both formal and informal planning, yet the gap in formal planning (i.e., living will and ACP) was no longer statistically significant after estate planning was controlled. By contrast, the racial gap in discussions persisted when estate planning was controlled. These results may reflect the fact that discussions, unlike living wills and DPAHC appointments, do not require professional assistance. Persons with financial assets to protect or bequeath may seek out a legal professional to write or revise a will, and then are encouraged to do health care planning in tandem. The results suggest that blacks and Latinos and, to a lesser extent, persons with no or few assets to protect are not motivated to have a will and, thus, may lack the opportunity, knowledge, or professional support that facilitates health-related end-of-life planning.

One reason why estate planning fully accounted for the race gap in formal health care planning, yet accounted for only one-third of the gap between the lowest and highest assets categories, is that estate planning is far less common among blacks and Latinos in the NJEOL compared to even the most financially disadvantaged subgroups in the WLS. Sixty percent of WLS respondents in the lowest two assets categories had a will, yet only 28 and 11 percent of blacks and Latinos, respectively, in the NJEOL did. These disparities may reflect absolute levels of wealth, where even the worst-off whites fare better on average than blacks or Hispanics (Oliver and Shapiro 2006). Assets data were not collected in the NJEOL, but studies based on national data show that at every level of educational attainment and income, blacks lag considerably behind whites with respect to wealth (Oliver and Shapiro 2006). The implications of this gap are far-reaching and may extend, indirectly, to the nature and quality of the dying experience.

### *Implications for policy and practice*

The SES gradient with respect to pain at the end of life among recent decedents and end-of-life preparations among older adults are troubling, from a policy/practice perspective.

Financially disadvantaged individuals and ethnic minorities are less likely to formally convey their treatment preferences and, consequently, are at greater risk of receiving treatments they do not want, or being spared of those treatments they desire (Silveira, Kim, and Langa 2010). These disparities in ACP may contribute, in part, to the higher levels of pain documented in the four samples analyzed here. For example, prior studies have documented low rates of palliative care use among patients living in poorer neighborhoods (Nicholas et al. 2011). Furthermore, one analysis of Medicare expenditures in 2001 found that the average cost of care in the last six months of life ranged from \$20,166 among whites, to \$26,704 among blacks, and \$31,702 among Latinos (Hanchate et al. 2009). Fully 85 percent of the observed higher costs for blacks and Hispanics were accounted for by their greater usage of

intensive (and costly) invasive rather than palliative treatments. ACP is encouraged precisely so that patients have the opportunity to reject intensive (and often futile) medical treatments, even if one is incapacitated at the moment the decision is required. In the absence of such documents, health care providers typically default to the use of all available treatments (Institute of Medicine 2014).

Disparities in life expectancy have persisted or widened throughout the late twentieth and early twenty-first centuries (Olshansky et al. 2012). The results presented here suggest that it is not only *when* and *of what cause* one dies that are stratified by SES, but the extent to which one controls the type of care received in the months and days prior to one’s death, and the level of pain experienced during that time. Furthermore, the study findings suggest that different points of intervention may be required to encourage ACP among different subgroups of patients. Supplementary analyses show that race and SES disparities in planning were not observed for the outcome of health planning only—although disparities persisted for financial planning only, or combined financial and health planning.

As FCT proposes, in situations where the resources of economically and social advantaged persons are of no use, disparities will not be detected. Since the passage of the Patient Self-Determination Act in 1990, all persons seeking care at federally funded health care settings are given the opportunity to do ACP. In health care settings where information must be conveyed to all patients, resources such as high SES “should confer no advantage” and the “usually robust [effect] . . . of SES should be greatly reduced” (Phelan, Link, and Tehranifar 2010, S31). Practically, these results suggest that if disadvantaged persons would like to make preparations for end of life medical care, the physician’s office or hospital is more likely (and attorney’s or financial planner’s office less likely) to be the site of such actions.

A recent policy shift may help to ensure that older adults have equal access to ACP tools. On October 30, 2015, the Obama administration issued a rule authorizing Medicare to pay doctors for consultations with patients on how they would like to be cared for as they are dying (Pear 2015). This voluntary ACP session is an option included in the annual wellness visit for Medicare beneficiaries. This benefit will give older patients—regardless of financial status—the opportunity to discuss their treatment preferences with a health care provider. This simple and relatively low-cost aspect of the Affordable Care Act has high potential to contribute to a better quality death for disadvantaged older adults. Furthermore, increased public awareness of the benefits of hospice and palliative care programs may encourage subgroups with historically low rates of usage to consider such services, given that they are covered by Medicare (if one meets medical criteria for these benefits).

### *Limitations*

This study has several limitations. First, death quality was assessed retrospectively by bereaved spouses and, as such, may be biased by one’s current affective state. However, if bereaved persons perceive their spouse’s death to be difficult, this is an important outcome in its own right. Widow(er)s’ perception of the quality, cause, and reasons for their loved ones’ death carry profound consequences for their adjustment to loss (Carr 2003). Second, the WLS and NJEOL did not

obtain data on the timing of one's end-of-life planning; thus, I cannot definitively conclude that financial planning "causes" health-related planning. However, this assumption of causal ordering is plausible given that persons who execute wills typically do so earlier in the life course, when they have children, whereas health-related planning is typically done in midlife or later, often in response to a health threat or changes in one's will. Third, the WLS represents a single cohort of white, high school-educated adults, most of whom still reside in Wisconsin. The NJEOL sample, while ethnically and socioeconomically diverse, is drawn from one urban region and two health centers. Given the relatively high SES of the WLS participants and NJEOL participants' universal contact with a major health system, both data sets yielded considerably higher rates of advance directive completion than researchers have documented in nationally representative samples (Institute of Medicine 2014). Future studies should investigate how socioeconomic resources and race/ethnicity affect end-of-life preparations among persons from other cohorts, regions, and care settings.

Finally, the analyses focused on single-item behavioral indicators of whether one engaged in planning. I did not explore the processes through which one learned about or initiated such practices. Qualitative approaches, including open-ended interviews and focus groups, may be particularly effective for revealing how and from whom adults learn about ACP. Of particular value would be identifying the ways that persons from a range of social class strata learn about and initiate (or avoid) end-of-life planning.

In conclusion, mounting research based primarily on aggregate-level and administrative data suggest that the final weeks of life may be marked by greater discomfort, and more costly and intrusive medical care, for those with the fewest resources. Furthermore, the disproportionately high costs of end-of-life medical care for low-income and ethnic minority older adults may have direct effects on the economic well-being of the dying patients' offspring (Institute of Medicine 2014). My research suggests that the potential disadvantages facing both generations—aging patient and adult children—may be reduced through the widespread use and availability of tools to ensure that older adults' end-of-life care conforms to their and their family members' wishes.

## Note

1. I found a weak and inconsistent relationship between total household income and ACP and, thus, do not focus on income as a predictor in the ACP analyses. Income, especially among older or unhealthy persons, is unstable and may not accurately represent one's SES. The association between income and health is more likely to be endogenous among retirement age adults, relative to younger adults.

## References

Arias, Elizabeth. 2010. United States life tables, 2006. *National Vital Statistics Reports* 58 (21). Hyattsville, MD: National Center for Health Statistics.

- Belluck, Pamela. 8 July 2015. Medicare plans to pay doctors for counseling on end of life. *The New York Times*. Available from <http://www.nytimes.com>.
- Carr, Deborah. 2003. A “good death” for whom? Quality of spouse’s death and psychological distress among older widowed persons. *Journal of Health and Social Behavior* 44:215–32.
- Carr, Deborah. 2011. Racial differences in end-of-life planning: Why don’t blacks and Latinos prepare for the inevitable? *Omega: The Journal of Death and Dying* 63:1–20.
- Carr, Deborah. 2012. The social stratification of older adults’ preparations for end of life health care. *Journal of Health and Social Behavior* 53:297–312.
- Carr, Deborah, and Dmitry Khodyakov. 2007. End of life health care planning among young-old adults: An assessment of psychosocial influences. *Journal of Gerontology: Social Sciences* 62B:135–41.
- Casarett, David J., Joan Teno, and Irene Higginson. 2006. How should nations measure the quality of end-of-life care for older adults? Recommendations for an international minimum data set. *Journal of American Geriatrics Society* 55:1765–71.
- Centers for Medicare & Medicaid Services (CMS). 2013. *Medicare hospice data trends, 1998-2009*. Available from [http://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/Hospice/Medicare\\_Hospice\\_Data.html](http://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/Hospice/Medicare_Hospice_Data.html) (accessed 24 May 2015).
- Emanuel, Ezekiel J., and Linda Emanuel. 1998. The promise of a good death. *The Lancet* 251:21–29.
- Federal Interagency Forum on Aging-Related Statistics. July 2012. *Older Americans 2012: Key indicators of well-being*. Federal Interagency Forum on Aging-Related Statistics. Washington, DC: U.S. Government Printing Office.
- George, Linda. 2002. Research design in end-of-life research: state of science. *The Gerontologist* 42: 86–98.
- Gruneir, Andrea, Vincent More, Sherry Weitzen, Rachael Truchil, Joan Teno, and Jason Roy. 2007. Where people die: A multilevel approach to understanding influences on site of death in America. *Medical Care Research and Review* 64:351–78.
- Hanchate, Amresh, Andrea C. Kronman, Yinong Young-Xu, Arlene S. Ash, and Ezekiel Emanuel. 2009. Racial and ethnic differences in end-of-life costs: Why do minorities cost more than whites? *Archives of Internal Medicine* 169:493–501.
- Institute of Medicine (IOM). 2014. *Dying in America: Improving quality and honoring individual preferences near the end of life*. Washington, DC: The National Academies.
- Lewis, Joanne M., Michelle DiGiacomo, David C. Currow, and Patricia M. Davidson. 2011. Dying in the margins: Understanding palliative care and socioeconomic deprivation in the developed world. *Journal of Pain and Symptom Management* 42:105–18.
- Melmed, Gil Y., Lorna Kwan, Kristen Reid, and Mark S. Litwin. 2002. Quality of life at the end of life: Trends in patients with metastatic prostate cancer. *Urology* 59:103–9.
- Moodie, Susanna. 1853/2010. *Life in the clearings versus the bush*. Ontario: New Canadian Library.
- Nicholas, Lauren Hersch, Kenneth M. Langa, Theodore J. Iwashyna, and David R. Weir. 2011. Regional variation in the association between advance directives and end-of-life medical expenditures. *Journal of the American Medical Association* 306:1447.
- Oliver, Melvin L., and Thomas M. Shapiro. 2006. *Black wealth, white wealth: A new perspective on racial inequality*. Abingdon: Taylor & Francis.
- Olshansky, S. Jay, Toni Antonucci, Lisa Berkman, Robert H. Binstock, Axel Boersch-Supan, John T. Cacioppo, and Bruce A. Carnes, et al. 2012. Differences in life expectancy due to race and educational differences are widening, and many may not catch up. *Health Affairs* 31:1803–13.
- Patient Self-Determination Act of 1990. 1990. 554206, 4751 of the Omnibus Reconciliation Act of 1990. Pubs. No. 101-508.
- Pear, Robert. 30 October 2015. New Medicare rule authorizes “end-of-life” consultation. *The New York Times*.
- Phelan, Jo C., Bruce G. Link, and Parisa Tehranifar. 2010. Social conditions as fundamental causes of health inequalities: Theory, evidence, and policy implications. *Journal of Health and Social Behavior* 51 (Suppl.): 28–40.
- Shugarman, Lisa R., D. E. Campbell, and C. E. Bird, et al. 2005. Differences in Medicare expenditures during the last 3 years of life. *Journal of General Internal Medicine* 19:127–35.
- Silveira, Maria J., Scott Y. Kim, and Kenneth M. Langa. 2010. Advance directives and outcomes of surrogate decision making before death. *The New England Journal of Medicine* 362:1211–18.

- Steinhauser, Karen E., Nicholas A. Christakis, Elizabeth Clipp, Maya McNeilly, Lauren M. McIntyre, and James A. Tulsky. 2000. Factors considered important at the end of life by patients, family, physicians, and other care providers. *Journal of the American Medical Association* 284:2476–82.
- Steinhauser, Karen E., Elizabeth Clipp, Maya McNeilly, Nicholas A. Christakis, Lauren M. McIntyre, and James A. Tulsky. 2006. In search of a good death: Observations of patients, families, and providers. *Annals of Internal Medicine* 132:825–32.
- Teno, Joan M., Andrea Gruneir, Zachary Schwartz, Aman Nanda, and Terri Wetle. 2007. Association between advance directives and quality of end-of-life care: A national study. *Journal of the American Geriatrics Society* 55:189–94.
- U.S. Census Bureau. 2003. *Current Population Survey, annual social and economic supplement*. Washington, DC: U.S. Census Bureau.