



Published in final edited form as:

Sociol Forum (Randolph N J). 2009 December 1; 24(4): 754–778. doi:10.1111/j.1573-7861.2009.01135.x.

End-of-Life Treatment Preferences Among Older Adults: An Assessment of Psychosocial Influences¹

Deborah Carr² and Sara M. Moorman³

Deborah Carr: carrds@sociology.rutgers.edu

² Department of Sociology and Institute for Health, Health Care Policy, and Aging Research, Rutgers University, 30 College Avenue, New Brunswick, New Jersey 08901

³ Department of Sociology and Institute on Aging, Boston College, McGuinn Hall 426, 140 Commonwealth Avenue, Chestnut Hill, Massachusetts 02467

Abstract

We explore the content and correlates of older adults' end-of-life treatment preferences in two hypothetical terminal illness scenarios: severe physical pain with no cognitive impairment, and severe cognitive impairment with no physical pain. For each scenario, we assess whether participants would reject life-prolonging treatment, accept treatment, or do not know their preferences. Using data from the 2004 wave of the Wisconsin Longitudinal Study (N = 5,106), we estimate multinomial logistic regression models to evaluate whether treatment preferences are associated with direct experience with end-of-life issues, personal beliefs, health, and sociodemographic characteristics. Persons who have made formal end-of-life preparations, persons with no religious affiliation, mainline Protestants, and persons who are pessimistic about their own life expectancy are more likely to reject treatment in both scenarios. Women and persons who witnessed the painful death of a loved one are more likely to reject treatment in the cognitive impairment scenario only. Consistent with rational choice perspectives, our results suggest that individuals prefer treatments that they perceive to have highly probable desirable consequences for both self and family.

Keywords

advance care planning; aging; cognitive impairment; end-of-life issues; health; psychosocial influences

INTRODUCTION

In its influential report *Crossing the Quality Chasm*, the Institute of Medicine (2001) called for “patient-centered care” that explicitly considers the preferences and desires of patients. Bioethicists concur that physicians should share, and in some cases delegate, medical decision-making control to dying patients and their families (President’s Council on Bioethics, 2005). In practice, however, many dying persons are unable to convey their preferences for medical treatments because they are incapacitated when the decision is required (Field and Cassel,

¹An earlier version of this article was presented at the 2007 Annual Meetings of the American Sociological Association. The authors were supported by National Institute on Aging Grant P01 AG21079–01. The Wisconsin Longitudinal Study has its principal support from National Institute on Aging Grants AG 9775, AG13613, and AG21079, with additional support from National Science Foundation Grant SES-9023082, the Spencer Foundation, and the Graduate School of the University of Wisconsin. A public-use version of the Wisconsin Longitudinal Study is available from the Inter-University Consortium for Political and Social Research at the University of Michigan or the Data and Program Library Service, University of Wisconsin–Madison. The authors thank the editor and three reviewers for their thoughtful feedback.

1997). As such, difficult decisions about stopping or continuing treatment often fall to family members, who may be distressed and may disagree among themselves about appropriate care (Kramer *et al.*, 2006). When families and health-care providers cannot agree on a course of action, the default decision typically is to continue treatments, which may be financially and emotionally draining for family members, and physically distressing to the patient (Field and Cassel, 1997).

In an effort to prevent problematic, futile, or contested end-of-life care, practitioners encourage older adults to express and document their treatment preferences when they are still in good health (American Medical Association, 1996). Adults may convey their treatment preferences *formally* through a living will or a durable power of attorney for healthcare (DPAHC) appointment, or *informally* via discussions with significant others. Public policies support these practices; the Patient Self-Determination Act, passed by Congress in 1990, was designed to foster patient autonomy by encouraging use of advance directives (i.e., documents that comprise a living will and DPAHC designation).

Despite professional endorsements and widely publicized reports of the advantages of planning for end-of-life care, studies consistently show that only 20–30% of dying patients have an advance directive in their medical chart (e.g., Ditto *et al.*, 2001; Morrell *et al.*, 2008). Some scholars argue that this pattern reflects a “death-denying” ethos in contemporary Western society (Kellehear, 1984). However, others have pointed out structural obstacles to end-of-life planning and discussions, including patients’ lack of knowledge about treatment options, limited access to health-care and legal professionals who could assist in advance care planning, and the (often erroneous) belief that such practices are unnecessary because one’s family members intuitively understand and thus can convey the patient’s preferences at the end of life (Coppola *et al.*, 2001; Field and Cassel, 1997; Porensky and Carpenter, 2008). Given these obstacles to holding timely and effective end-of-life conversations, little is known about the end-of-life health-care preferences of relatively healthy, community-dwelling older adults.

We use data from the Wisconsin Longitudinal Study (WLS) to investigate the end-of-life treatment preferences of men and women in their mid 60s. We assess whether older adults would want to accept or reject life-sustaining treatments, or whether they do not know their preferences, in two hypothetical scenarios: a terminal illness with severe physical pain and no cognitive impairment, and a terminal illness with no physical pain yet severe cognitive impairment. We further investigate the extent to which five sets of psychosocial factors are associated with treatment preferences: direct experiences with end-of-life issues, personal beliefs, health and health-care encounters, family roles, and demographic characteristics. Our analysis is guided by rational choice perspectives, where individuals endorse preferences and behaviors that they perceive will maximize their own well-being and the well-being of their significant others.

BACKGROUND

In the spring of 2005, the Terri Schiavo case captured national media attention. Schiavo, a 41-year-old Florida woman, had been immobile and uncommunicative for more than 15 years after having suffered heart failure and subsequent brain damage when she was 26 years old. Her family members vigorously debated whether to keep her on artificial life support, and these disagreements triggered both judicial intervention and a national conversation about end-of-life planning. Experts agreed that if Schiavo had articulated her preferences for (or against) life-sustaining treatments when she was still healthy and cognitively intact, the public controversy and private family distress could have been avoided (Ditto *et al.*, 2006).

In the months following Schiavo's death, the nonprofit organization Aging with Dignity received more than 800,000 requests for advance directives—more than 50 times the usual rate (Ditto *et al.*, 2006). Despite this outpouring of interest, mounting evidence reveals many threats to the effectiveness of advance directives (Collins *et al.*, 2006). For instance, health-care providers may not have access to the document at the moment when a decision is required, or the specific treatment preferences stated may not be applicable to the patient's current health condition.

Further, patient advocate groups have criticized advance directives for focusing on preferences for specific treatments (e.g., use of a ventilator), rather than broad personal values, such as self-determination or acceptance at the end of life (Collins *et al.*, 2006). Consequently, both medical and patient advocate communities have developed alternative forms of advance care planning, where health-care providers obtain a patient's "values history," which assesses general beliefs regarding healthcare that are then used to identify the patient's preferred approach to a variety of specific end-of-life situations (Doukas and McCullough, 1991). New forms of advance directives, called combined directives, merge components of the traditional advance directive and the values history as a way to obtain a more comprehensive record of a patient's wishes (President's Council on Bioethics, 2005).

Despite the nascent movement toward combined directives and attention to patients' *general* preferences and values, most scholarly research focuses on identifying the prevalence and correlates of older adults' *specific* treatment preferences. Studies typically rely on small clinical samples of terminally ill older adults suffering from a single condition, such as cancer (Claessens *et al.*, 2000; Phelps *et al.*, 2009); frail elders residing in a nursing home (Resnick and Andrews, 2002); or patients with limited life expectancy, based on medical chart review (Fried *et al.*, 2002). This reliance on narrowly defined subpopulations has created three serious limitations to studies of end-of-life preferences: they focus on specific treatment options only, which may not be understood by or applicable to many individuals at the end of life; they fail to explore the prevalence and correlates of *not having* a preference; and they focus on a limited set of demographic and health characteristics of study participants and do not consider the broader range of experiential, attitudinal, and relational factors that may influence preferences.

Assessing General Versus Specific Treatment Preferences

Most studies assess whether individuals would accept or reject specific treatments such as cardiopulmonary resuscitation (CPR), ventilators, or feeding tubes if faced with a particular health condition (Emanuel, 1998; Gordon and Shade, 1999). However, such questions require that study participants possess the medical knowledge necessary to evaluate each option—and relatively few hold such knowledge (Porensky and Carpenter, 2008).

A focus on preferences for specific treatments also is problematic because preferences may change between the time one completes a living will and the time that the treatment is offered to the patient (Fried *et al.*, 2007). Psychological research on affective forecasting suggests that individuals cannot accurately predict the specific feelings and preferences they will have in the distant future, although general orientations or "high-level construals" (Trope and Liberman, 2003) are relatively stable over time (Wilson and Gilbert, 2003). Thus, we evaluate older adults' *general preferences* to accept or reject life-prolonging treatments when presented with two hypothetical terminal illness scenarios.

Who "Doesn't Know" Their Treatment Preferences?

A second limitation of prior studies is that most assess whether individuals would accept or reject treatment, yet they fail to consider that some persons do not know what they would do. The modest sample sizes of prior studies prevent researchers from identifying the

characteristics that distinguish this small yet important subpopulation. Researchers typically group together persons who are uncertain and those who desire life-prolonging treatments (Ditto *et al.*, 2001). This analytic strategy is consistent with clinical practice: if patients do not know their treatment preferences, they typically receive life-extending treatments (Field and Cassel, 1997). Documenting the characteristics of those who do not know their preferences is of practical importance because difficult decisions about withholding, withdrawing, or continuing treatment will fall to significant others if the patient is incapacitated and has not conveyed his or her own preferences. Identifying the psychosocial correlates of “don’t know” responses also has implications for research on preferences and attitudes, more broadly. Researchers have debated whether survey responses of “don’t know” reflect a “nonattitude” because one has too little information to articulate an opinion (Converse, 1964), or information overload, which causes uncertainty (Zaller, 1992). Our analysis is based on a large sample of more than 5,000 men and women; thus we can explore a broad range of potential factors that may distinguish those persons who cannot articulate their end-of-life preferences.

Identifying Correlates of End-of-Life Treatment Preferences

A third limitation is that most prior studies were designed primarily to document preferences; thus researchers did not aim to identify the broad array of personal, interpersonal, and experiential factors that may shape these preferences. Rather, prior studies focused on a limited range of demographic and health factors, including race and ethnicity (Bayer *et al.*, 2006; True *et al.*, 2005), gender (Gordon and Shade, 1999), and health status (Claessens *et al.*, 2000; Coppola *et al.*, 1999). The WLS, by contrast, is a large study of aging and the lifecourse that obtained information on a wide range of potential influences. We explore the extent to which five sets of influences are associated with general preferences for end-of-life care: direct experience with end-of-life issues (observing painful death of family member, making formal end-of-life preparations), personal beliefs (death avoidance, attitudes toward physician vs. patient control over healthcare, religious affiliation), health (perceived lifespan, self-rated health, illnesses, depressive symptoms, recent hospitalizations, and health insurance), family roles (marital and parental status), and demographic characteristics (gender, education).

The Reasoned Action Framework

Our investigation draws on the theory of reasoned action, which proposes that individuals are more likely to endorse a preference for a particular action if: (1) they evaluate the action and its anticipated consequences positively; (2) they view the purported positive consequences as highly probable (and purported negative consequences as highly unlikely); and (3) they believe that the action and its consequences will be viewed positively by significant others (Ajzen and Fishbein, 1980). We argue further that preferences will be shaped by one’s perception that a particular course of treatment will have positive consequences for his or her significant others.

We conceptualize five sets of factors as indirect indicators of beliefs about the probable positive or negative consequences of accepting versus rejecting treatment. First, we expect that persons who witnessed the painful deaths of loved ones will be more likely than nonbereaved persons to reject treatment. They may be highly motivated to avoid the physical and emotional distress experienced by their (now-deceased) loved one, and may want to spare their own family members from the duress of observing a painful death. Qualitative studies show that older adults’ feelings about end-of-life care are influenced by the deaths of others (Inman, 2002; Lambert *et al.*, 2005). For example, witnessing the painful deaths of others imbued in older persons a sense of futility about resuscitation or other life-sustaining efforts (Lambert *et al.*, 2005). We do not expect that persons who witnessed a “good death” will also differ significantly from nonbereaved persons because negatively charged information has a greater influence on decision making and perceptions than positive or neutral information (Tversky and Kahneman, 1991).

Second, given that individuals who engage in advance care planning often are motivated by or receive information consistent with the “death with dignity” and palliative care movements (Schwartz and Estrin, 2005), we expect that they will be less likely than nonplanners to desire life-sustaining treatments.⁴ We also expect that persons who engage in end-of-life planning will be less likely than nonplanners to endorse the “don’t know” option; direct experience with a behavior or practice increases the likelihood that one holds a well-articulated and strong attitude toward it (Fazio and Olson, 2003). Although knowledge of one’s preferences is not a prerequisite for engaging in some components of advance care planning (e.g., appointing a DPAHC), the process of planning may help individuals to formulate and refine their preferences.

Third, we expect that persons who believe that life-extending treatments are desirable and have a high probability of sustaining life will be more likely to desire such treatments. We propose that individuals who believe that they will have a long lifespan, who place great trust in the medical profession, and who fear death will desire life-sustaining treatments. We expect that perceived rather than objective aspects of health will be associated with treatment preferences. Our hypothesis draws on health beliefs research; Leventhal and colleagues (1980) have found that perceptions—rather than objective indicators—of the duration and curability of one’s illness are powerful predictors of health behaviors. Consistent with the health beliefs model, research finds that objective health conditions do not significantly predict whether one has a living will (SUPPORT, 1995), and persons who are optimistic about the “chance for a cure” are more likely to desire life-prolonging medical measures (Everhart and Pearlman, 1990).

Fourth, we expect that persons belonging to religious groups that historically have condemned euthanasia and endorsed “pro-life” ideologies will be more likely to desire life-sustaining treatments. Specifically, we expect that Catholics and conservative Protestants will be more likely than mainline Protestants, persons who do not have a formal religious affiliation, and those with another religion to desire life-sustaining treatments. The former two religious groups differ from the latter three in broad worldviews that are associated with the use of life-sustaining treatments, including beliefs about personal control, adherence to religious doctrine, and definitions as to what constitutes quality of life (Talone, 1996).

Finally, we expect that persons who are highly motivated to spare significant others from the burden of caregiving duties or end-of-life decision making will be less likely to desire life-sustaining treatments. Specifically, we expect that women, parents, and married persons will be more likely than men, childless persons, and unmarried persons to reject life-sustaining care. Women are more likely than men to fear becoming an emotional and financial burden on loved ones, in part, because they have greater knowledge of precisely what intensive caregiving entails (Bookwala *et al.*, 2001). The desire to spare others from a caregiving burden has been found in qualitative studies to be associated with a desire to hasten one’s death (Schroepfer, 2006).

METHODS

Data

We use data from the most recent wave of the Wisconsin Longitudinal Study (WLS), 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

⁴Some would argue that organizations promoting end-of-life planning characterize life-extending treatments in a negative light, and thus contribute to one’s belief that medical interventions are undesirable. For example, Compassion and Choices, a nonprofit organization that provides information on “choice at the end of life,” explicitly states that it fights policies “that would force patients to *endure futile, invasive treatment*” (italics added for emphasis). See <http://www.compassionandchoices.org/learn>.

at ages 36 (1975), 54 (1993), and 65 (2004). Of the 9,025 living graduates, 7,265 (80.5%) participated in the 2004 interview. Some strata of the U.S. population are not represented in the WLS. All sample members graduated from high school; by contrast, 75% of all Wisconsin youth graduated from high school in the late 1950s. Nearly all study participants are white. Despite these limitations, the sample is broadly representative of older white American men and women who have completed at least a high school education. Non-Hispanic whites who have completed at least a high school education accounted for more than two-thirds all American women and men ages 60–64 in 2000 (U.S. Bureau of the Census, 2003).

Topical modules were administered to random subsamples to reduce the overall length of the interview. We limit our analysis to the random 70% who received a module on end-of-life preparations. Our analytic sample includes 5,106 persons (2,354 men and 2,752 women).

Dependent Variables

We focus on two outcomes: preferences for end-of-life medical care in the hypothetical cases of (1) severe physical pain and (2) severe cognitive impairment. Participants are asked: “Suppose you had a serious illness today with very low chances of survival. If you were mentally intact, but in severe and constant physical pain, would you want to continue all medical treatments or stop all life-prolonging treatments?” and “If you had no physical pain, but were not able to speak, walk, or recognize others, and had very low chances of survival, would you want to continue all medical treatments or stop all life-prolonging treatments?” These items are adapted from a 1999 Detroit Area Study module (“Health Care and End of Life Decisions”), administered by the Survey Research Center at the University of Michigan. Response options were: “Continue all treatment so I could survive (staying alive is most important to me no matter what)” and “Stop all treatment to prolong my life (for me, quality of life is more important than length of life).” A small proportion (8% in physical pain and 5% in cognitive impairment scenario) volunteered alternative responses, such as “I don’t know” and “It depends.” We constructed three mutually exclusive outcome categories: continue all treatments; stop all life-prolonging treatments; and uncertain.

Independent Variables

Direct Experiences with End-of-Life Issues—We consider two indicators of direct experience with end-of-life issues: *the quality of death experienced by a close relative, and one’s own legal preparations for end-of-life healthcare*. Participants who survived the death of either a spouse or parent in the 10 years prior to the 2004 interview are asked a series of questions about the perceived quality of the death. Persons who experienced both parental and spousal deaths are asked about spousal death only, while those who experienced the deaths of two parents are asked about the most recent decedent. Bereaved participants are asked: “During his/her last week of life, how much pain did your spouse/parent have?” Response categories include no pain, slight pain, moderate pain, and severe pain. We constructed dichotomous variables to indicate: no deaths to parent or spouse in last 10 years (reference category); parent or spouse died with no or slight pain; and parent or spouse died in moderate or severe pain.

One’s own legal end-of-life preparations are assessed with two questions: “Do you have a living will? This is a set of written instructions about the type of medical treatment you would want to receive if you were unconscious or somehow unable to communicate” and “Have you made legal arrangements for someone to make decisions about your medical care if you become unable to make those decisions yourself? This is sometimes called a durable power of attorney for health care (DPAHC).” Participants who answer yes to either question are coded as 1; persons who have not engaged in either form of planning comprise the reference category.

Personal Beliefs—We consider attitudes toward death, beliefs about patient versus physician control over healthcare, and religion. *Death avoidance* ($\alpha = .70$) is a two-item scale, drawn from the Death Attitude Profile-Revised (Wong *et al.*, 1994). Participants indicate their level of agreement with two statements: “I avoid thinking about death altogether” and “Whenever the thought of death enters my mind, I try to push it away.” Items are averaged. The six response categories range from agree strongly to disagree strongly; items were reverse coded such that higher scores reflect more avoidant attitudes. *Beliefs about personal versus physician control over medical decision making* ($\alpha = .70$) are assessed with two items drawn from widely used measures of patients’ attitudes toward medical decision making (Ende *et al.*, 1989; Flynn *et al.*, 2006; Krantz *et al.*, 1980). Participants indicate their level of agreement with the statements: “I would rather have my doctor make the decisions about what’s best for my health than to be given a whole lot of choices” and “The important medical decisions should be made by my doctor, not by me.” Five response categories range from strongly disagree to strongly agree. Items are averaged, and higher scores indicate a greater level of acquiescence to physician control.

Religious Affiliation—Religious affiliation is measured with the question: “What is your religious preference?” Specific affiliations are coded into the categories: Catholic (reference group); mainline Protestant (e.g., Lutheran); conservative Protestant (e.g., Baptist); other (e.g., Jewish); and no religion.

Health and Health-Care Encounters—We consider two measures of physical health: self-rated health and presence of a life-threatening illness. *Self-rated health* is assessed with the question: “How would you rate your health at the present time: excellent, good, fair, poor, or very poor?” “Fair” and “poor” are coded as 1, and “good” or better is the reference category. *Life-threatening illness* is assessed with three questions: “Has a doctor ever told you that you have cancer or a malignant tumor, not including minor skin cancers? A heart attack, coronary heart disease, angina, congestive heart failure, or other heart problems? A stroke?” If the participant reported one or more of these illnesses, he or she is coded as 1. We constructed this dichotomous measure because three-quarters of respondents indicated that they had none of the three illnesses.

Access to healthcare is captured with two dichotomous measures: recent hospitalization and whether one has health insurance. *Recent hospital admission* is measured with the question: “In the past 12 months, have you been a patient in the hospital for at least one night?” *Health insurance* refers to whether the participant had any type of health insurance.

We also consider subjective lifespan and depressive symptoms. *Perceived life expectancy* is assessed with the question: “On a scale from 0 to 10 where 0 is absolutely no chance and 10 is absolutely certain, what are the chances that you will live for another 20 years?” *Depressive symptoms* ($\alpha = .87$) are measured with the Center for Epidemiological Studies Depression Scale (CES-D) (for item wordings, see Radloff, 1977). Participants report the number of days in the week prior to interview that they experienced each of 20 symptoms. We recoded responses in accordance with the original citation (Radloff, 1977): 0 (*rarely or none of the time, or less than one day a week*), 1 (*some or a little of the time, or 1–2 days a week*), 2 (*occasionally or a moderate amount of the time, 3–4 days a week*), 3 (*most or all of the time, 5–7 days a week*). We calculated a mean score for participants if they answered at least 10 of the 20 items. Scale scores were skewed; many people reported no depressive symptoms in the past week. We took the natural log, after adding a value of 1 to all scores to eliminate values of 0.

Family Roles Marital status refers to a participant’s current (2004) status. Categories include currently married or cohabiting with romantic partner (reference category); never married; and formerly married. *Parental status* refers to the number of living children one has; a continuous

measure (ranging from 0 to 13) was recoded into the categories: no children (reference category); 1–2 children; 3–4 children; and 5 or more children.

Socioeconomic and Demographic Characteristics Gender is a dichotomous variable where 1 refers to women. *Education* categories include: 12 (reference category); 13–15, and 16 or more years of schooling. Descriptive statistics for all variables are presented in Table I.

RESULTS

Bivariate Analyses

Table I shows the proportion who prefer to continue treatment, to stop treatment, or who do not know their preferences in each of the two end-of-life scenarios. The majority of participants report that they would not want life-prolonging treatment, although the proportion is higher in the cognitive impairment condition than the physical pain condition (87% vs. 72%, respectively). A minority desires treatment, yet this preference is much more common in the physical pain scenario than the cognitive impairment scenario (20% vs. 8%, respectively). A small proportion say they “don’t know”; 5% in the cognitive impairment scenario and 8% in the pain scenario. Men and women differ with respect to one outcome only; a greater proportion of men than women would prefer to receive treatment in the case of terminal illness with cognitive impairment; however, the magnitude of this difference is quite small (9% vs. 7%, respectively).

Multivariate Analyses

Table II presents results from multinomial logistic regression models documenting the variables associated with treatment preferences in the case of terminal illness with cognitive impairment (left panel) and physical pain (right panel). The models compare participants who do not want treatment, and who do not know their treatment preferences with participants who would accept treatment (reference category). A modest number of cases had missing data on the independent variables; 76% of cases had no item-specific missing data. To address concerns about missing values, we conducted multiple imputation by chained equations (MICE) on the independent variables. The final estimates for multivariate analyses are the result of averaging findings from the five imputed data sets (Royston, 2005).

Cognitive Impairment Scenario—Preferences in the cognitive impairment scenario are significantly related to five characteristics: surviving the painful death of a loved one, engaging in formal advance care planning, perceived life expectancy, religion, and gender. Persons who survived the painful death of a loved one are significantly more likely than nonbereaved persons (OR = 1.73, $p < .01$) and those who engaged in formal end-of-life planning are significantly more likely than nonplanners (OR = 1.59, $p < .001$) to say they would stop treatment.

Mainline Protestants and persons with no religious affiliation are more likely than Catholics to reject life-prolonging treatment (OR = 1.78 and 2.38, respectively, $p < .001$). The greater one’s perceived likelihood of surviving until the mid 80s, the more likely one is to say they would accept treatment. Responses of “don’t know” are significantly related to just one characteristic: gender. Women are significantly more likely than men to say that they “don’t know” (OR = 1.51, $p < .05$), and that they would want to stop treatment (OR = 1.39, $p < .01$).

Physical Pain Scenario—Generally similar results emerged for the two end-of-life treatment scenarios; this is not surprising, given that 78.5% of study participants reported the same preferences in both scenarios. As with cognitive impairment, treatment preferences in the physical pain condition are significantly associated with perceived lifespan, religion, and

advanced care planning. Two characteristics—education and family statuses—are associated with preferences in the physical pain scenario only.

The more pessimistic one's projected life expectancy, the less likely one is to want treatments (OR = 0.94, $p < .001$). Mainline Protestants (OR = 1.33, $p < .001$) and persons with no religious affiliation (OR = 1.66, $p < .001$) are more likely than Catholics to reject treatment. Persons who made legal preparations for the end of life are more likely than nonplanners to want treatments curtailed (OR = 1.58, $p < .001$). Finally, college graduates are less likely than high school graduates to say they would want to withhold treatment (OR = 0.72, $p < .001$).

The only characteristic associated with “don't know” responses in the pain scenario is parental status. Compared to childless persons, those with small (1–2 children) or large families (5 or more children) are less likely to say that they do not know their preferences (OR = 0.52 and 0.46, respectively). The coefficient for participants with 3 or 4 children is consistent with this trend, but is not statistically significant.

DISCUSSION

The United States has been characterized as a “death-denying society” (Kellehear, 1984), yet we find that the vast majority of older adults can articulate their preferences for end-of-life care, and most say that they would reject rather than accept life-extending treatment in the case of terminal illness. The older adults in our study are more likely to accept life-sustaining treatments in the case of physical pain than cognitive impairment. Only 8% of WLS participants said they would want to continue treatment in the case of cognitive impairment, whereas 20% would accept life-sustaining treatment in the case of serious physical pain.

Respondents' stronger preference for treatment in the face of physical pain compared to cognitive impairment may reflect patients' values and definitions of what constitutes a “good death” (Coppola *et al.*, 1999). Dying patients consistently rank burdening loved ones, being treated without dignity, and lacking mental acuity as the least desirable end-of-life conditions (Ditto *et al.*, 1996; Zweibel and Cassel, 1989). However, health-care providers rank physical pain as a more important concern than mental awareness at the end of life (Steinhauser *et al.*, 2000). This discrepancy between what patients value and what physicians rate as important could lead physicians to advocate for (or encourage the patient's family to select) treatments that do not mesh with the patient's preferences. By articulating their values to family and health-care providers, patients may help their loved ones to effectively carry out the role of surrogate.

A further aim of our study was to assess the extent to which treatment preferences reflect experiential, psychosocial, and demographic factors. Our findings are broadly consistent with the reasoned action models of behavioral intentions. Individuals endorse a preference for a course of action if: (1) they evaluate the action and its anticipated consequences positively; (2) they view the purported positive consequences as highly probable; and (3) they believe that the action and its consequences will be viewed positively by significant others (Ajzen and Fishbein, 1980). We elaborate our findings below, and discuss their implications for health-care policy and practice.

Importance of End-of-Life Experiences

Direct observation of problematic deaths to significant others is an important correlate of treatment preferences in the cognitive impairment scenario only. Respondents who recently witnessed the painful death of a spouse or parent have nearly twice the odds of saying they would reject life-prolonging treatment compared to a nonbereaved person. Observing another individual's physical suffering may lead one to actively seek palliative or nonintrusive treatments both for one's own well-being and for the sake of the loved ones who may witness

the death. Persons who have experienced the painful death of a loved one may be particularly motivated to protect their own children and spouse, who are the likely candidates for the roles of caregiver and decisionmaker at the end of life (Carr and Khodyakov, 2007). Rational choice models suggest that individuals prefer behaviors that carry more rewards than costs for one's self (Fazio and Olson, 2003) or for one's family (Becker, 1974), with most studies emphasizing rewards obtained in the near term. Our research suggests further that individuals may desire benefits for their loved ones in the distant future, even if they are ultimately unable to witness those benefits—if accrued after one becomes cognitively incapacitated or deceased.

Treatment preferences also are strongly related to formal preparations for end of life. Persons with an advance directive are significantly more likely than nonplanners to say that they do not want life-sustaining treatments, in both the physical pain and cognitive impairment scenarios. We cannot ascertain the direction of the relationship between end-of-life preferences and preparations, however, because we use data from a single wave of the WLS (2004). On one hand, the processes of drafting a living will and appointing a DPAHC may lead individuals to develop negative attitudes toward life-sustaining treatments. Information on end-of-life planning, including living will templates, typically is provided by organizations that promote “death with dignity” such as Aging with Dignity, Americans for Better Care of the Dying, Dying Well, and Last Acts. These templates generally prompt individuals to indicate those treatments that they would *not want* at the end of life. Thus, the process of preparing an advance directive may expose individuals to the argument that withholding treatment has positive consequences, whereas life-sustaining treatments may bring discomfort and a prolonged death.

However, it is equally plausible that persons who prefer to withhold treatment are more likely to prepare an advance directive, given that the continuation of all treatment often is the “default” strategy when an incapacitated patient has not formally stated his or her preferences (Field and Cassel, 1997). Thus, persons who want treatment withheld or withdrawn under certain circumstances may be more vigilant about advance care planning than are people who desire continued treatment. High-profile legal cases such as Terri Schiavo may have led individuals to believe that advance directives are orders to stop life-prolonging treatment, and that in their absence, doctors must ethically and legally continue treatment. In fact, doctors may withhold or withdraw futile care, although fear of litigation and the difficulty of determining when care is “futile” lead many doctors to continue treatment (American College of Physicians, 2005).

Health Beliefs Shape Preferences

Greater optimism about one's life expectancy is associated with a lower likelihood that one rejects treatment, in both the physical pain and cognitive impairment scenarios. This association persists even when objective health conditions are controlled. Moreover, health conditions (including self-rated health, the presence of life-threatening illness, and depressive symptoms) do not have statistically significant, direct effects on preferences. Among individuals who believe that they have a long life ahead, life-sustaining treatments may seem both desirable and necessary; withholding treatments, by contrast, may impede what one projects to be a long and healthy lifespan. Our finding is consistent with prior research showing that the nature and severity of one's illness are weak predictors of preferences (e.g., SUPPORT Principal Investigators, 1995; Stapleton *et al.*, 2005; Wittink *et al.*, 2008). Taken together, these results are consistent with a core theme of the rational choice model; behaviors are guided by one's perception of the consequences of their acts. Our results also are consistent with a core theme of the health beliefs model, which holds that an individual's health behaviors and preferences are not necessarily affected by one's actual condition, but by one's own perceptions about the duration, consequences, and curability of one's health condition (Leventhal *et al.*, 1980).

Religion and End-of-Life Preferences

Religious affiliation is associated with end-of-life preferences. Our findings are consistent with a mounting literature that links religious attitudes and practices with preferences for end-of-life care (e.g., Jacobs *et al.*, 2008; Phelps *et al.*, 2009). We find that Catholics are significantly less likely than mainline Protestants and persons with no religious affiliation to reject life-sustaining treatment. This pattern is consistent with the formal teachings of the Catholic Church, which condemns both active euthanasia (i.e., physician-assisted suicide) and passive euthanasia, or the withholding of life-sustaining treatments (John Paul II, 1995). In the year of data collection for the WLS, Pope John Paul II (2004) asserted that when an incapacitated patient's death is not inevitable, interventions such as artificial nutrition and hydration are "morally obligatory." Catholics who have internalized the church's teachings may view life-sustaining treatments positively, if for the mere fact that behaving in accordance with one's religious teachings brings psychological rewards, and may minimize disagreements with significant others who share one's religious views. That is, Catholics may perceive that the use of life-sustaining treatments will both yield desirable outcomes and will be assessed favorably by one's significant others (Ajzen and Fishbein, 1980).

Gender Roles and Treatment Preferences

Women are more likely than men to reject treatment in the case of cognitive impairment. This finding may reflect the ways that gender shapes family relationships, particularly with respect to caregiving (Bookwala *et al.*, 2001). Women typically have more direct experience with caregiving (Wolff and Kasper, 2006), and may recognize that caring for a person with cognitive impairment is particularly burdensome. Thus, women may prefer to withhold treatment to spare their loved ones from the burden of caring for a cognitively impaired patient (Bookwala *et al.*, 2001; McPherson *et al.*, 2007). Further, women are more likely than men to outlive their spouse (Federal Interagency Forum on Aging Related Statistics, 2008), and may anticipate that their adult children will be their primary caregivers. As such, women may be highly motivated to spare their children from this potentially intrusive responsibility (McPherson *et al.*, 2007).

Older men, by contrast, typically are cared for by their wives and may not question the caregiving burden they impose, given that this taken-for-granted gendered practice is normative for current cohorts of older adults (Calasanti and Bowen, 2006). Rational choice theories conceptualize rewards in terms of benefits to one's self, yet our results suggest that rewards (or costs) borne to others may be highly salient for women, particularly for members of a cohort in which women were socialized to act as caregiver throughout the life course (Moorman, 2009).

Who Does Not Know Their End-of-Life Preferences?

Few factors differentiated participants who "do not know" their preferences and those who prefer to continue all treatment. Our results corroborate work by Ditto and colleagues (2001), who found that the correlates of end-of-life preferences were similar regardless of whether they treated "don't know" as a separate response category or merged the category with the outcome of "continue treatment."⁵ "Don't know" responses may partly reflect individuals' uncertainty about the availability of significant others to assist with their care and decision making at the end of life (Moorman, 2009). Childless persons are significantly more likely than parents to say they "don't know" their preferences for care in the pain scenario. Women are more likely than men to say they "don't know" their preferences in the cognitive impairment scenario.

⁵In the Ditto *et al.* study, it was not clear whether the nonsignificant difference was due to small sample size and low statistical power, or substantive similarities between the subgroups.

As rational choice models propose, individuals endorse practices that they perceive will maximize rewards and minimize costs to both self and to their significant others who will play an active role in end-of-life care and decision making. However, childless persons may not have a clear vision of who exactly that significant other will be. While the vast majority of parents turn to their children (or spouse, if married) as their DPAHC, childless persons show tremendous heterogeneity in their choices—often reaching beyond the immediate family and relying on siblings, friends, and co-workers (Carr and Khodyakov, 2007). These social relationships are more fluid and less obligatory than parent-child or spousal relationships (Fischer, 1982); thus older unmarried adults may feel a sense of uncertainty in trying to predict the role that significant others will play in their own end-of-life care. Similarly, women who anticipate that they will outlive their spouse may be uncertain about which child—if any—will be most integrally involved with their end-of-life decision making. Our findings provide suggestive evidence that responses of “don’t know” reflect a lack of information about what the future may hold (Converse, 1964), rather than information overload (Zaller, 1992).

LIMITATIONS

Our study has several important limitations. First, we focused on the hypothetical preferences of persons in their mid-60s. Some research suggests that end-of-life treatment preferences are discussed and contemplated most thoroughly and seriously among older adults who are near the end of life (Inman, 2002). The WLS participants, by contrast, are quite healthy; only 10% rate their health as fair or poor, 12% were admitted to a hospital in the year prior to interview, and 25% had a serious health condition such as cancer or heart disease. Future studies should assess how general preferences and values change with advancing age, and as healthy older adults experience health declines; to date, most studies focus on how preferences of terminally ill persons change as their disease progresses (e.g., Fried *et al.*, 2007).⁶

Second, we examined the preferences of a single birth cohort only, born in 1939. We look forward to seeing future research that explores the extent to which these patterns vary across birth cohorts. Members of the large Baby Boom cohorts (b. 1946–1964) are more highly educated than prior cohorts, and are believed to be particularly proactive in making health-care decisions (Focalyst, 2007). Compared to members of the WLS birth cohort, members of the Baby Boom cohort are less likely to be married, more likely to have stepchildren, and more likely to have parents who survive until very late life and thus they may witness firsthand the advantages and disadvantages of life-sustaining treatments (Hughes and O’Rand, 2004). How these contextual factors shape future cohorts’ general attitudes toward end of life will be of critical interest to scholars, practitioners, and policymakers in coming decades.

Third, our sample included only non-Hispanic white men and women who had earned at least a high school diploma. The ethnic and socioeconomic characteristics of our sample may partially account for the slightly elevated proportions that wanted to withhold treatment (72% in physical pain and 87% in cognitive impairment scenario).⁷ By contrast, polls of the overall U.S. population show that 70–80% of Americans would not want to be kept alive through artificial means if in a persistent vegetative state (Patrick *et al.*, 1997). Prior studies show that African Americans, Latinos, and persons with lower levels of educational attainment are more likely than whites, non-Hispanics, and highly educated persons to desire all available treatments (Barnato *et al.*, 2009). Future studies should explore the extent to which these ethnic

⁶Winnink *et al.*, (2008) is an important exception; however, they focus on the changing preferences of a sample of older physicians (average age = 69) over a 3-year period (1999–2002). Persons experiencing declines in health are slightly more likely than those in stable, good health to change their preferences. An important question is whether laypersons experience similar changes in preferences over the life course and as their health declines.

⁷Our relatively high levels of planning are consistent with other recent studies based on samples of healthy white adults (e.g., Nishimura *et al.*, 2007).

and socioeconomic differences in preferences reflect one's observations of loved ones' end-of-life encounters, religion, family structure, and attitudes toward doctor versus patient autonomy.

Finally, we explored only a limited set of possible correlates of preferences. Our very low pseudo- R^2 values (4% in cognitive impairment scenario, and 2% in pain scenario) suggest that future studies should consider a broader set of contextual (e.g., state policy), family-level (e.g., relationship quality), psychological (e.g., risk aversion), and experiential (e.g., whether loved one died with severe cognitive impairment) factors. Unstructured open-ended interviews with healthy, community-dwelling older adults also may reveal insights into how individuals formulate their end-of-life treatment preferences.

CONCLUSION

Despite these limitations, we found that most WLS participants prefer to withhold rather than continue treatment, and that direct experience with end-of-life issues, expectations about one's lifespan, and religious affiliation were the most powerful correlates of one's preferences. These findings carry potentially important implications for health-care policy and practice. The widely documented limitations of the living will reveal the urgency of holding end-of-life discussions prior to the onset of a serious health concern (Briggs, 2003; Perkins, 2007). These discussions should focus on patients' *general* values and preferences, rather than *specific* illnesses and treatments. Our results suggest that doctors could talk to patients about their prior experiences with a loved one's death and their feelings about that experience (Hopp, 2000). Recalling these experiences, especially distressing memories, may help patients to clarify their own preferences, and may help practitioners develop strategies to ensure that the patient's values and preferences are articulated, understood, and respected.

We hope that our study provides a springboard for future sociological studies of end-of-life planning. Research on end-of-life issues is conducted almost exclusively by gerontologists, medical researchers, ethicists, and, to a lesser degree, psychologists. Sociologists are virtually absent from this line of inquiry, as our reference list reveals. However, our study suggests that concepts at the very core of sociology—family roles and relations, religion, and attitudes—are powerful influences on the ways that older adults think about death and dying. Greater attention to psychosocial and experiential influences on end-of-life planning may offer researchers innovative insights into a critically important decision-making process.

References

- Ajzen, Icek; Fishbein, Martin. Understanding Attitudes and Predicting Behavior. Engle-wood Cliffs, NJ: Prentice-Hall; 1980.
- American College of Physicians. Ethics Manual: Fifth Edition. *Annals of Internal Medicine* 2005;142(7):560–582. [PubMed: 15809467]
- American Medical Association, Council on Scientific Affairs. Good Care of the Dying Patient. *Journal of the American Medical Association* 1996;275(6):474–478. [PubMed: 8627970]
- Barnato, Amber E.; Anthony, Denise L.; Skinner, Jonathan; Gallagher, Patricia M.; Fisher, Elliott S. Racial and Ethnic Differences in Preferences for End-of-Life Treatment. *Journal of General Internal Medicine* 2009;24(6):695–701. [PubMed: 19387750]
- Bayer, William; Mallinger, Julie B.; Krishnan, Ashok; Shields, Cleveland G. Attitudes Toward Life-Sustaining Interventions Among Ambulatory Black and White Patients. *Ethnicity and Disease* 2006;16(4):914–919. [PubMed: 17061746]
- Becker, Gary S. A Theory of Marriage: Part II. *Journal of Political Economy* 1974;82(6):S11–S26.
- Bookwala, Jamila; Coppola, Kristen M.; Fagerlin, Angela; Ditto, Peter H.; Danks, Joseph H.; Smucker, William D. Gender Differences in Preferences for Life-Sustaining Medical Treatments Among Community-Dwelling Older Adults. *Death Studies* 2001;25(2):127–149. [PubMed: 11708352]

- Briggs, Linda. Shifting the Focus of Advance Care Planning: Using an In-Depth Interview to Build and Strengthen Relationships. *Interventions in End of Life Care* 2003;5(2):1–11.
- Calasanti, Toni; Bowen, Mary Elizabeth. Spousal Caregiving and Crossing Gender Boundaries: Maintaining Gendered Identities. *Journal of Aging Studies* 2006;20(3):253–263.
- Carr, Deborah; Khodyakov, Dmitry. Health Care Proxies in Later Life: Whom Do We Choose and Why? *Journal of Health and Social Behavior* 2007;48(2):180–194. [PubMed: 17583273]
- Claessens, Michael T.; Lynn, Joanne; Zhong, Zhenshao; Desbiens, Norman A.; Phillips, Russell; Wu, Albert W.; Harrell, Frank E.; Connors, Alfred F. Dying with Lung Cancer or Chronic Obstructive Pulmonary Disease: Insights from SUPPORT. *Journal of American Geriatric Society* 2000;48(5):S146–S153.
- Collins, Lauren G.; Parks, Susan M.; Winter, Laraine. The State of Advance Care Planning: One Decade after SUPPORT. *American Journal of Hospice and Palliative Medicine* 2006;23(5):378–384. [PubMed: 17060305]
- Converse, Philip E. The Nature of Belief Systems in Mass Publics. In: Apter, David, editor. *Ideology and Discontent*. New York: Free Press; 1964. p. 206–261.
- Coppola, Kristen M.; Bookwala, Jamila; Ditto, Peter H.; Lockhart, Lisa K.; Danks, Joseph H.; Smucker, William D. Elderly Adults' Preferences for Life-Sustaining Treatments: The Role of Impairment, Prognosis, and Pain. *Death Studies* 1999;23(7):617–634. [PubMed: 10915454]
- Coppola, Kristen M.; Ditto, Peter H.; Danks, Joseph H.; Smucker, William D. Accuracy of Primary Care and Hospital-Based Physicians' Predictions of Elderly Outpatients' Treatment Preferences With and Without Advance Directives. *Archives of Internal Medicine* 2001;161(3):431–440. [PubMed: 11176769]
- Ditto, Peter H.; Danks, Joseph H.; Smucker, William D.; Bookwala, Jamila; Coppola, Kristen M.; Dresser, Rebecca; Fagerlin, Angela; Gready, R Mitchell; Houts, Renate M.; Lockhart, Lisa K.; Zyzanski, Stephen. Advance Directives as Acts of Communication: A Randomized Controlled Trial. *Archives of Internal Medicine* 2001;161(3):421–430. [PubMed: 11176768]
- Ditto, Peter H.; Druley, Jennifer A.; Kathleen, A.; Danks, Joseph H.; Smucker, William D. Fates Worse Than Death: The Role of Valued Life Activities in Health State Evaluations. *Health Psychology* 1996;15(5):332–343. [PubMed: 8891712]
- Ditto, Peter H.; Hawkins, Nikki A.; Pizzaro, David A. Imagining the End of Life: On the Psychology of Advance Decision Making. *Motivation and Emotion* 2006;27(2):481–502.
- Doukas, David J.; McCullough, Laurence B. The Values History: The Evaluation of the Patient's Wishes and Advance Directives. *Journal of Family Practice* 1991;32(2):145–153. [PubMed: 1990042]
- Emanuel, Linda L. Facing Requests for Physician-Assisted Suicide: Toward a Practical and Principled Clinical Skill Set. *Journal of American Medical Association* 1998;280(7):643–647.
- Ende, Jack; Kazis, Lewis; Ash, Arlene. Measuring Patients' Desire for Autonomy: Decision Making and Information-Seeking Preferences Among Medical Patients. *Journal of General Internal Medicine* 1989;4(1):23–30. [PubMed: 2644407]
- Everhart, Maria A.; Pearlman, Robert A. Stability of Patient Preferences Regarding Life-Sustaining Treatment. *Chest* 1990;97(1):159–164. [PubMed: 2104791]
- Fazio, Russell H.; Olson, Michael A. Attitudes: Foundations, Functions, and Consequences. In: Hogg, Michael A.; Cooper, Joel, editors. *The Handbook of Social Psychology*. London: Sage; 2003. p. 139–160.
- Federal Interagency Forum on Aging-Related Statistics. *Older Americans 2008: Key Indicators of Well-Being*. Washington, DC: U.S. Government Printing Office; 2008.
- Field, Marilyn; Cassel, Christine. *Approaching Death*. Washington, DC: National Academy Press; 1997.
- Fischer, Claude S. *To Dwell Among Friends*. Chicago, IL: University of Chicago Press; 1982.
- Flynn, Kathryn E.; Smith, Maureen A.; Vanness, David. A Typology of Preferences for Participation in Healthcare Decision Making. *Social Science & Medicine* 2006;63(5):1158–1169. [PubMed: 16697096]
- Focalyst. *Focalyst Insight Report*. Washington, DC: Focalyst and American Association of Retired Persons; 2007 Sep. *Boomers and Decisions About Their Health: It's All About Control*.

- Fried, Terri R.; Bradley, Elizabeth H.; Towle, Virginia R.; Allore, Heather. Understanding the Treatment Preferences of Seriously Ill Patients. *New England Journal of Medicine* 2002;346(14):1061–1066. [PubMed: 11932474]
- Fried, Terri R.; Van Ness, Peter H.; Byers, Amy; Towle, Virginia; O’Leary, John; Dubin, Joel. Changes in Preferences for Life-Sustaining Treatment Among Older Persons with Advanced Illnesses. *Journal of General Internal Medicine* 2007;22(11):495–501. [PubMed: 17372799]
- Gordon, Nancy P.; Shade, Sharley B. Advance Directives More Likely Among Seniors Asked About End-of-Life Preferences. *Archives of Internal Medicine* 1999;159(7):701–704. [PubMed: 10218749]
- Hopp, Faith. Preferences for Surrogate Decision Makers, Informal Communication and Advance Directives Among Community-Dwelling Elders: Results from a National Study. *Gerontologist* 2000;40(4):449–457. [PubMed: 10961034]
- Hughes, Mary Elizabeth; O’Rand, Angela. *Lives and Times of the Baby Boomers*. Washington, DC: Population Reference Bureau; 2004.
- Inman, Lorinda. Advance Directives: Why Community Based Older Adults Do Not Discuss Their Wishes. *Journal of Gerontological Nursing* 2002;28(9):40–46. [PubMed: 12240520]
- Institute of Medicine. *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academy Press; 2001.
- Jacobs LM, Burns K, Jacobs B Bennett. Trauma Death: Views of the Public and Trauma Professionals on Death and Dying from Injuries. *Archives of Surgery* 2008;143(8):730–735. [PubMed: 18711031]
- Paul, John, II. *Evangelium Vitae: On the Value and Inviolability of Human Life*. Washington, DC: U.S. Conference of Catholic Bishops; 1995.
- Paul, John, II. *Life Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas*. Address presented to the International Congress; Rome, Italy. March; 2004.
- Kellehear, Allan. Are We a Death-Denying Society? A Sociological Review. *Social Science & Medicine* 1984;18(9):713–723. [PubMed: 6729531]
- Kramer, Betty J.; Boelk, Amy; Auer, Casey. Family Conflict at the End-of-Life: Lessons Learned in a Model Program for Vulnerable Older Adults. *Journal of Palliative Medicine* 2006;9(3):791–801. [PubMed: 16752985]
- Krantz, David S.; Baum, Andrew; Wideman, Margaret. Assessment of Preferences for Self-Treatment and Information in Health Care. *Journal of Personality and Social Psychology* 1980;39(5):977–990. [PubMed: 7441487]
- Lambert, Heather C.; McColl, Mary Ann; Gilbert, Julie; Wong, Jiahui; Murray, Gale; Shortt, Samuel ED. Factors Affecting Long-Term Care Residents’ Decision-Making Processes as They Formulate Advance Directives. *Gerontologist* 2005;45(5):626–633. [PubMed: 16199397]
- Leventhal, Howard; Meyer, Daniel; Nerenz, David. The Common-Sense Representation of Illness Danger. In: Rachman, S., editor. *Contributions to Medical Psychology*. Vol. 2. New York: Pergamon Press; 1980. p. 7-30.
- McPherson, Christine J.; Wilson, Keith G.; Murray, Mary Ann. Feeling Like a Burden to Others: A Systematic Review Focusing on the End of Life. *Palliative Medicine* 2007;21(2):115–128. [PubMed: 17344260]
- Moorman, Sara. Unpublished PhD Dissertation. Department of Sociology, University of Wisconsin; Madison, WI: 2009. *Facing End-of-Life Together: Marital Relationship Quality and End-of-Life Health Care Preferences*.
- Morrell, Eric D.; Brown, Brandon P.; Qi, R.; Drabiak, Katharine; Helft, Paul R. The Do-Not-Resuscitate Order: Associations with Advance Directives, Physician Specialty and Documentation of Discussion 15 Years After the Patient Self-Determination Act. *Journal of Medical Ethics* 2008;34(9):642–647. [PubMed: 18757631]
- Nishimura, Adam; Mueller, Paul S.; Evenson, Laura K.; Downer, Lisa L.; Bowron, Catherine T.; Thieke, Michael P.; Wroblewski, Diane M.; Crowley, Mary E. Patients Who Complete Advance Directives and What They Prefer. *Mayo Clinic Proceedings* 2007;82(2):1480–1486. [PubMed: 18053455]
- Patient Self-Determination Act of 1990. 1990. 554206, 4751 of the Omnibus Reconciliation Act of 1990. Pub. No. 101-508.

- Patrick, Donald L.; Pearlman, Robert A.; Starks, Helene E.; Cain, Kevin C.; Cole, William G.; Uhlmann, Richard F. Validation of Preferences for Life-Sustaining Treatment: Implications for Advance Care Planning. *Annals of Internal Medicine* 1997;127(7):509–517. [PubMed: 9313018]
- Perkins, Henry S. Controlling Death: The False Promise of Advance Directives. *Annals of Internal Medicine* 2007;147(1):51–57. [PubMed: 17606961]
- Phelps, Andrea C.; Maciejewski, Paul K.; Nilsson, Matthew; Balboni, Tracy A.; Wright, Alexi A.; Paulk, M Elizabeth; Trice, Elizabeth; Schrag, Deborah; Peteet, John R.; Block, Susan D.; Prigerson, Holly G. Religions Coping and Use of Intensive Life-Prolonging Care Near Death in Patients with Advanced Cancer. *Journal of American Medical Association* 2009;301(11):1140–1147.
- Porensky, Emily K.; Carpenter, Brian D. Knowledge and Perceptions in Advance Care Planning. *Journal of Aging and Health* 2008;20(1):89–106. [PubMed: 18252936]
- President's Council on Bioethics. *Taking Care: Ethical Caregiving in Our Aging Society*. Washington, DC: Government Printing Office; 2005.
- Radloff, Lenore S. The CES-D Scale: A Self-Report Depression Scale for Research in the General Population. *Applied Psychological Measurement* 1977;1(3):385–401.
- Resnick, Barbara; Andrews, Caryn. End-of-Life Treatment Preferences Among Older Adults: A Nurse Practitioner Initiated Intervention. *Journal of American Academy of Nurse Practitioners* 2002;14(11):517–522.
- Royston, Patrick. Multiple Imputation of Missing Values: Update of ICE. *Stata Journal* 2005;5:527–536.
- Schroepfer, Tracy. Mind Frames Towards Dying and Factors Motivating Their Adoption by Terminally Ill Elders. *Journal of Gerontology: Social Sciences* 2006;61B(3):S129–S139.
- Schwartz, John; Estrin, James. Many Seeking One Final Say on the End. *New York Times*; 2005 Jun 17. p. A1p. A22
- Stapleton, Renee D.; Nielsen, Elizabeth L.; Engelberg, Ruth A.; Patrick, Donald L.; Curtis, J Randall. Association of Depression and Life-Sustaining Treatment Preferences in Patients with COPD. *Chest* 2005;127(1):328–334. [PubMed: 15654000]
- Steinhauser, Karen E.; Christakis, Nicholas A.; Clipp, Elizabeth C.; McNeilly, Maya; McIntyre, Lauren; Tulsky, James A. Factors Considered Important at the End of Life by Patients, Family, Physicians, and Other Care Providers. *Journal of the American Medical Association* 2000;284(19):2476–2482. [PubMed: 11074777]
- SUPPORT Principal Investigators. A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients. *Journal of the American Medical Association* 1995;274(20):1591–1599. [PubMed: 7474243]
- Talone, Pat A. *American University Studies Series VII, Theology and Religion*. New York: Peter Lang; 1996. *Feeding the Dying: Religion and End-of-Life Decisions*.
- Trope, Yaacov; Liberman, Nira. Temporal Construal. *Psychological Review* 2003;110(2):403–421. [PubMed: 12885109]
- Tversky, Amos; Kahneman, Daniel. Loss Aversion in Riskless Choice: A Reference Dependence Model. *Quarterly Journal of Economics* 1991;106(4):1039–1061.
- U.S. Bureau of the Census. *Current Population Survey, Annual Social and Economic Supplement*. Washington, DC: U.S. Bureau of the Census; 2003.
- Wilson, Tim; Gilbert, Daniel T. Affective Forecasting. *Advances in Experimental Social Psychology* 2003;35:345–411.
- Wittink, Marsha N.; Morales, Knashawn H.; Meoni, Lucy A.; Frod, Daniel E.; Wang, Nae-yuh; Klag, Michael J.; Gallo, Joseph J. Stability of Preferences for End-of-Life Treatment After 3 Years of Followup. *Archives of Internal Medicine* 2008;168(19):2125–2130. [PubMed: 18955642]
- Wolff, Jennifer L.; Kasper, Judith D. Caregivers of Frail Elders: Updating a National Profile. *Gerontologist* 2006;46(3):344–356. [PubMed: 16731873]
- Wong, Paul T.; Reker, Gary T.; Gesser, Gina G. Death Attitude Profile-Revised: A Multidimensional Measure of Attitudes Toward Death. In: Neimeyer, Robert A., editor. *Death Anxiety Handbook: Research, Instrumentation and Applications*. Washington, DC: Taylor and Francis; 1994. p. 121-148.
- Zaller, John R. *The Nature and Origins of Mass Opinions*. New York: Cambridge University Press; 1992.

Zweibel, Nancy R.; Cassel, Christine K. Treatment Choices at the End of Life: A Comparison of Decisions by Older Patients and Their Physician-Selected Proxies. *Gerontologist* 1989;29(5):615–621. [PubMed: 2599421]

Table I

Descriptive Statistics, All Variables Used in Analysis. Wisconsin Longitudinal Survey 2004

| | Total Sample N = 5,106 | Men N = 2,354 | Women N = 2,752 | Test Statistic for Gender Comparisons |
|---|----------------------------|----------------------------|----------------------------|---|
| | Mean (SD) or Proportion | Mean (SD) or Proportion | Mean (SD) or Proportion | |
| <i>Dependent Variables</i> | | | | |
| Cognitive impairment: Continue treatment | .08 | .09 | .07 | 6.59** |
| | — | — | — | |
| Cognitive impairment: Stop treatment | .87 | .86 | .88 | 2.19 |
| | — | — | — | |
| Cognitive impairment: Don't know | .05 | .05 | .05 | 0.89 |
| | — | — | — | |
| Pain: Continue treatment | .20 | .20 | .21 | 0.39 |
| | — | — | — | |
| Pain: Stop treatment | .72 | .73 | .71 | 2.81 |
| | — | — | — | |
| Pain: Don't know | .08 | .07 | .08 | 3.54 |
| | — | — | — | |
| <i>Independent Variables</i> | | | | |
| Direct experience with end-of-life issues | | | | |
| Did not experience a death in the past 10 years (reference) | .72 | .74 | .71 | 8.53** |
| | — | — | — | |
| Parent or spouse died in past 10 years, no / little pain in final weeks | .17 | .15 | .18 | 13.26*** |
| | — | — | — | |
| Parent or spouse died in past 10 years, moderate / severe pain in final weeks | .11 | .11 | .11 | 0.05 |
| | — | — | — | |
| Has living will and / or durable power of attorney for healthcare | .60 | .61 | .60 | 1.05 |
| | — | — | — | |
| Personal beliefs | | | | |
| Death avoidance (1 = <i>least avoidant</i> ; 6 = <i>most avoidant</i>) | 3.15 (1.25) | 3.29 (1.23) | 3.03 (1.26) | 6.81*** |
| Physician should control decisions (1 = <i>strongly disagree</i> ; 5 = <i>strongly agree</i>) | 2.50 (1.02) | 2.63 (1.00) | 2.39 (1.02) | 7.90*** |
| Catholic (reference) | .38 | .37 | .39 | 2.55 |
| | — | — | — | |
| Mainline Protestant | .45 | .44 | .46 | 1.63 |
| | — | — | — | |
| Conservative Protestant | .05 | .05 | .05 | 0.32 |
| | — | — | — | |
| Other religious affiliation | .04 | .03 | .04 | 2.30 |
| | — | — | — | |
| No religious affiliation | .08 | .11 | .06 | 32.73*** |
| | — | — | — | |

| | Total Sample <i>N</i> = 5,106 | Men <i>N</i> = 2,354 | Women <i>N</i> = 2,752 | Test Statistic for Gender Comparisons |
|--|-------------------------------------|-------------------------------------|-------------------------------------|---|
| | Mean (<i>SD</i>) or Proportion | Mean (<i>SD</i>) or Proportion | Mean (<i>SD</i>) or Proportion | |
| Health and health-care encounters | | | | |
| Fair or poor self-reported health | .10 | .10 | .10 | 0.09 |
| | — | — | — | |
| Hospital admission in the past year | .12 | .13 | .11 | 5.76* |
| | — | — | — | |
| Perceived chances of living another 20 years (0 = <i>no chance</i> ; 10 = <i>certain</i>) | 5.84 (2.73) | 5.60 (2.70) | 6.05 (2.74) | -5.29*** |
| Has health insurance | .97 | .97 | .96 | 3.67 |
| | — | — | — | |
| Depressive symptoms (0 = <i>fewest</i> ; 3 = <i>most</i>) ^a | .43 (0.39) | .39 (0.36) | .46 (0.41) | -6.37*** |
| Has life-threatening illness | .25 | .29 | .21 | 43.80*** |
| | — | — | — | |
| Family roles | | | | |
| Currently married (reference) | .78 | .86 | .72 | 127.60*** |
| | — | — | — | |
| Never married | .04 | .03 | .04 | 0.64 |
| | — | — | — | |
| Formerly married | .18 | .11 | .24 | 137.40*** |
| | — | — | — | |
| Has no children (reference) | .07 | .07 | .07 | 0.05 |
| | — | — | — | |
| Has 1–2 children | .33 | .36 | .30 | 21.90*** |
| | — | — | — | |
| Has 3–4 children | .44 | .42 | .45 | 5.01* |
| | — | — | — | |
| Has 5 + children | .17 | .15 | .18 | 9.45** |
| | — | — | — | |
| Demographic and socioeconomic characteristics | | | | |
| High school (12 years of education; reference) | .56 | .50 | .62 | 75.84*** |
| | — | — | — | |
| Some college (13–15 years of education) | .17 | .17 | .16 | 1.08 |
| | — | — | — | |
| College (16 or more years of education) | .27 | .33 | .22*** | 78.15*** |
| | — | — | — | |

^aReported prior to transformation to reduce skew.

Notes: Means (and standard deviations) are presented for continuous measures; proportions are shown for categorical measures. Chi-square tests (for categorical measures) and *t*-tests (for continuous measures) were conducted to assess statistically significant gender differences, where

* $p < .05$;

**
 $p < .01$;

 $p < .001$. Statistics are reported prior to multiple imputation.

Table II
 Multinomial Logistic Regression: Correlates of Treatment Preferences in Cognitive Impairment and Physical Pain Scenarios ($N = 4,929$)

| | Cognitive Impairment | | Physical Pain | |
|--|--|-------------------------------------|--|-------------------------------------|
| | Stop Treatment (vs. Continue Treatment) | Don't Know Odds Ratio (95% C.I.) | Stop Treatment (vs. Continue Treatment) | Don't Know Odds Ratio (95% C.I.) |
| <i>Direct Experience with End-of-Life Issues</i> | | | | |
| Parent or spouse died in past 10 years, no / little pain in final weeks | 1.19 (0.89–1.60) | 0.97 (0.61–1.53) | 1.22 (0.99–1.49) | 1.06 (0.74–1.52) |
| Parent or spouse died in past 10 years, moderate / severe pain in final weeks | 1.73** (1.15–2.62) | 1.39 (0.77–2.50) | 1.08 (0.85–1.38) | 1.14 (0.75–1.74) |
| Has living will and / or durable power of attorney for healthcare | 1.59*** (1.29–1.96) | 0.89 (0.64–1.23) | 1.58*** (1.36–1.83) | 0.80 (0.63–1.02) |
| <i>Personal Beliefs</i> | | | | |
| Death avoidance (1 = <i>least avoidant</i> ; 6 = <i>most avoidant</i>) | 1.05 (0.95–1.16) | 1.14 (0.99–1.32) | 0.99 (0.93–1.06) | 1.01 (0.89–1.15) |
| Physician should control decisions (1 = <i>strongly disagree</i> ; 5 = <i>strongly agree</i>) | 0.91 (0.80–1.03) | 1.01 (0.85–1.19) | 1.01 (0.93–1.09) | 0.95 (0.82–1.10) |
| Mainline Protestant | 1.78*** (1.41–2.25) | 1.22 (0.85–1.76) | 1.33*** (1.14–1.56) | 1.06 (0.81–1.38) |
| Conservative Protestant | 0.67 (0.44–1.00) | 1.46 (0.82–2.63) | 0.82 (0.60–1.14) | 1.15 (0.69–1.91) |
| Other religious affiliation | 1.26 (0.73–2.17) | 0.90 (0.35–2.27) | 1.19 (0.80–1.75) | 0.94 (0.48–1.83) |
| No religious affiliation | 2.38*** (1.46–3.87) | 1.84 (0.92–3.70) | 1.66*** (1.23–2.24) | 1.35 (0.84–2.18) |
| <i>Health and Health Care Encounters</i> | | | | |
| Fair or poor self-reported health | 0.77 (0.52–1.13) | 0.89 (0.49–1.63) | 1.11 (0.85–1.47) | 1.34 (0.85–2.12) |
| Hospital admission in the past year | 1.13 (0.79–1.62) | 0.87 (0.45–1.70) | 0.96 (0.76–1.21) | 0.85 (0.52–1.41) |
| Perceived chances of living another 20 years (0 = <i>no chance</i> ; 10 = <i>certain</i>) | 0.89*** (0.86–0.93) | 0.93 (0.87–1.01) | 0.94*** (0.91–0.97) | 0.96 (0.91–1.02) |
| Has health insurance | 1.01 (0.58–1.76) | 1.19 (0.49–2.89) | 0.75 (0.49–1.16) | 0.67 (0.35–1.26) |
| Depressive symptoms (natural log (CES-D score + 1)) | 1.14 (0.71–1.84) | 0.97 (0.46–2.04) | 1.00 (0.72–1.39) | 0.79 (0.44–1.40) |
| Has life threatening illness | 1.07 (0.82–1.39) | 0.81 (0.53–1.24) | 0.88 (0.74–1.04) | 0.80 (0.59–1.08) |
| <i>Family Roles</i> | | | | |
| Never married | 0.75 (0.37–1.53) | 0.69 (0.23–2.06) | 1.01 (0.60–1.70) | 0.44 (0.19–1.01) |
| Formerly married | 0.91 (0.67–1.22) | 1.16 (0.75–1.79) | 1.02 (0.84–1.25) | 1.10 (0.79–1.53) |
| Has 1–2 children | 1.16 (0.65–2.07) | 0.75 (0.32–1.75) | 1.06 (0.71–1.58) | 0.52* (0.30–0.92) |
| Has 3–4 children | 1.13 (0.64–2.00) | 1.00 (0.43–2.29) | 1.15 (0.77–1.71) | 0.62 (0.36–1.09) |
| Has 5 + children | 0.91 (0.50–1.66) | 0.69 (0.28–1.68) | 0.95 (0.63–1.45) | 0.46** (0.25–0.85) |
| <i>Demographic and Socioeconomic Characteristics</i> | | | | |

| | Cognitive Impairment | | | Physical Pain | | |
|---|--------------------------|-----------------------|-----------------------|--------------------------|-----------------------|-----------------------|
| | Stop Treatment | Don't Know | Don't Know | Stop Treatment | Don't Know | Don't Know |
| | (vs. Continue Treatment) | | | (vs. Continue Treatment) | | |
| | Odds Ratio (95% C.I.) | Odds Ratio (95% C.I.) | Odds Ratio (95% C.I.) | Odds Ratio (95% C.I.) | Odds Ratio (95% C.I.) | Odds Ratio (95% C.I.) |
| Female | 1.39** (1.12–1.74) | 1.51* (1.07–2.12) | | 0.92 (0.79–1.07) | | 1.17 (0.91–1.51) |
| Some college (13–15 years of education) | 0.81 (0.61–1.09) | 1.00 (0.64–1.55) | | 0.97 (0.79–1.19) | | 1.28 (0.91–1.79) |
| College (16 or more years of education) | 0.87 (0.67–1.13) | 0.96 (0.64–1.44) | | 0.72*** (0.60–0.86) | | 1.02 (0.76–1.37) |
| χ^2, df | 176.18; 46 | | | 166.40; 46 | | |
| N | 4,288 | | | 3,561 | | |
| | 241 | | | 374 | | |

* $p \leq .05$;

** $p \leq .01$;

*** $p \leq .001$.