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Older Adults' Preferences for Independent or Delegated End-of-Life Medical Decision-Making

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Abstract

Objectives—This study assesses the proportions of participants who prefer independent or delegated medical decision-making at end-of-life, and examines the relationships of personal beliefs, affiliative beliefs, and end-of-life planning behaviors to decision-making preference.

Methods—Data are drawn from the Wisconsin Longitudinal Study, a sample of nearly 4,500 healthy white Midwestern high school graduates in their mid-60s.

Results—Four-fifths of participants wanted to make decisions independently. Valuing independence, being less avoidant of thoughts of death, and valuing quality of life over length of life had strong associations with a preference for independent decision-making. Those concerned about burdening a caregiver wanted to make independent decisions. Persons who both executed a living will and appointed a durable power of attorney for health care preferred independent decision-making.

Discussion—Older adults cite personal and affiliative beliefs, not lack of autonomy, as reasons for their choice to decide independently or delegate.

Keywords

attitudes; autonomy; control; death and dying; durable power of attorney for health care

Introduction

In the United States today, terminally ill older adults have the right to exercise extensive control over their health care, dictating the course of treatment even if the physical or cognitive capacity to make decisions is lost (Snyder & Leffler, 2005). In such cases, health care providers are legally obligated to enact the terms of the older adult's living will (should one exist), and consult with legally-designated surrogate decision-makers, who are typically family members. Bioethicists recommend that surrogates use the standard of substituted judgment, basing their decisions upon knowledge of the patient's preferences rather than upon their independent assessment of the patient's best interests.

In practice, many of these provisions are not enacted: Three-quarters of doctors have not discussed life expectancy with their elderly patients who have a serious chronic illness (Fried, Bradley, & O'Leary, 2003). Less than a quarter of adults in the United States have completed a living will, and even completed living wills may be minimally useful in light of failure to record the document in medical records, changing treatment preferences, and imperfect ability to predict the circumstances in which they will be needed (Fagerlin &

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Schneider, 2004). Many surrogates do not meet the standard of substituted judgment, often at the behest of the older person. About half of older patients *prefer* to share end-of-life decision-making with family, and about a third prefer to delegate decision-making entirely to family (e.g., Degner et al., 1997; Sehgal et al., 1992). Strikingly, when presented with a hypothetical scenario in which they are dying and incapacitated, as many as three-quarters of older adults say that they would want their health care providers to override their recorded preferences in favor of their family's directly opposing preferences (Puchalski et al., 2000; Terry et al., 1999).

The present study is concerned with older adults' opinions about the process of surrogate decision-making and has two research goals: (a) to update information on the proportions of older adults who prefer independent or delegated decision-making at end-of-life, and (b) to examine the relationships of personal beliefs, affiliative beliefs, and end-of-life planning behaviors to decision-making preference. These questions are explored in a survey sample of over 4,000 community dwelling adults in their mid-60s. The answers can shed light on ideals regarding the exercise of personal autonomy in U.S. society, which can aid the medical community in determining best practices in end-of-life care.

What Is Autonomy?

Medical scholars and clinicians often express concern that older adults who share or delegate decision-making are relinquishing their right to autonomy. Health care providers have reported cases in which they believed that family members coerced vulnerable elders into decisions they would not otherwise have made (see Ho, 2008), and many older adults are dissatisfied with the low levels of participation in decision-making that their health care providers permit (Degner et al., 1997). Therefore, researchers have focused on strategies for increasing rates of independent decision-making (e.g., Davison, Goldenberg, Gleave, & Degner, 2003).

However, not *all* older adults who share or delegate decision-making think that they are relinquishing autonomy. For example, Terry and colleagues (1999) asked participants to explain their choice to have their preferences followed or overridden. In that study, some older adults who wanted their preferences to be overridden thought that the family's best interests should be included in the decision, while others trusted the surrogate's judgment over their own in medical situations.

Indeed, scholars of control have developed several definitions of autonomy, three of which are relevant to the present paper. First, Heckhausen and Schulz (1995) differentiate between relinquished control and *secondary control*. When individuals exercise secondary control, they try to change their thoughts and feelings rather than their circumstances. For example, medical decisions sometimes require more knowledge and experience than the average patient has, and someone else (e.g., a physician, a surrogate) may make the decision. If the way the decision was made makes the patient feel incapable or depressed, then that patient relinquished control. But if the patient instead blames his or her inaction on the illness, or feels proud to have chosen such a capable surrogate, then that patient exercised secondary control. When a person cannot control circumstances, he or she can retain autonomy by controlling cognition and emotion.

A second definition concerns the articulation between persons and social groups. Fischer (2008) finds that individualistic and collectivistic values coexist in the United States. Americans report valuing collectives such as the family and religious groups more highly than do people in other Western nations. Fischer (2008) points to Americans' belief in free will to resolve the apparent contradiction between desire for autonomy and attachment to the collective: He asserts that Americans believe nearly all social affiliations to be voluntary.

That is, people choose to belong to a group. They exercise autonomy, but their choice is not apparent if researchers examine devotion to a group without regard for the process that led to it. Therefore, patients who delegate decision-making may elect to defer to the family group rather than elect to decide independently.

Finally, the concept of *relational autonomy* recognizes that people always make choices in the context of their relationships to others. Kittay (2006) argues for the widespread adoption of a broad model of relational autonomy wherein patients and their care providers (both family caregivers and health care professionals) pool their knowledge and come to agree upon decisions that achieve the patient’s goal, which may be something other than the longest possible life. The relational model focuses attention on the key ethical concern, honoring patients’ moral authority, whereas the traditional model focuses on the potential for paternalism wrought by the unequal medical authority of patients, their families, and physicians.

In light of these multiple definitions of autonomy, research can move from the question of *whether* patients want autonomy to *why* they hold particular preferences. This article reports the preferences of a group of older adults, and goes on to examine the correlates of those preferences. In the most thorough explanation of preferences for end-of-life decision-making to date, Terry and colleagues (1999) found that older people consider their personal beliefs (e.g., the desire to exercise rights) and social affiliations (e.g., the relationship with a surrogate).

Personal Beliefs Relevant to Treatment and Death

Little is known about personal beliefs and medical decision-making, but literature on personality traits as determinants of preferences for involvement in routine (i.e., not end-of-life) medical decision-making suggests that beliefs may be important factors. Personality research finds that certain traits predispose people to favor a particular way of making decisions. Factors that scholars have identified as important include shyness and confidence when under stress (Arora, Ayanian, & Guadagnoli, 2005). Flynn and Smith (2007) found that higher neuroticism (propensity to tension, worry or nervousness) was associated with the desire to delegate health care decisions to a physician rather than make independent decisions. This literature indicates that persons with a sense of self-efficacy and personal mastery prefer independent decision-making. At their root, these traits are beliefs about the self.

This study includes multiple measures of personal beliefs. First, the analyses include preference for independence in daily life and in routine health care situations, which may be associated with the specific desire to make independent decisions at end-of-life (Flynn, Smith, & Vanness, 2006). Second, the analyses include avoidance of thoughts of death, which may be associated with a preference to delegate decisions to another person, or to God or fate. Third, the analyses include feelings about quality versus length of life, on the assumption that persons who value quality of life may feel that they are best able to define quality for themselves (Singer, Martin, & Kelner, 1999).

Social Affiliations and Beliefs Relevant to End-of-Life Care

Relational models of autonomy emphasize that people are interdependent, and social relationships can affect the choices patients make. For example, surrogates are almost always persons with whom an older person has long-term, emotionally meaningful relationships, such as a spouse or adult child (Carr & Khodyakov, 2007). Physicians are interested in finding efficient ways of conducting decision-making with patient/family groups (e.g., Charles, Gafni, & Whelan, 1999), but empirical researchers have yet to present clear models of the associations among social ties and decision-making, much less feasible practices.

The analyses include three measures of affiliative beliefs. First, participants were asked the degree to which they involve religious beliefs in their medical decision-making. Religious persons may prefer to delegate decision-making so that their surrogate can consult with health care providers and clergy to ensure that religious dictates about death and dying are followed. Second, the study includes concern about burdening others with one's care, because many older adults worry that their needs are too much for their families and may wish to limit their medical treatment accordingly (McPherson, Wilson, & Murray, 2007b). Finally, the study includes a measure of "mattering," or the sense that one is important to and needed by others (Rosenberg & McCullough, 1981). Persons may have social affiliations yet feel lonely or superfluous in them, and be unwilling to rely on these ties for medical decision-making (de Jong Gierveld, Broese van Groenou, Hoogendoorn, & Smit, 2009).

End-of-Life Planning Behaviors

A person's end-of-life planning behaviors might indicate personal and affiliative beliefs beyond those that they articulate. There are two major legal mechanisms of planning for end-of-life health care: executing a living will and appointing a durable power of attorney for health care (DPAHC). A living will is a document that contains specific directives regarding the treatments that a person would or would not want under certain conditions. For example, an older patient might write that if he or she were to suffer a heart attack, cardiopulmonary resuscitation (CPR) should not be administered. A DPAHC is a legal surrogate who makes decisions on behalf of an ill person. In the heart attack scenario, a DPAHC would decide whether CPR should be administered. Most people who execute a living will also appoint a DPAHC, but not all do. A person who only executes a living will might prefer to detail his or her independent decisions, while a person who only appoints a DPAHC might prefer to delegate decision-making to another person (Baumrucker, 2007). Therefore, in the study participants are grouped by their completion of a living will, a DPAHC, both, or neither.

Method

Participants

The Wisconsin Longitudinal Study (WLS) is a long-term study that began with a random sample of 10,317 men and women who graduated from Wisconsin high schools in 1957. They were surveyed at ages 18 (1957), 36 (1975), 54 (1993), and 65 (2004). The analyses rely on the 2004 wave, when 7,265 (80.5% of living graduates) participated. The 70% who received a telephone module on end-of-life – modules were given to randomly selected subsamples to reduce the length of the overall survey – and the participants who also returned a paper mailback questionnaire – were selected. The final analytic sample size is 4,477 persons.

The WLS does not represent all strata of the U.S. population. All primary sample members are non-Hispanic white high school graduates. Despite these limitations, the sample is representative of a majority of Americans in this cohort: In 2004, 68.2% of 65- and 66-year-old American men and women were white non-Hispanic high school graduates (U.S. Census Bureau, 2004).

Dependent Variable

Preference for independent or delegated decision-making at end-of-life—Participants were asked, “How strictly do you want your family or care provider to follow your wishes for end-of-life medical care? Would you like them to strictly follow your wishes, or do what they think is best- even if their preferences are different from your own?” Response options included 0 (*do what they think is best*) and 1 (*strictly follow my wishes*). “Strictly” corresponds to independent decision-making, while “do what they think is best” corresponds to delegated decision-making. This measure was designed for the WLS.

Treatment preference if dying in physical pain—An item from the 1999 Detroit Area Study module (“Health Care and End-of-Life Decisions”) was adapted to assess treatment preferences. Participants were asked: “Suppose you had a serious illness today with very low chances of survival. What if you were mentally intact, but in severe and constant physical pain? The response options were 0 “*Continue all treatment so I could survive (staying alive is most important to me no matter what)*” and 1 “*Stop all treatment to prolong my life (for me, quality of life is more important than length of life)*.” Other answers (e.g., “I don’t know) were coded as missing.

Preference for independent versus delegated decision-making served as the primary outcome. However, this item had only extreme response options, and most patients desire some degree of collaboration in decision-making (e.g., Sulmasy et al., 2007). To shed light on what participants may have meant when they chose “strictly follow my wishes” or “do what they think is best,” this item was cross-tabulated with the treatment preferences item to form a four-category secondary dependent variable: independent/stop treatment, independent/continue treatment, delegated/stop treatment, delegated/continue treatment.

Independent Variables

Independence in everyday life—Participants were asked a five-item short form of the autonomy dimension of the Ryff Psychological Well-Being Scales (Ryff, 1989). They were asked “To what extent do you agree that you have confidence in your opinions even if they are contrary to the general consensus? That you are not afraid to voice your opinions, even when they are in opposition to the opinions of most people? That it’s difficult to voice your opinions on controversial matters? That you tend to be influenced by people with strong opinions? That you judge yourself by what you think is important, not by what others think is important?” Response options included 1 (*agree strongly*) through 6 (*disagree strongly*). Items one, two, and five were reverse coded such that higher scores on all items indicated greater autonomy. A scale was created ($\alpha = .64$) by taking the average of the items, provided that the participant had responded to at least three of the five items.

Preference for independent or physician decision-making—Participants indicated their level of agreement with a statement from the decision-making preference scale of the Autonomy Preference Index (Ende, Kazis, Ash, & Moskowitz, 1989): “The important medical decisions should be made by my doctor, not by me.” Five response categories ranged from 1 (*strongly agree*) to 5 (*strongly disagree*). Higher scores indicate a stronger preference for independence.

Death avoidance—Two items drawn from the Death Attitude Profile-Revised (Wong, Reker, & Gesser, 1994) assessed participants’ desire to avoid thinking about death. Participants indicated their level of agreement with the statements: (a) “I avoid thinking about death altogether;” and (b) “Whenever the thought of death enters my mind, I try to push it away.” Response categories ranged from 1 (*agree strongly*) to 6 (*disagree strongly*).

Items were reverse-coded and averaged (α = .71); higher scores reflect a higher level of death avoidance.

Importance of quality of life—The importance of quality of life was assessed with the question, “To what extent do you agree that having a good quality of life is more important than just keeping alive?” Response options ranged from 1 (*strongly agree*) to 5 (*strongly disagree*). Scores were reverse-coded such that a higher score reflects greater importance placed on quality of life.

Influence of religious beliefs—Participants responded to the question, “How much would your religious or spiritual beliefs influence your medical decisions if you were to become gravely ill?” Response options included 1 (*not at all*), 2 (*not very*), 3 (*somewhat*), 4 (*very*), and 5 (*extremely*).

Concern about burdening others—Concern about burdening others was assessed with the question, “To what extent do you agree that you’d rather not live than be a burden on someone?” Response options ranged from 1 (*strongly agree*) to 5 (*strongly disagree*). Scores were reverse-coded such that a higher score reflects greater concern about burdening others.

Interpersonal mattering—Two items drawn from the reliance subscale of an index developed by Elliott, Kao, and Grant (2004) assessed participants’ perceptions that they are needed by others. Participants responded to the items: (a) “To what extent do you agree that people tend to rely on you for support?” and (b) “To what extent do you agree that people count on you to be there in times of need?” Response categories included 1 (*strongly agree*), 2 (*agree*), 3 (*neither agree nor disagree*), 4 (*disagree*), and 5 (*strongly disagree*). Items were reverse-coded and averaged (α = .74); higher scores reflect a higher level of perceived mattering.

Legal planning for end-of-life—Participants were asked about a living will with the question, “Do you have a living will or advance directive? These are written instructions about the type of medical treatment you would want to receive if you were unconscious or somehow unable to communicate.” Legal surrogacy was assessed with the question “Have you made any 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.” The variable was dummy coded to represent three groups: *executed living will only*, *appointed DPAHC only*, and *executed living will and appointed DPAHC*. Persons who neither executed a living will nor appointed the spouse as DPAHC formed the reference category.

Educational attainment—Educational attainment refers to years of completed schooling. Reponses ranged from 12 through 21 years. Twelve years of education (*high school only*) served as the reference category and dichotomous variables indicated 13–15 years of education (*some college*), and 16 years or more of education (*college graduate/graduate studies*).

Health status—Self-reported health was measured with the item: “How would you rate your health at the present time: excellent, very good, good, fair, or poor?” Because reports were skewed towards “excellent,” a dichotomous variable was created where 1 represented “*fair/poor*” and 0 represented “*good/very good/excellent*.”

Gender—A dichotomous variable where 1 represented “*female*” and 0 represented “*male*” was used.

Analytic Strategy

Multivariate statistics—Binary logistic regression was used to analyze the primary dependent variable. The model contained personal beliefs, affiliative beliefs, and end-of-life planning behaviors, as well as educational attainment, self-reported health, and gender. (Prior research indicates that persons with low educational attainment, persons in poor health, and men tend to prefer to delegate decision-making [Degner et al., 1997; Flynn et al., 2006; Sulmasy et al., 2007].) Multinomial logistic regression was used to analyze the secondary dependent variable. The independent variables were the same as in the first model.

Missing data—No more than 3.5% of cases were missing data on any independent variable, and 89.4% of participants provided valid responses to all of the independent variables. Nevertheless, to address concerns about missing values, multiple imputation by chained equations was conducted on the independent variables (Royston, 2005). The final estimates presented for multivariate analyses are the result of averaging findings from across five imputed datasets. Estimates obtained through listwise deletion did not vary appreciably from the estimates presented here (results available upon request).

Results

Descriptive Statistics

Descriptive statistics for all variables used in the analysis are presented in Table 1. Most participants in this study – 79.6% – preferred independent decision-making: They wanted their family or care provider to follow their end-of-life medical care wishes strictly. Over three-quarters wanted life-prolonging treatment stopped if they were dying in physical pain.

Multivariate Statistics

Results from multivariate analyses are presented in Table 2. With regard to personal beliefs, preference for independence in everyday life (odds ratio 1.18, $p < .01$), preference for independence in routine medical encounters (odds ratio 1.17, $p < .001$), and valuing quality over length of life (odds ratio 1.31, $p < .001$) were associated with preferring to make independent end-of-life decisions. Conversely, death avoidance was associated with a preference to delegate (odds ratio 0.89, $p < .001$). With regard to affiliative beliefs, those who more strongly agreed that they would rather not live than be a burden were likely to choose independent decision-making (odds ratio 1.13, $p < .01$). Having both executed a living will and appointed a DPAHC were behaviors associated with preferring independent decision-making (odds ratio 1.73, $p < .001$).

The majority (65.7%) of participants wanted their wishes to be followed strictly, and also preferred to stop life-prolonging treatment if in physical pain and dying. Fifteen percent wanted their wishes followed strictly and life-prolonging treatment continued, 13.2% wanted to delegate the decision to stop life-prolonging treatment, and 6.2% wanted to delegate the decision to continue life-prolonging treatment. Results from a multinomial regression using these categories as the dependent variable are presented in Table 3. Two findings stood out: Quality of life was more important to those who wanted their wish to stop life-prolonging treatment followed strictly than to all other groups. Correspondingly, those who wanted to decide independently to stop treatment were the most likely to have executed a living will and appointed a DPAHC.

Discussion

This study examined the correlates of preferring independent or delegated end-of-life decision-making in a large sample of well-educated white persons in their mid-60s. Personal and affiliative beliefs, including a preference for independence in general and medical settings, low death avoidance, high valuation of quality over length of life, and not wanting to burden one's relationship partners are associated with the preference to make decisions independently. Additionally, persons who both executed a living will and appointed a DPAHC prefer independent decision-making. In sum, beliefs about independence and care receipt are central in older adults' ideas about end-of-life medical decision-making.

Overall Proportions of Preference for Independent versus Delegated Decision-Making

In this study, four-fifths of participants preferred independent decision-making over delegated decision-making. This proportion is large compared to earlier reports: Puchalski and colleagues (2000) found that three-quarters of their participants preferred to delegate, and Terry and colleagues (1999) found that half would delegate. Jacobson and colleagues (1994) found that one-quarter would delegate, a proportion much more similar to the proportion reported here. These differences are likely due to differences in sample composition. For instance, higher levels of education are associated with a stronger preference for independent decision-making (Sulmasy et al., 2007). All participants in this study and 90% of participants in the Jacobson study had at least a high school education, compared to 75% and 50% in the Terry and Puchalski studies, respectively. Further, sicker persons are more likely to prefer to delegate (Degner et al., 1997). Less than 10% of participants in this study reported that their health was fair or poor, and Jacobson's participants, though hospitalized, were not critically ill. The participants in the Terry and Puchalski studies were terminally ill and/or quite elderly. Therefore, more research is necessary to determine whether cohort replacement has resulted in a greater desire for independent decision-making among older adults, and this research must take care to evaluate participants' sociodemographic characteristics.

Personal and Affiliative Beliefs and the Preference for Independent Decision-Making

Beliefs about the self and others are strongly associated with one's preference for independent or delegated decision-making. First, people who prefer independence in everyday life and in doctor/patient interactions also prefer independent end-of-life decision-making. This finding is consistent with the literature on general decision-making, in which people are thought to have a consistent preferred manner of making decisions that is due to cognitive ability and self-evaluation (e.g., self-esteem) (Thunholm, 2004). People appear to view end-of-life decisions as similar to other major life decisions; they prefer to die as they have lived.

Second, persons who are avoidant of thoughts of death delegate decision-making, especially if they also want life-prolonging treatment. The strategy of delegating decision-making probably does not negatively affect the end-of-life medical care of death avoidant persons, even if they did not complete end-of-life planning. Life-prolonging treatment is the "default" in the absence of the directive of a living will and/or durable power of attorney, as physicians wish to avoid errors of undertreatment (Moorman & Carr, 2008).

Third, persons who strongly value quality of life want to make decisions independently. Quality of life was especially important to people who wanted to stop life-prolonging measures. In the single study to have asked participants to give reasons for their preferred decision-maker, some participants wanted to make decisions independently because they felt that a surrogate might be too emotional to stop treatment (Terry et al., 1999). Kaufman

(2000) observed families of comatose patients in a custodial care facility and found that they predominantly talked about their hope for a cure. Patients may want their wishes followed strictly so that their families do not prolong their lives out of unrealistic optimism about the possibility of recovery.

Finally, the sole affiliative belief to be associated with decision-making preference was concern about burden: People who would rather not live than burden others with their care wish to make decisions independently, and they often wish to stop life-prolonging treatment. At least two-thirds of dying patients feel as though they are burdening their families financially, physically (i.e., with caregiving), socially, and/or emotionally (Chochinov et al., 2007; McPherson et al. 2007a; 2007b). Patients who feel as though they are burdening their families are often quite depressed and anxious and want to minimize their own distress and the interpersonal problems they perceive themselves to be causing (Chochinov). In qualitative studies, family members who made decisions for patients who died describe decision-making as intensely burdensome, and say that fulfilling patients' previously-stated wishes eased their burden (Braun, Beyth, Ford, & McCullough, 2008). People may prefer to make decisions independently so that their family is spared.

End-of-Life Planning Behaviors and the Preference for Independent Decision-Making

Contrary to expectations, participants who planned for end-of-life by executing a living will *and* appointing a DPAHC were likely to want to make independent decisions. Neither execution of a living will alone, which might indicate a preference for independent decision-making, nor appointment of a DPAHC alone, which might indicate a preference for delegated decision-making, were statistically significant. Completion of both is the norm: Nearly half of participants had done so. Participants were especially likely to do both if they did not want life-prolonging treatment. According to the Mayo Clinic (Nishimura et al., 2007), the plans of most white high school graduates in their 60s contain instructions to withhold or withdraw treatment, so this result may be similar to the result regarding quality of life: People want their wishes followed strictly so that their lives are not prolonged.

Autonomy in End-of-Life Decision-Making

This paper speaks to the larger psychological and sociological issue of personal control and structural constraint in American society. Critics contend that discussions of independent or delegated decision-making are irrelevant because patient choice at end-of-life is an elaborate fiction (e.g., Drought & Koenig, 2002). These scholars argue that power resides with health care providers, insurance companies, and the uncertain course of terminal illness itself, such that patients and families are forced into "choosing" the inevitable. We agree with these scholars, yet assert that the *ideal* of choice is extremely important for patients, families, and health care providers. When patients, families, and health care providers share the illusion of patient and family autonomy, everyone benefits.

Patients may value the notion of choice but not its practice. The idea of autonomy affirms dying patients' dignity at a time when they perceive themselves to be progressively losing the ability to fulfill productive roles and participate equitably in social relationships. A qualitative study of patients with advanced cancer identified sense of dependence as a major component of perceiving oneself to be a burden (McPherson et al., 2007a). Conversely, patients identify preservation of a sense of control as integral to high quality end-of-life care and a good death (Kehl, 2006; Singer et al., 1999). But patients may not want actual control over medical decisions. A qualitative study of Australian renal disease patients found that those who chose to stop dialysis and subsequently outlived their prognoses blamed their health care providers for allowing them to stop (Ashby et al., 2005).

Many families may have similar experiences. Family members consider being a surrogate to be an important family responsibility, but an extremely difficult one. In one study, family members who had acted as surrogates spoke of having to sacrifice patient outcome because of financial cost (Braun et al., 2008). The nursing literature reports that conflict within the family is common (e.g., Wiegand, Deatrick, & Knafl, 2008). Families desire more guidance from health care professionals (e.g., Braun).

Finally, decisions to withdraw treatment are difficult for health care providers. A prevalent norm within medicine is that responsible health care providers treat so long as there is some probability of reversing a problem (Kaufman, 1998). A patient or family member's decision to withhold further treatment frees the care provider from the expectation that he or she must stave off death, resulting in more comfortable deaths for patients (Kaufman).

Limitations

This study is limited in several ways. First, the outcome measure does not distinguish between family and health care providers as the party in charge of decision-making. Prior research reveals that patients do differentiate along these lines: They are more likely to want family members to follow their wishes strictly than to want physicians to do so, for example (Sulmasy et al., 2007). Further, patients differentiate among members of their families, although not in consistent ways. In one study, patients who chose adult children as their surrogates were more likely to believe that the surrogate knew their wishes and would follow them strictly than were patients who choose spouses as surrogates (Hawkins, Ditto, Danks, & Smucker, 2005). In another study, older adults who discussed their end-of-life medical preferences with their spouses and with their adult children perceived that their spouses understood their preferences best (Moorman, under review).

Second, the WLS contains no items about deliberation. Patients may wish to deliberate in collaboration with their family and health care providers, but make the final decision independently. Further, the response options are vague about whether the participant is incompetent at the time of decision-making. Many patients prefer to make independent decisions so long as they are able, but would delegate decision-making to the family rather than have their recorded wishes followed should they become incompetent (Nolan et al., 2005).

Third, non-Hispanic, white, well-educated persons of a single cohort were examined. These results should be replicated in other populations before they are generalized. For example, Kwak and Haley (2005) report that Hispanic Americans and Asian Americans, two groups that have strong norms regarding the importance of family and filial piety, are particularly likely to want to involve family members in end-of-life decision-making.

Directions for Future Research

The limitations of this study point to directions for future research. First, this study and the other studies discussed posit scenarios in which the surrogate's preferences are presumed to differ from the patient's preferences. In reality, patients and surrogates often agree; independent decision-making and delegated decision-making result in the same choices (Fried, Bradley, & Towle, 2003). In the 2004 WLS, participants and their spouses reported their preferences for stopping or continuing life-prolonging treatment for themselves if dying in pain or with dementia. Partners report the same preference 69.7% of the time in the pain scenario and 87.1% of the time in the dementia scenario. Participants who have the same preference as their spouse in the pain scenario are significantly more likely to want their preferences followed strictly than are participants whose preferences differ from their spouse's (not shown; results are available upon request). This similarity indicates that participants may consider the “strict” response to mean “I foresee my family agreeing with my wishes” in some cases. Future research should explore the extent to which “independent” and “delegated” decision-making are meaningful categories in the eyes of older adults.

Second, while a final end-of-life decision may be made independently, deliberation leading up to that decision may be collaborative or delegated (Charles, Gafni, & Whelan, 1999). Flynn, Smith, and Vanness (2006) found that in routine medical decision-making, about half of healthy white adults in their mid-60s wanted to discuss multiple options for treatment with their doctors and then to make the final decision independently. These findings suggest that future research on end-of-life decision-making within the family should account for larger portions of the decision-making process, as independent decision-making that results from shared or delegated deliberation may be different from independent decision-making that results from independent deliberation.

Conclusion

As life expectancy in the United States increases and as medical technology advances, greater numbers of older persons, their families, and their health care providers will need to make difficult decisions about end-of-life care. The findings of this study have implications for health care practice and medical decision making. Health care providers should ask patients not only what their decision would be, but also *how they would like decisions to be made*. At this time, most care providers do not currently determine patients’ preferred decision-making style. Care providers should probe for reasons for the patient’s choice, so that they can address any constraints, such as lack of health information or family conflict. If no constraints are apparent, care providers should support the patient’s choice, whether be it independent, shared, or delegated decision-making.

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Table 1

Characteristics of Respondents to the Wisconsin Longitudinal Survey Module on End-of-Life Preparations, 2004–2005

	Mean (*SD*) or Proportion
Treatment Preferences	
Wants end-of-life health care wishes followed strictly (vs. other makes decision)	.796 --
Prefers to stop (vs. continue) life-prolonging treatment if dying in physical pain	.789 --
Personal Beliefs Relevant to Treatment and Death	
Preference for independence in everyday life (1 *lowest* through 6 *highest*)	4.55 (0.74)
Prefers to make own treatment decisions (vs. doctor decides) (1 *doctor* through 5 *self*)	3.48 (1.16)
Death avoidance (1 *least avoidant* through 6 *most avoidant*)	3.15 (1.25)
Quality of life is more important than length of life (1 *strongly disagree* through 5 *strongly agree*)	4.20 (0.91)
Affiliative Beliefs Relevant to End-of-Life Care	
Religious/spiritual beliefs influence medical decisions (1 *not at all* through 5 *extremely much*)	3.22 (1.29)
Would rather not live than be a burden (1 *strongly disagree* through 5 *strongly agree*)	3.70 (1.08)
Interpersonal mattering (1 *not relied upon* through 5 *strongly needed*)	4.12 (0.60)
End-of-Life Planning Behaviors	
Executed living will only	.079 --
Appointed DPAHC only [a]	.051 --
Executed living will and appointed DPAHC[a]	.479 --
Completed neither living will nor DPAHC[a]	.391 --
Sociodemographic Characteristics	
High school (12 years of education)	.562 --
Some college (13–15 years of education)	.161 --
College (16 or more years of education)	.277 --
Fair / poor self-reported health (vs. good / very good / excellent health)	.092 --
Female	.544 --
N	4,477

Notes. Statistics are reported prior to multiple imputation. Means and standard deviations are presented for continuous measures; proportions are shown for categorical measures.

[a] "DPAHC" stands for durable power of attorney for health care.

[*] $p \leq .05$,

[**] $p \leq .01$,

[***] $p \leq .001$

Table 2

Binary Logistic Regression, Odds of Wanting End-of-Life Health Care Wishes Followed Strictly vs. Wanting another Person to Decide What Is Best

	Odds Ratio (95% C.I.)
Personal Beliefs Relevant to Treatment and Death	
Preference for independence in everyday life (1 *lowest* through 6 *highest*)	1.18** (1.05–1.32)
Prefers to make own treatment decisions (vs. doctor decides) (1 *doctor* through 5 *self*)	1.17*** (1.09–1.26)
Death avoidance (1 *least avoidant* through 6 *most avoidant*)	0.89*** (0.83–0.95)
Quality of life is more important than length of life (1 *strongly disagree* through 5 *strongly agree*)	1.31*** (1.19–1.44)
Affiliative Beliefs Relevant to End-of-Life Care	
Religious/spiritual beliefs influence medical decisions (1 *not at all* through 5 *extremely much*)	0.93 (0.87–1.00)
Would rather not live than be a burden (1 *strongly disagree* through 5 *strongly agree*)	1.13** (1.04–1.23)
Interpersonal mattering (1 *not relied upon* through 5 *strongly needed*)	0.89 (0.77–1.02)
End-of-Life Planning Behaviors (vs. completed no planning)	
Executed living will only	1.16 (0.86–1.54)
Appointed DPAHC only	1.14 (0.81–1.60)
Executed living will and appointed DPAHC	1.73*** (1.46–2.05)
Sociodemographic Characteristics	
Some college (13–15 years of education) (vs. completed high school)	1.15 (0.91–1.46)
College (16 or more years of education) (vs. completed high school)	0.79* (0.66–0.95)
Fair / poor self-reported health (vs. good / very good / excellent health)	0.80 (0.62–1.03)
Female	0.88 (0.75–1.04)
N	4,477
Wald χ^2; *df*	213.2; 14

[*] $p \le .05$,

[**] $p \le .01$,

[***] $p \le .001$

Table 3

Multinomial Logistic Regression, Odds of Wanting Independent or Delegated Decision-Making and Continued or Stopped Life-Prolonging Treatment

	Continue / Delegate	**Continue / Independent**	**Stop / Delegate**
		vs. Stop / Independent	
	Odds Ratio (95% C.I.)	**Odds Ratio (95% C.I.)**	**Odds Ratio (95% C.I.)**
Personal Beliefs Relevant to Treatment and Death			
Preference for independence in everyday life (1 *lowest* through 6 *highest*)	0.92 (0.74–1.14)	0.94 (0.81–1.08)	0.79*** (0.69–0.90)
Prefers to make own treatment decisions (vs. doctor decides) (1 *doctor* through 5 *self*)	0.86* (0.76–0.97)	1.07 (0.98–1.17)	0.86*** (0.79–0.94)
Death avoidance (1 *least avoidant* through 6 *most avoidant*)	1.19** (1.06–1.34)	1.02 (0.94–1.11)	1.09 (1.00–1.18)
Quality of life is more important than length of life (1 *strongly disagree* through 5 *strongly agree*)	0.52*** (0.44–0.61)	0.59*** (0.53–0.67)	0.74*** (0.65–0.85)
Affiliative Beliefs Relevant to End-of-Life Care			
Religious/spiritual beliefs influence medical decisions (1 *not at all* through 5 *extremely much*)	1.09 (0.96–1.23)	1.11** (1.03–1.21)	1.09* (1.01–1.18)
Would rather not live than be a burden (1 *strongly disagree* through 5 *strongly agree*)	0.61*** (0.52–0.71)	0.66*** (0.60–0.73)	0.90 (0.81–1.01)
Interpersonal mattering (1 *not relied upon* through 5 *strongly needed*)	1.21 (0.93–1.58)	1.07 (0.90–1.27)	1.17 (0.98–1.40)
End-of-Life Planning Behaviors (vs. completed no planning)			
Executed living will only	0.72 (0.43–1.20)	0.55** (0.37–0.82)	0.74 (0.51–1.06)
Appointed DPAHC only	0.94 (0.54–1.66)	1.00 (0.65–1.53)	0.83 (0.53–1.29)
Executed living will and appointed DPAHC	0.42*** (0.31–0.58)	0.73** (0.60–0.89)	0.55*** (0.45–0.68)
Sociodemographic Characteristics			
Some college (13–15 years of education) (vs. completed high school)	0.84 (0.54–1.31)	1.04 (0.79–1.36)	0.91 (0.68–1.20)
College (16 or more years of education) (vs. completed high school)	1.82*** (1.32–2.50)	1.35** (1.08–1.70)	1.21 (0.95–1.53)
Fair / poor self-reported health (vs. good / very good / excellent health)	1.22 (0.77–1.92)	0.75 (0.52–1.08)	1.21 (0.89–1.65)
Female	1.22 (0.91–1.63)	1.18 (0.97–1.44)	1.07 (0.87–1.31)
N	247	602	529
Wald χ^2; *df*		549.7; 42	

* $p \le .05$,

** $p \le .01$,

*** $p \le .001$