Spouses’ Effectiveness as End-of-Life Health Care Surrogates: Accuracy, Uncertainty, and Errors of Overtreatment or Undertreatment

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Purpose: We document the extent to which older adults accurately report their spouses’ end-of-life treatment preferences, in the hypothetical scenarios of terminal illness with severe physical pain and terminal illness with severe cognitive impairment. We investigate the extent to which accurate reports, inaccurate reports (i.e., errors of undertreatment or overtreatment), and uncertain reports (responses of “do not know”) are associated with spouses’ advance care planning and surrogates’ involvement in the planning. Design and Methods: We used data from married couples who participated in the Wisconsin Longitudinal Study in 2004. These 2,750 couples were in their mid-60s and in relatively good health. We conducted multinomial logistic regressions. Results: Surrogates were accurate in the majority of cases, made errors in 12% to 22% of cases, and were uncertain in 11% to 16% of cases. Errors of overtreatment and undertreatment were equally prevalent. For both scenarios, discussing preferences was associated with lower odds of an uncertain surrogate response. Implications: We suggest ways that health care practitioners could facilitate family-level conversations in order to ensure that patients’ preferences are accurately represented in end-of-life care settings.

Key Words: Death and dying, Medical decision making, Advance care planning, Marriage, Couple-level data

Over the past three decades, health care policies in the United States have been designed with the explicit goal of preserving the decision-making autonomy of dying patients. Patients have the opportunity to guide the health care they receive—even if they ultimately become incapacitated and thus unable to convey their treatment preferences. The Patient Self-Determination Act (1990) requires federally funded health care providers to give patients information about advance care planning, or the legal arrangements that establish care preferences prior to the time of incapacitation. Advance care planning involves executing a living will that states one’s preferences for specific treatment; appointing a durable power of attorney for health care (DPAHC) to act as a surrogate decision maker in the event of incapacitation; or both. If a patient becomes incapacitated without having appointed a DPAHC, then the next of kin becomes surrogate in most states (American Medical Directors Association, 2003). A surrogate typically selects a course of treatment by using the standard of substituted judgment; that is, the surrogate makes the decision that she or he believes the dying person would make if competent to do so. Under the alternate standard, the standard of best interests, the surrogate chooses the treatment she or he feels is in the best interests of the patient. Bioethicists favor the former standard (President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983).

Despite a patient’s right to self-determination, many incapacitated dying persons do not receive the care that they desire. Patients often are undertreated (i.e., not administered desired treatment) or overtreated (i.e., administered undesired treatment; see Field & Cassel, 1997). Surrogates tend to make...
errors of overtreatment, rather than undertreatment, when considering common symptoms in their older terminally ill loved ones. For example, in a hypothetical scenario in which the patient was dying in pain from cancer, Ditto and colleagues (2001) found that surrogates made errors of overtreatment in 16% of cases and errors of undertreatment in 9% of cases. In hypothetical scenarios involving a patient who is cognitively impaired, surrogates rarely make errors of undertreatment: if one type of error is significantly more likely than the other, it is always overtreatment (e.g., Hare, Pratt, & Nelson, 1992).

When a patient or surrogate cannot reach a decision about care, treatment is usually continued (President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983). This practice is intended to protect both patients and care providers, but it may lead to unnecessary cost and distress. Medical care that has been deemed futile accounts for an estimated 4% of Medicare expenditures (Emanuel et al., 2002). Interpersonal and emotional costs also are high; end-of-life care is frequently a source of conflict among family members of dying patients (Kramer, Boelk, & Auer, 2006).

Given the financial and personal costs of overtreatment and undertreatment, why do patients often receive end-of-life care that is discrepant with their personal preferences? Since the passage of the Patient Self-Determination Act (1990), health care providers have actively encouraged the use of advance care planning, on the assumption that such planning would ultimately result in lower rates of overtreatment and undertreatment (e.g., Aitken, 1999). Over the past decade, however, the limitations of advance care planning have been widely documented (e.g., Drought & Koenig, 2002). Living wills may contain vague word choices rather than concrete courses of treatment; they may contain directives that are not relevant to the patient’s condition; and they may be unavailable to physicians at the critical decision-making moment.

A DPAHC can attempt to compensate for an inadequate living will, but research on substituted judgment consistently reveals that surrogates are no better than chance at naming the treatments that patients desire (Shalowitz, Garrett-Mayer, & Wendler, 2006). One reason for surrogates’ ineffectiveness is that many cannot distinguish their own preferences from those of the patient (e.g., Moorman, Hauser, & Carr, 2007; Pruchno, Lemay, Feild, & Levinsky, 2005). Cognitive theorists argue that processes of assumed similarity or projection bias are virtually unavoidable (Krueger & Clement, 1994), leading DPAHCs to make recommendations for care that reflect their own—though not necessarily the patient’s—preferences.

Recognizing the limitations of living wills and DPAHCs, health care providers now try to improve communication so that patients more effectively convey—and surrogates better understand—their preferences (e.g., Gutheil & Heyman, 2005). This practice is consistent with the desires of patients: One study revealed that nearly one third of patients preferred a discussion with loved ones to legal planning, and 57% thought that both should be done (Hawkins, Ditto, Danks, & Smucker, 2005). However, although some studies document that discussions are effective in conveying patient preferences to the surrogate (Coppolino & Ackerson, 2001; Sulmasy et al., 1998), others find that such conversations do not significantly improve surrogate accuracy (e.g., Ditto et al., 2001; Matheis-Kraft & Roberto, 1997). Libbus and Russell (1995) found that in 40% of dyads, patients and surrogates disagreed about whether a conversation actually occurred.

The inconsistent findings revealed in studies of surrogate performance may reflect methodological issues, including small sample sizes, small proportions of patients reporting that they have done any end-of-life planning, and design limitations (e.g., surrogates chosen by convenience rather than by DPAHC or next-of-kin status). Furthermore, although some studies have documented the prevalence of overtreatment and undertreatment, most studies examining the correlates of inaccuracy have failed to make the important distinction between errors of overtreatment and errors of undertreatment. The outcome of uncertainty also is absent from prior surveys. Identifying the factors that are associated with uncertainty is an important goal, as lack of knowledge may be amenable to intervention. Our study goal is to identify the correlates of these three distinctive yet overlooked outcomes.

We focus on a large sample of healthy, community-dwelling, older married couples in order to examine the extent to which discussions, living will completion, and DPAHC appointment affect the accuracy of surrogates’ assessments of their spouses’ preferences. (Note that our sample includes surrogates who are high school graduates, and their spouses, who are not “patients” but rather relatively healthy, community-dwelling individuals. When referring to our participants in the remainder of this article, we call the partner who reported on the treatment preferences of his or her spouse the “surrogate” or “graduate,” and we call the partner who reported only on his or her own treatment preferences the “spouse.”) Further, we differentiate between preparations that directly engage one’s surrogate (e.g., appointing him or her as DPAHC) versus preparations that involve other persons (e.g., having a discussion with another relative). We evaluate the extent to which the effect of planning on surrogate (in)accuracy persists after we control for surrogates’ own treatment preferences (Carr & Moorman, 2007), and for demographic, religious, and experiential factors that have been shown elsewhere to be associated with accuracy (Sulmasy et al., 1998). If our findings reveal that a specific type of planning is associated with
surrogate accuracy or error, then health care providers can develop practices that encourage or discourage that aspect of planning.

**Methods**

**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. Nearly all were born in 1939. Graduates participated in surveys at ages 18 (in 1957), 36 (in 1975), 54 (in 1993), and 63 (in 2004). Of the 9,025 graduates who survived until 2004, 7,265 (80.5%) participated in a telephone survey at that time. Of these, 5,681 (78.2%) were currently married; 3,890 spouses of graduates (68.5%) also completed telephone surveys. Graduates (but not spouses) also completed a mail survey in 2004.

Topical modules were administered to randomly selected subsamples to reduce the overall length of the survey; in 2004, a 70% subsample of graduates received a module on end-of-life planning. If a graduate received this module, so did his or her spouse. Our analysis focuses on the 2,750 married couples in which both partners completed the module. (In the 2004 interview, if a graduate was not legally married but provided information on a romantic partner, then we considered that graduate to be “married or partnered” and his or her partner to be a spousal equivalent. Fewer than 5 graduates reported nonmarital romantic partnerships.)

The WLS does not represent all strata of the U.S. population. All primary sample members graduated from high school, as did nearly all of their spouses. Nearly all graduates are non-Hispanic Whites. Despite these limitations, our sample is broadly representative of older married Americans. In 2003, 72.6% and 74.5% of married American men and women aged between 55 and 64 years, respectively, were non-Hispanic White and had completed at least a high school education (U.S. Census Bureau, 2003).

**Dependent Variables**

We assessed preferences by using items adapted from a 1999 Detroit Area Study module (“Health Care and End-of-Life Decisions”). Spouses were asked the following questions: “Suppose you had a serious illness today with very low chances of survival. First, what if you were mentally intact, but in severe and constant physical pain? Second, what if you had minimal physical pain, but had limited ability to speak, walk, or recognize others?” Two parallel items assessed the graduates’ knowledge of their spouses’ preferences (i.e., “Suppose your spouse had a serious illness.”). Although graduates reported on spouses’ preferences, spouses did not report on graduates’ preferences. For all items, the 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).” Some participants volunteered, “I don’t know.”

We constructed our measures of surrogate accuracy by cross-tabulating the spouse’s stated preference and the graduate’s report of the spouse’s preference in each scenario (i.e., pain and cognitive impairment). Each outcome measure has four categories: if both spouse and graduate reported that the spouse would prefer to continue treatment or to stop treatment in the scenario, then we classified the graduate as accurate or congruent. If the spouse preferred to stop treatment but the graduate believed that the spouse preferred to continue treatment, then we classified the graduate as having made an error of overtreatment. If the spouse preferred to continue treatment but the graduate believed that the spouse preferred to stop treatment, then we classified the graduate as having made an error of undertreatment. If either or both partners indicated “I don’t know,” then we classified the graduate as an uncertain responder. (If the spouse responded “I don’t know,” then the graduate could not make an accurate substituted judgment. Even if spouse and surrogate both responded “I don’t know,” this outcome cannot be considered accurate because “I don’t know” is not a valid decision in a clinical situation. For two reasons, we retained those cases in which the spouse was the source of the uncertain response: first, health care providers actually encounter such cases; second, the results of analyses in which we removed spouse-uncertain cases did not differ from the results presented here. The spouse was uncertain in 40.9% and 44.4% of cases in the cognitive impairment scenario and the pain scenario, respectively.)

**Independent Variables: Spouse’s End-of-Life Planning**

**Discussion.**—An interviewer asked the spouses this question: “Have you made plans about the types of medical treatment you want or don’t want if you become seriously ill in the future?” If they responded “yes,” then the interviewer asked them whether they had discussed their plans with anyone. Spouses could name up to three persons or groups of people (e.g., “my children”) with whom they had discussions. We constructed two dichotomous variables, one indicating that the spouse had discussions with the graduate, and the other indicating that the spouse had discussions with a person other than the graduate. These categories are mutually exclusive; a person who named his or her spouse also may have named others, yet we coded that person as “discussed with graduate” only. The omitted category included spouses who did not hold discussions.

**DPAHC.**—An interviewer asked the spouses this 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.” If a spouse had appointed a DPAHC, he or she reported who that person was. We constructed two dummy variables, one indicating that the graduate is the DPAHC and another indicating that someone other than the graduate is the DPAHC. The omitted category included spouses who had not appointed a DPAHC. (In those cases in which someone other than the graduate is the DPAHC, the graduate will not be called upon to make decisions should the spouse become incapacitated. We retain the cases to shed light on DPAHC choices and surrogate behavior; for example, are these graduates particularly prone to err?)

Living Will.—An interviewer asked the spouses this 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.” If a spouse responded positively, he or she reported who (if anyone) had a copy. We constructed two mutually exclusive dichotomous variables, one representing that the graduate has the spouse’s living will and another representing that someone other than the graduate has the spouse’s living will.” The omitted category comprised spouses who had not completed a living will. (The omitted category also includes 53 spouses who reported completing a living will, yet did not give a copy to anyone. We reason that a living will that has not been distributed cannot contribute to surrogate accuracy.)

Control Variables

Graduate Gender.—A dichotomous indicator represented women versus men (omitted category).

Graduate Educational Attainment.—Education is measured as high school education only (omitted category), 13 to 15 years of education (some college), and 16 years or more of education (college graduate).

Graduate Religious Affiliation.—A random 80% subsample of graduates were asked about their religious affiliation. For participants not included in the subsample, we used reports of religious affiliation from the 1993 wave or—if missing data in 1993—the 1975 wave. Categories included the following: mainline Protestant, conservative Protestant, no formal religion, other (e.g., Jewish), and Catholic (omitted category).

Projected Spouse Life Expectancy.—Graduates were asked this question: “What are the chances that your spouse will live for another 20 years?” The scale was anchored by 0 (no chance at all) and 10 (absolutely certain). This item was in the mail survey.

Spouse’s Life-Threatening Illness.—Interviewers asked the spouses the following question: “Has a doctor told you that you have or have had any of the following: 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?” We constructed a dichotomous variable indicating that the participant had at least one serious illness or did not have a serious illness (omitted category). Although the WLS assessed multiple health conditions, we focused on the leading causes of death among older Americans (Gorina, Hoyert, Lentzner, & Goulding, 2006).

Death Avoidance.—We evaluated the graduate’s death-avoidant attitudes with two items from the Death Attitude Profile Revised (Wong, Reker, & Gesser, 1994): “I avoid thinking about death altogether,” and “Whenever the thought of death enters my mind, I try to push it away.” Response categories ranged from 1 (strongly disagree) to 6 (strongly agree). Scale scores equal the average of responses; higher scores reflect greater death avoidance ($\alpha = .70$). These items were in the mail survey.

Experience With Death.—We evaluated whether the graduate experienced the death of a parent in the past 10 years. Bereaved persons were asked about the level of pain the deceased experienced during the last week of his or her life. We constructed dichotomous variables indicating that the graduate experienced a moderately or severely painful death, experienced a painless or slightly painful death, or did not experience a death (omitted category).

Graduate Treatment Preferences.—Graduates were asked to report on their own preferences for end-of-life treatment, using the pain and cognitive impairment scenarios already described. We constructed a dichotomous variable for each scenario, indicating persons who would want to stop all life-prolonging treatments versus those who did not know or preferred to continue all treatment (omitted category). Note that people who respond “I don’t know” are not significantly different from people who report “continue all treatment” in terms of socioeconomic status, health, end-of-life planning, or prior experiences with loved ones’ deaths; see Carr & Moorman (2007).

Analytic Strategy

First, we conducted one-way analyses of variance with post hoc Tukey tests to evaluate significant differences in the means of the independent variables among the four subgroups of graduates (i.e., accurate, overtreatment, undertreatment, and uncertain).
Second, we estimated multinomial logistic regressions for each scenario to identify the correlates of accurate assessments (reference category) versus errors of overtreatment, errors of undertreatment, and uncertain responses. Model 1 showed the effects of spouses’ end-of-life planning behaviors. Model 2 was further adjusted for graduate sociodemographic characteristics, religious affiliation, and death attitudes, cognitions, and experiences.

We intended to include a third model that further adjusted for graduates’ own treatment preferences. However, these models could not be estimated appropriately because graduates almost always chose for their spouses the same treatment that they chose for themselves. Cross-tabulations of the dependent variables with the graduates’ own treatment preferences revealed very strong associations (cognitive impairment, \( \chi^2 = 914.38, df = 3, p < .001 \); pain, \( \chi^2 = 727.29, df = 3, p < .001 \)). Several cell counts were fewer than 50; one cell contained fewer than five cases. In multivariate analyses, the maximum of the likelihood for the coefficient associated with graduate treatment preferences approached infinity. Thus, we did not include graduate treatment preferences in our multivariate analyses. We tested for omitted variable bias by estimating a third multinomial logistic regression model (available from the first author upon request) to examine the influence of graduate treatment preferences on the direction and statistical significance of the spousal planning coefficients. The effects of surrogate preferences on accuracy were largely independent of the effects of spousal planning on accuracy; we note exceptions below.

A modest number of cases were missing data on the independent and control variables, primarily those from the mail survey. (In our sample, 212 graduates, or 7.7%, completed the telephone survey but not the mail survey.) We conducted multiple imputation by chained equations (Royston, 2005). Results from analyses employing listwise deletion did not differ from those presented here; they are available from the first author upon request.

**Results**

Sample characteristics are presented in Table 1. Most graduates were 65 years of age in 2004. The average ages of the graduates’ wives and husbands were 61.5 years \( (SD = 4.2 \text{ years}) \) and 66.9 years \( (SD = 3.9 \text{ years}) \), respectively.

Spouses’ end-of-life planning practices, by surrogate accuracy, are presented in Table 2. In the cognitive impairment scenario, 77% of the reports were accurate, 7% showed errors of overtreatment, 5% showed errors of undertreatment, and 11% reflected uncertainty. In the pain scenario, 62% of reports were accurate, 11% showed errors of overtreatment, 11% showed errors of undertreatment, and 16% reflected uncertainty.

<table>
<thead>
<tr>
<th>Item</th>
<th>M (SD)</th>
</tr>
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<tbody>
<tr>
<td>Sociodemographic characteristics</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>.47</td>
</tr>
<tr>
<td>Education: 13–15 years</td>
<td>.16</td>
</tr>
<tr>
<td>Education: 16+ years</td>
<td>.31</td>
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<tr>
<td>Religious affiliation</td>
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<tr>
<td>Mainline Protestant</td>
<td>.48</td>
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<tr>
<td>Conservative Protestant</td>
<td>.05</td>
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<tr>
<td>Other religious affiliation</td>
<td>.03</td>
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<tr>
<td>No religious affiliation</td>
<td>.08</td>
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<tr>
<td>Death-related attitudes, cognitions, and experiences</td>
<td></td>
</tr>
<tr>
<td>Chances spouse will live another 20 years</td>
<td>6.27 (2.67)</td>
</tr>
<tr>
<td>Spouse has life-threatening illness</td>
<td>.27</td>
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<tr>
<td>Death avoidance</td>
<td>3.12 (1.22)</td>
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<tr>
<td>Parent or spouse died in past 10 years, with no or little pain</td>
<td>.15</td>
</tr>
<tr>
<td>Parent or spouse died in past 10 years, with moderate or severe pain</td>
<td>.10</td>
</tr>
<tr>
<td>Own treatment preferences</td>
<td></td>
</tr>
<tr>
<td>Graduate prefers to stop treatment for self: cognitive impairment</td>
<td>.88</td>
</tr>
<tr>
<td>Graduate prefers to stop treatment for self: pain</td>
<td>.73</td>
</tr>
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The analyses of variance revealed a number of significant differences across the four treatment assessment categories. The results for the cognitive impairment scenario (Table 2, top panel) showed that when a spouse involved the graduate in any form of planning—discussion, DPAHC, or living will—the graduate was more likely to accurately name the spouse’s preference than to be uncertain. Graduates whose spouses gave the living will to another person were also more likely to be accurate than uncertain. The results for the pain scenario (Table 2, bottom panel) showed that when the spouse had a discussion with anyone or appointed a DPAHC, the graduate was more likely to accurately name the spouse’s preference than to be uncertain. As in the cognitive impairment scenario, graduates whose spouses gave a living will to another person were more likely to be accurate than uncertain.

**Multivariate Analysis: Cognitive Impairment**

Multivariate analyses are presented in Table 3. (Coefficients for control variables are not presented, as many of these changed significantly when graduate treatment preferences were included in the model. Changes occurred because the control variables are correlates of graduate treatment preferences, see Carr & Moorman, 2007.) The multivariate results...
show that graduates whose spouses held discussions—regardless of whether they were with the graduate or with another person—were significantly less likely than those whose spouses had no discussions to report that they “didn’t know” their spouses’ preferences. Neither having a living will nor having a DPAHC was a significant predictor of surrogate accuracy. These patterns persisted when demographics, religious affiliation, and death attitudes and encounters were controlled (Model 2), and they were independent of surrogate treatment preferences (not shown).

### Multivariate Analysis: Pain

The results in Table 4 reveal that graduates whose spouses had discussed their end-of-life preferences with either the graduate or another person were more likely to accurately report the spouse’s preferences than to be uncertain. Graduates whose spouses had appointed them as DPAHC were more likely to be accurate than uncertain, and graduates whose spouses had appointed someone else as DPAHC were more likely to be accurate than to make an error of overtreatment. When we added
controls to the equation (Model 2), graduate DPAHC appointments were no longer significantly associated with accuracy, but all other findings remained the same. In the model testing for omitted variable bias (not shown), graduates whose spouses appointed someone else as DPAHC were not significantly more likely to accurately name their spouses’ preferences than to make an error of overtreatment. Graduates whose spouses had appointed them as DPAHC were significantly more likely to be accurate than uncertain.

**Discussion**

We investigated the correlates of surrogates’ errors of overtreatment, errors of undertreatment, and uncertainty when reporting their spouse’s end-of-life treatment preferences in a large sample of White married couples in their mid-60s. We considered preferences for continuing or stopping life-prolonging treatment in two hypothetical scenarios, one involving terminal illness with cognitive impairment and the other involving terminal illness with pain. We evaluated whether discussions, living wills, and DPAHC appointments were associated with surrogate accuracy, and whether these patterns varied on the basis of whether the surrogate or another person participated in the preparations. None of these methods of planning were associated with reduced odds of surrogate error, either of overtreatment or undertreatment. However, discussions with either the surrogate or another person are associated with reduced odds that the surrogate is uncertain about the spouse’s treatment preferences in both the pain and cognitive impairment scenarios. These findings suggest that discussions are a potentially effective means for combating surrogate uncertainty in the clinical decision-making context.

To the best of our knowledge, uncertainty has not been examined in prior survey-based studies. However, uncertainty plays an important role in clinical practice: When a patient or surrogate cannot decide upon or articulate a desired course of treatment, all treatment typically continues. This practice can result in conflict between health care providers and families (Breen, Abernethy, Abbott, & Tulsky, 2001), and it is costly—the average family of a Medicare beneficiary in his or her last year of life pays $8,000 in out-of-pocket expenses (Hogan, Lunney, Gabel, & Lynn, 2001). Recently bereaved persons and health care providers identify uncertainty as a problem that can contribute to an unnecessarily distressing death, and they identify discussion as a solution to this problem (Steinhauser et al., 2000). Our results highlight the importance of documenting the correlates of both uncertainty and error in the decision-making context.

Uncertainty has two sources: The uncertain party can be either the patient who does not have strongly felt preferences, or the surrogate who is unable to articulate his or her spouse’s preferences. Holding discussions with persons other than one’s surrogate may reduce uncertainty because they allow spouses to clarify their thoughts. Discussions with the surrogate may reduce uncertainty because they provide the surrogate with the opportunity to become aware of the similarities and differences between the spouse’s values and his or her own (Loewenstein, 2005). Discussions may be memorable because of their emotional climate; conversations can result in a “covenant” between surrogate and spouse that may be viewed as a renewal of the vow to care for one another (Doukas & Hardwig, 2003).

Although we do not find evidence in our multivariate analyses that living wills and DPAHC appointments enhance surrogate understanding of
treatment preferences, the nonsignificant effects partly reflect high levels of overlap among the end-of-life planning practices. Of those persons who gave the graduate a living will or appointed him or her DPAHC, three fourths also held a discussion with the graduate. Our bivariate analyses reveal that living wills and DPAs are generally associated with lower uncertainty. If writing a living will and giving the document to someone or appointing a DPAHC facilitates discussions, then these plans may be important, albeit indirect, contributors to surrogate accuracy.

Surrogate demographics, religious affiliation, and death attitudes and encounters had little effect on the relationship between spousal end-of-life planning and surrogate accuracy. We suspect that the nonsignificant effect of religion reflects the fact that nearly all spouses were of the same religious affiliation as their surrogates, and religiosity is associated with content, but not completion, of plans (Balboni et al., 2007). The other findings are more perplexing, and they raise questions for future analyses. For example, we expected that if the couple had experienced the painful death of the surrogate’s parent, then both would be spurred to make their own end-of-life preparations to avoid a similarly undesirable fate (Carr & Khodyakov, 2007). Apparently the death of a parent affects one’s own end-of-life preferences and preparations, yet the experience does not shape the behavior of the bereaved child-in-law (that is, one’s spouse). Future research should investigate whether the closeness of relationship between the bereaved and the deceased person affects the bereaved person’s end-of-life planning behavior.

Limitations

Our study has several limitations. First, WLS participants were relatively young and healthy. Their responses to hypothetical end-of-life scenarios may not accurately represent how surrogates would behave at the actual decision-making moment, or what spouses would want at the end of life. As a patient’s health declines, she or he tends to reject life-prolonging treatment in favor of measures that enhance quality of life (e.g., Fried et al., 2007).

Second, the WLS did not ask participants about specific illness scenarios (e.g., cancer) or treatment options (e.g., artificial nutrition and hydration). Rather, it focused on general preferences for care under broad circumstances (pain and cognitive impairment). Our study may understate the degree of inaccuracy or uncertainty in surrogate assessments. More precise scenarios would require a fuller understanding of the underlying health condition and possible courses of treatment, and thus they may pose more difficulty to spouses trying to accurately gauge their own and one another’s preferences (Thorevska et al., 2005).

Finally, we studied one cohort of non-Hispanic White high school graduates. Our results may not be broadly generalizable to other populations, given prior studies documenting racial and ethnic differences in the ways older Americans conceive of end-of-life decision making and surrogacy (Kwak & Haley, 2005).

Implications for Practice and Future Research

Most married people who appoint a DPAHC name their spouse (Carr & Khodyakov, 2007). In cases in which a married patient has not appointed a DPAHC, the state may rely on the patient’s spouse as a default surrogate (American Medical Directors Association, 2003). Despite widespread reliance on spouses, our results show that surrogates are accurate in just 62% and 77% of cases, in pain and cognitive impairment scenarios, respectively. Four studies have examined the relationship between accuracy and relationship to the patient and found no effect (see Shalowitz et al., 2006). However, all four studies were of small samples, so researchers could not ascertain whether the nonsignificant effects reflected a meaningful finding or low statistical power. If future research establishes that other persons (e.g., siblings) are more accurate surrogates than spouses are, health care providers may wish to suggest that their married patients appoint someone other than their spouse as DPAHC.

If no surrogates are found to be more accurate than spouses, or if the patient has already appointed a spouse as DPAHC, then health care providers should work to identify patients who do not know their own preferences for care, and surrogates who do not know their spouses’ preferences. Interventions that foster discussion could help both parties understand the patient’s preferences. Future research is necessary to determine the optimal time for holding discussions. Some patients may be concerned that psychological distress or physical discomfort might color the preferences they express when terminally ill, and therefore wish to articulate their preferences while healthy (Ditto, Hawkins, & Pizarro, 2005).

The content of discussions may be more important than the occurrence of discussions, however. A critical concern is the patient’s belief about how important it is that his or her preferences are heeded directly (substituted judgment), versus how important it is that surrogates make the decision that they feel is best for all parties involved (best interests). Although four fifths of spouses in the WLS want their wishes to be strictly followed, a significant number of patients prefer that others make health care decisions for them (e.g., Puchalski et al., 2000). The demographic characteristics of these two groups are known (e.g., Terry et al., 1999), but future research could explore the motivations behind these preferences. In those cases in which patients want their wishes followed strictly, family members should have discussions—facilitated by health care providers—in which precise information about the
patient’s treatment preferences is conveyed. In the latter case, conversations should focus on broad values and attitudes, so that surrogates can make decisions they feel will best serve the patient and family.

Conclusion

Our study contributes to the emerging literature on end-of-life planning by showing that current advance care planning practices—DPABC, living will, and discussions unmediated by professionals—contribute modestly to surrogates’ ability to accurately represent their spouses’ preferences for end-of-life care. Our study finds that discussions show the greatest promise as a planning tool. We hope our findings encourage others to identify additional family-level planning practices that are effective in increasing both patient and surrogate knowledge and comprehension of appropriate courses of care at the end of life.

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