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Sara M. Moorman, Robert M. Hauser and Deborah Carr

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# Do Older Adults Know Their Spouses' End-of-Life Treatment Preferences?

Sara M. Moorman

Robert M. Hauser

*University of Wisconsin–Madison*

Deborah Carr

*Rutgers University*

When terminally ill patients become mentally incapacitated, their surrogates often make treatment decisions in collaboration with health care providers. The authors examined how surrogates' errors in reporting their spouses' preferences are affected by their gender, status as durable power of attorney for health care (DPAHC), whether they and their spouses discussed end-of-life preferences, and their spouses' health status. Structural equation models were applied to data from married couples in their mid-60s from the 2004 wave of the Wisconsin Longitudinal Study. Surrogates reported their spouses' preferences incorrectly 13% and 26% of the time in end-of-life scenarios involving cognitive impairment and physical pain, respectively. Surrogates projected their own preferences onto their spouses'. Similar patterns emerged regardless of surrogate gender and status as DPAHC, marital discussions about end-of-life preferences, or spousal health status. Implications for the process of surrogate decision making and for future research are discussed.

**Keywords:** *assumed similarity; death and dying; medical decision making; projection bias; structural equation modeling*

As recently as 1960, nearly all physicians were opposed to telling their patients that they had terminal cancer, because they believed that the knowledge would have shattering psychological effects (Oken 1961). Subsequent psychosocial research showed that the awareness that one is dying does not emotionally harm one (Kübler-Ross 1969). Physicians' attitudes evolved such that the standard for care is now full disclosure and collaboration among patients, health care providers, and surrogate decision makers in cases in which patients are unable to convey their own treatment preferences (Brody 1997; Novack et al. 1979; Snyder and Leffler 2005). Changes in physicians' attitudes have occurred alongside policy changes: In

1990, Congress passed the Patient Self-Determination Act (1990) to ensure that dying people would have a greater say in their care. Under this law, federally funded health care providers are required to give patients information that helps them execute living wills and legally confer on surrogates durable power of attorney for health care (DPAHC) status, to oversee their care in the event of decisional incapacitation.

A concern of patients and health care providers is that surrogates accurately convey patients' wishes. An effective surrogate, according to bioethicists, is someone who can apply the standard of *substituted judgment* (President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research 1983). Substituted judgment occurs when a surrogate makes a medical decision that a patient would have made if he or she were competent to do so. In practice, however, surrogates often do not choose the treatments dying persons would have chosen. A review of the 16 studies of surrogate accuracy published between 1966 and 2005 found that overall, surrogates responding to a hypothetical decision-making scenario were inaccurate 32% of the time (Shalowitz, Garrett-Mayer, and Wendler 2006). Surrogates often presume (erroneously) that patients' preferences are identical to their own: Surrogates' own preferences account for more of the variance in their decisions than do patients' actual preferences (Bar-Tal, Barnoy, and Zisser 2005; Fagerlin et al. 2001; Pruchno et al. 2005).

## Study Aims

Our primary goal was to explore demographic and social factors that might moderate surrogates' proneness to error and tendency to rely on their own preferences when attempting to make substituted judgments for their spouse. The majority of married older adults who name DPAHCs name

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their spouses (Carr and Khodyakov 2007a, 2007b; Hopp 2000). When individuals do not legally appoint surrogates, the appointments may occur by default. In most states, if a married patient does not have a DPAHC, decision-making responsibility falls to the spouse (American Medical Directors Association 2003). We replicated the findings of surrogates' errors and reliance on their own preferences in our full sample of White, married surrogates in their mid-60s using structural equation modeling (SEM). We then tested whether surrogates' gender, surrogates' status as DPAHC, spouses' discussions of preferences with surrogates, and spouses' health status were moderators of these reporting errors.<sup>1</sup>

Although prior studies have documented the main effects of sociodemographic and health factors on surrogate errors, most have used samples too small to permit the statistical detection of interaction effects, or they have lacked variation on characteristics of interest, such as surrogate gender. Our large sample of surrogate-spouse dyads allowed us to examine subgroup differences in surrogate performance. If surrogates differ systematically in their ability to accurately convey spouses' preferences, this information could aid health care providers. Providers could better advise patients in their choices of surrogates and know ahead of time which surrogates may need assistance in fulfilling patients' wishes.

Our study built on prior research in three additional ways. First, we investigated surrogate errors in a sample of healthy, community-dwelling older adults, whereas most prior studies have investigated samples of terminally ill and/or institutionalized older adults. Although some individuals may prefer to articulate their preferences when they are near death, others may prefer to articulate their general preferences and values while healthy, out of concern that fear, depression, or physical discomfort may unduly color preferences articulated while terminally ill (Ditto, Hawkins, and Pizarro 2005). Furthermore, older adults recognize that late-life discussions initiated by physicians often occur at a point patients deem "too late" to be helpful to either themselves or family members (Johnston, Pfeifer, and McNutt 1995). For these reasons, it is important to know if surrogates make errors at all points in the life course or only under the duress of the illness of loved ones.

Second, participants in our study were recruited by sociologists for involvement in a multitopic longitudinal study, whereas potential participants in prior studies of end-of-life care were recruited through health care providers and knew the topic of the study in advance. The decision to participate in the latter studies may have depended on knowledge about and interest in the topic. Ditto et al. (2001) found that individuals who had made

plans for end-of-life care and who felt that planning was important were most likely to participate in their study.

Third, we used SEM in the analysis; we know of no other studies that have used such models to study the patterning and sources of surrogate error in end-of-life decision making. This omission may reflect the fact that large sample sizes are required, and as noted earlier, prior studies have typically relied on small samples. SEM allows for the simultaneous estimation of linear relationships among combinations of observed (independent and dependent) and unobserved (latent) variables. SEM was uniquely suited to our research question because it allowed us to (1) estimate measurement error (i.e., we did not need to assume that our measures had perfect reliability) and (2) distinguish between effects of surrogates' own preferences and spouses' own preferences on the surrogates' proxy reports (i.e., estimate the degree to which surrogates' reports were based on their own preferences).

### **Social-Psychological Perspectives on Surrogate Decision Making**

Past research and theory offer two distinct yet complementary explanations for surrogates' tendency to err by applying their own preferences to their surrogate decisions. Some studies have suggest that surrogates act on the principle of *assumed similarity* (Cronbach 1955; Kenny and Acitelli 2001).<sup>2</sup> That is, a surrogate may assume that self and partner hold similar preferences and thus allow his or her own preferences to guide the assessment of partner preferences. On its face, this assumption is sensible, given that patients and their surrogates are typically in close, long-term relationships and may share similar views on important issues, such as end-of-life care. Assumed similarity may pose no problem, and indeed may even be desirable when a surrogate and a patient do have the same preferences for care (Fagerlin et al. 2001; Hoch 1987; Kenny and Acitelli 2001). Although relationship closeness does confer an advantage in terms of knowledge of one's partner's general preferences and characteristics, spouses may become overconfident and thus erroneously believe they are experts on each other (Kenny and Acitelli 2001). Theories of cognitive consistency further suggest that closeness produces a strong motivation to hold positive beliefs about one's partner (e.g., that he or she is a good person, that he or she is like oneself) and to assume shared beliefs in addition to shared affection (Heider 1958).

*Projection bias* also has been proposed as an explanation for surrogates' compromised ability to set aside their own preferences (Loewenstein,

O'Donoghue, and Rabin 2003). Projection bias is a type of error that individuals commonly make when they engage in "affective forecasting," or predicting how they will feel under a new or unfamiliar set of circumstances (Wilson and Gilbert 2003). Individuals who are making decisions about the future may have difficulty disregarding their current preferences, however irrelevant those preferences are to the future, and are unable to fully anticipate the implications of a change in conditions (e.g., a decline in health status). These biases extend to thinking about other people as well. Individuals who are not currently experiencing a particular condition, such as physical pain, cannot entirely empathize with those who are experiencing the state, even if they have experienced the state themselves in the past. People who are making decisions for others first make the decisions for themselves and then account for differences between themselves and the others (VanBoven and Loewenstein 2003). According to this perspective, surrogates are inaccurate because they make errors when predicting what treatment they would want for themselves and thus carry these errors over when making decisions for loved ones (Loewenstein 2005).

### **Moderating Influences on Surrogate Decision Making**

Assumed similarity and projection bias are considered to be pervasive, yet neither immutable nor universal, cognitive processes (Cronbach 1955). Hoch (1987) found considerable individual-level differences in how unique participants perceived themselves to be. Identifying those persons most likely to rely on assumed similarity or projection bias may provide guidelines to practitioners hoping to effectively target end-of-life planning interventions. To this end, we explored the extent to which four factors affect one's tendency to make errors in reporting one's spouse's preferences: surrogate gender, surrogate's legal role as the spouse's DPAHC, discussion between surrogate and spouse, and spouse's health status.

The extent to which individuals effectively perform the role of surrogate may vary by gender, reflecting gender differences in experiences with health care and in family roles. Women are more knowledgeable about illness and treatment than men and have more frequent contact with the health care system (Beier and Ackerman 2003; Green and Pope 1999). Women live longer on average than men and may expect to see their husbands become incapacitated and ultimately die. Anticipating that they will need to provide care for dying husbands at some point, women may collect information about their husbands' preferences. Furthermore, women traditionally do most of the care work in families and may have direct experience with caring for dying relatives. One recent study found wives to be more accurate surrogates

than husbands (Zettel-Watson et al. 2008). However, the only other study to date to find significant gender differences found that wives were less accurate surrogates than husbands, because wives relied on their own preferences to a greater degree than husbands did (Bar-Tal et al. 2005). The two studies sampled quite different populations: Zettel-Watson et al. (2008) studied healthy American patients in their early 70s, whereas Bar-Tal et al. (2005) studied Israeli patients with cancer in their mid-50s. We aimed to clarify the results of prior studies by addressing the following question:

*Research question 1:* Do husbands and wives differ in their accuracy as surrogates, and do they rely on their own preferences to the same degree?

A simple and practical strategy for reducing the use of assumed similarity and projection bias may be to ensure that surrogates have access to information about patients' preferences so that they do not need to make guesses. Therefore, preparations for end-of-life care, including appointing a DPAHC and holding discussions, may affect surrogate decision making. The legal intent of a DPAHC appointment is to have a surrogate who will make decisions that preserve a patient's autonomy and well-being. With this goal in mind, a rational individual will select the person he or she believes most capable of the job. However, not all individuals value substituted judgment: Some persons appoint DPAHCs to ensure that their preferences are followed strictly, but others do so because they would prefer that someone else make treatment decisions (Terry et al. 1999). Therefore, DPAHCs may or may not be better at substituted judgment than others.

*Research question 2:* Do surrogates who are their spouses' legally appointed DPAHCs, surrogates who have appointed others as DPAHCs, and surrogates whose spouses have not appointed DPAHCs differ in their accuracy, and do they rely on their own preferences to the same degree?<sup>3</sup>

Prior studies have revealed that older persons, including terminally ill persons, often are reluctant to discuss their end-of-life preferences with loved ones or health care providers (Layson et al. 1994). Thus, one might expect that when discussions about final preferences do occur, they are perceived as highly salient and are easily recalled. But empirical research does not uniformly support this assumption. Ditto et al. (2001) found that surrogates who participated in a discussion intervention with healthy patients were no better at identifying patients' preferences than a control group of surrogates who did not hold discussions with patients. However, a discussion intervention targeted at patients about to undergo heart surgery

showed success (Song et al. 2005). We aimed to clarify the results of prior studies by addressing the following question:

*Research question 3:* Do spouses who have discussed end-of-life treatment preferences with their surrogates, spouses who have discussed end-of-life treatment preferences with others, and spouses who have not discussed end-of-life treatment preferences with anyone have surrogates who differ in accuracy and who rely on their own preferences to the same degree?

Finally, in contexts in which end-of-life issues are particularly salient or imminent, we might expect surrogates to be more or less effective. People exhibit a strong preference to have the opportunity to change their minds (Gilbert and Ebert 2002) and therefore may hold only abstract preferences for end-of-life treatment until major illness forces concrete, realistic thinking (Leventhal, Leventhal, and Cameron 2001). Partners of healthy persons may have limited knowledge of their spouses' preferences and may have great difficulty imagining dying spouses. Alternatively, healthy couples may be willing to think about end-of-life issues because they are not immediately threatened, whereas couples facing serious illnesses may enter a particularly acute state of death denial. Couples facing illnesses might prefer to focus on the positive (e.g., "Yes, it's cancer, but he's being treated") and so do not prepare to make end-of-life decisions (Löckenhoff and Carstensen 2004).

*Research question 4:* Do surrogates whose spouses have serious illnesses and surrogates whose spouses have no serious illnesses differ in their accuracy as surrogates, and do they rely on their own preferences to the same degree?

Our research questions were predicated on the assumption that surrogate error and assumed similarity and/or projection bias existed in our full sample. They did; we demonstrate this replication below. A sizable minority of our surrogates' reports of their spouses' end-of-life preferences were erroneous, and surrogates' reports of their spouses' end-of-life preferences depended on preferences for their own care in addition to their spouses' actual preferences.

## Methods

### Sample

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. Most were born in 1939. Graduates were surveyed at ages 18 (1957), 36 (1975), 54 (1993), and 65 (2004). Among 9,025 living graduates, 7,265 (80.5%) participated in the 2004 telephone survey.<sup>4</sup> Of these, 5,681 (78.2%) were currently married, and 3,890 spouses (68.5%) completed parallel surveys.

Topical modules were administered to randomly selected subsamples to reduce the overall length of the survey. A module on end-of-life planning was administered by telephone to a random 70% subsample of graduate-spouse pairs in 2004. Thus, our analysis focused on the 2,750 married couples (5,500 individuals) in which both members responded to the module on end-of-life planning.

Some strata of the U.S. population are not represented in the WLS. By design, all sample members graduated from high school. Nearly all WLS participants are non-Hispanic Whites; few minorities lived in Wisconsin in the late 1950s. Despite these limitations, the sample is broadly representative of older, White, married American men and women who have completed at least a high school education. Seventy-five percent of all Wisconsin youth graduated from high school in the late 1950s (Sewell and Hauser 1975). 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). In 2003, 77.3% of American men aged 55 to 64 years and 64.4% of American women aged 55 to 64 years were married (U.S. Census Bureau 2003). In the same year, 72.6% of married American men and 74.5% of married American women aged 55 to 64 were non-Hispanic White and had completed a high school education or more.

## Measures

*Own treatment preferences.* The WLS ascertained both graduate and spouse end-of-life treatment preferences with the following two 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? Would you want to continue all medical treatments or stop all life-prolonging treatments? Second, what if you had minimal physical pain, but had limited ability to speak, walk, or recognize others? Would you want to continue all medical treatments or stop all life-prolonging treatments?

These items were adapted from a 1999 Detroit Area Study module ("Health Care and End-of-Life Decisions"). 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.” Responses of “I don’t know” were treated as missing data. The percentage of individuals who responded “I don’t know” ranged from 3.6% in the graduate–cognitive impairment scenario to 6.8% in the spouse-pain scenario.

*Proxy reports.* The graduate’s perceptions of his or her spouse’s preferences were assessed with parallel items (i.e., “Suppose your spouse had a serious illness today with very low chances of survival. . . . Would he/she want to continue all medical treatments or stop all life-prolonging treatments?”) The percentage of graduates who volunteered “I don’t know” was 9.3% in the pain scenario and 6.8% in the cognitive impairment scenario. Spouses were not asked parallel questions about the preferences of graduates; therefore, hereafter, we refer to the graduates as “surrogates.”

*Gender.* Surrogates were separated into two groups: men and women.

*DPAHC.* Spouses responded “yes” or “no” to 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.” If a spouse had a DPAHC, he or she reported who that person was. Spouses were separated into three groups: those who had not appointed DPAHCs, those who had appointed persons other than the surrogates as DPAHCs, and those who had appointed the surrogates as DPAHCs.

*Discussed preferences with surrogate.* Spouses were asked if they had “made plans about the types of medical treatment you want or don’t want if you become seriously ill in the future.” If they had, they were asked if they had discussed these plans with anyone. Spouses could mention up to three people or groups of people (e.g., surrogate and children) with whom they had discussions. Spouses were separated into three groups: those who reported having discussions with the surrogates, those who reported having discussions with persons other than the surrogates, and those who reported no discussions. These groups were mutually exclusive; a spouse who mentioned the surrogate also may have mentioned others, but we coded that spouse as “discussed with surrogate” only.

*Serious illness.* Spouses were asked whether doctors had ever told them that they had “diabetes; cancer or a malignant tumor, not including minor

skin cancers; a heart attack, coronary heart disease, angina, congestive heart failure, or other heart problems; or a stroke.” Spouses were separated into two groups: those who had at least one serious illness and those who had none of the illnesses. Although WLS sample members are asked to indicate which of 14 illnesses or conditions have been diagnosed by health care providers, we focused on the four major groups of illnesses that are documented as the leading causes of death among older Americans today (Gorina et al. 2006).

### Analytic Strategy

*Missing data.* Our original analytic sample included 2,750 cases. Listwise deletion reduced the sample size to 2,045 cases, 2,022 cases, 2,040 cases, and 2,035 cases for testing research questions 1 through 4, respectively. Results obtained after using imputation by chained equations did not differ appreciably from results obtained using listwise deletion. (Materials sufficient for replicating the results reported in this article will be deposited with the Inter-University Consortium for Political and Social Research Publications-Related Archive.)

*Statistical approach.* We used SEM to evaluate the four research questions. The variables to be correlated were dichotomous, so we estimated a matrix of tetrachoric correlations. That is, we specified that the dichotomous reports by WLS participants were indicators of continuous, bivariate normal variates. Respondents were forced to choose “stop” or “continue,” but we assumed that true preferences varied along a continuum reflecting strength of agreement. Some participants may have been extremely sure that they would want to stop all treatment, whereas others may have been somewhat sure.<sup>5</sup> Maximum likelihood estimation yields biased estimates and incorrect goodness-of-fit values when ordinal or nonnormal variables are included in a correlation matrix; weighted least squares estimation is appropriate. Therefore, we also estimated an asymptotic covariance matrix, the inverse of which is used in weighted least squares estimation. We conducted analyses using the software package LISREL 8.8 (Jöreskog and Sörbom 1996).

*Model.* The structural equations describing the model were as follows:

$$\begin{aligned} Y_{PG} &= \eta_1 + \varepsilon_1, \\ Y_{CIG} &= \eta_1 + \varepsilon_2, \\ Y_{PS} &= \lambda_{31}\eta_1 + \lambda_{32}\eta_2 + \varepsilon_3, \\ Y_{CRS} &= \lambda_{41}\eta_1 + \lambda_{42}\eta_2 + \varepsilon_4, \end{aligned}$$

$$Y_{PS} = \eta_2 + \varepsilon_5,$$

and

$$Y_{CIS} = \eta_2 + \varepsilon_6,$$

where  $\eta_1$  is surrogate preferences (latent);  $\eta_2$  is spouse preferences (latent);  $Y_{PG}$  is surrogate response for self, pain condition;  $Y_{CIG}$  is surrogate response for self, cognitive impairment condition;  $Y_{PS}$  is surrogate report on spouse preference, pain condition;  $Y_{CRS}$  is surrogate report on spouse preference, cognitive impairment condition;  $Y_{PIS}$  is spouse response for self, pain condition;  $Y_{CIS}$  is spouse response for self, cognitive impairment condition;  $\lambda_{ij}$  are coefficients to be estimated; and  $\varepsilon_i$  are random errors. In addition to  $\lambda_{ij}$ , the parameters of the model were the variances and covariances of the latent preferences ( $\Psi_j$ ) and the variances and covariances of the errors in variables ( $\Theta_j^e$ ).

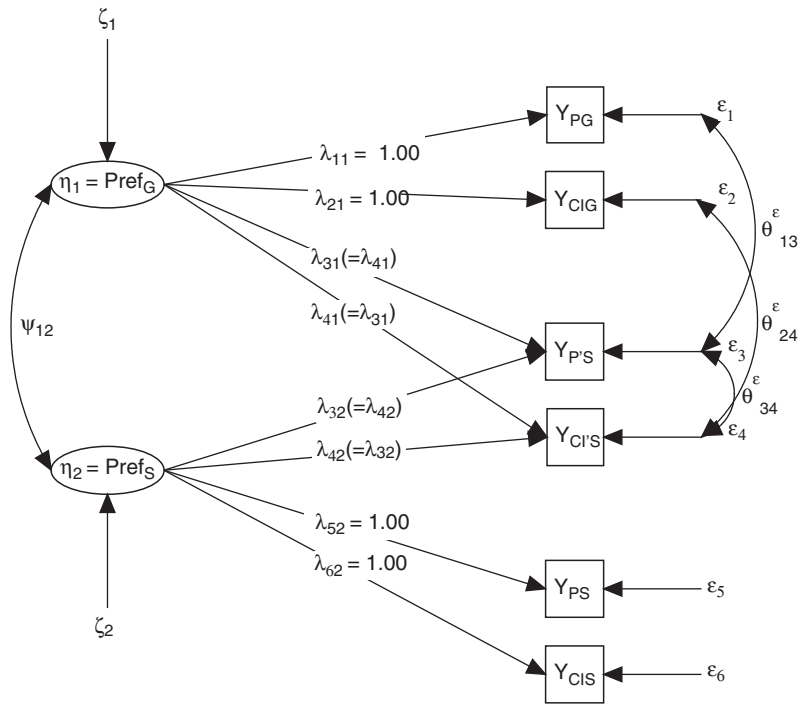
Figure 1 graphically depicts our analytic model. Latent variables represent the “true” end-of-life preferences of surrogates and their spouses. The four reports of own preferences each depend on the surrogate’s or spouse’s true preferences, and the surrogate’s proxy reports depend on both of the true preferences.

To obtain plausible estimates of the parameters (i.e., positive estimates of error variance), we specified selected correlations among errors. We found a positive correlation between the errors in the two proxy reports, suggesting that surrogates tended not to distinguish between the pain and cognitive impairment scenarios. The errors in self and proxy reports by the surrogates also were correlated for each scenario. That is, surrogates’ reports of their own preferences and reports of their spouses’ preferences under each scenario were even more similar than would be expected from the actual similarity in surrogates’ and spouses’ true (latent) preferences and the general tendency of surrogates’ proxy reports to resemble their own preferences.

The model equated each of the loadings ( $\lambda_{ij}$ ) and error variances ( $\Theta_j^e$ ) pertaining to reports under the two scenarios by the same surrogate about the same spouse because there were negligible variations in these parameters when they were allowed to differ. This is further evidence that people tended not to distinguish between the pain and cognitive impairment scenarios. Although there were only two indicators of spouses’ preferences, the parameters of the model were all identified. They would remain identified had we not initially equated selected loadings and error variances.

Our model assumed that an individual could report his or her own preferences incorrectly. In a clinical setting, a patient’s stated preferences must be taken at face value. But patients sometimes make mistakes when answering questions. Even survey respondents’ repeated self-reports of

**Figure 1**  
**Structural Equation Model of Couples' End-of-Life Preferences, Married Participants in the Wisconsin Longitudinal Study Module on End-of-Life Treatment Preferences, 2004**



Note:  $\text{Pref}_G$  = preferences, surrogate (latent);  $\text{Pref}_S$  = preferences, spouse (latent);  $Y_{PG}$  = surrogate response for self, pain condition;  $Y_{CIG}$  = surrogate response for self, cognitive impairment condition;  $Y_{PS}$  = surrogate report on spouse preference, pain condition;  $Y_{CIS}$  = surrogate report on spouse preference, cognitive impairment condition;  $Y_{PS}$  = spouse response for self, pain condition;  $Y_{CIS}$  = spouse response for self, cognitive impairment condition.

objective, unchanging social and economic characteristics, such as years of schooling completed, have been found to vary across survey waves (Bielby, Hauser, and Featherman 1977). Fortunately, statistical methods can account for these errors. Our latent variables referred to what was common in the self-reported preferences of surrogates or spouses under the two scenarios, leaving the “errors in variables” to refer to the combination of what was

specific to each scenario and reporting error. Our major findings were unchanged under this interpretation, yet we prefer it because statements of preference are often unreliable. In the course of an actual medical decision-making process, patients' expressed preferences change over time and vary with circumstances (Ditto et al. 2005, 2006; Kressel and Chapman 2007; Loewenstein 2005).

*Replication.* Our research questions were predicated on the assumption that surrogate error and assumed similarity and/or projection bias existed in our full sample. These issues were tested through comparison of the baseline model with models that equated select  $\lambda$  paths ( $\lambda_{ij}$ ) and error variances ( $\Theta_{ij}^e$ ). There was one test for the existence of surrogate error. It equates  $\lambda_{52}$  to  $\lambda_{32}$ ,  $\Theta_{55}^e$  to  $\Theta_{33}^e$ ,  $\lambda_{62}$  to  $\lambda_{42}$ , and  $\Theta_{66}^e$  to  $\Theta_{44}^e$ . If we accept this model (i.e., prefer it to the baseline model that does not equate  $\lambda$  paths and error variances), we conclude that spouses' self-reports are more dependent on their true (latent) preferences than are surrogates' reports of spouses' preferences. In other words, there is more error in proxy reports than in self-reports. There are two tests for assumed similarity and projection bias. The first test equates  $\lambda_{11}$  to  $\lambda_{31}$ ,  $\Theta_{11}^e$  to  $\Theta_{33}^e$ ,  $\lambda_{21}$  to  $\lambda_{41}$ , and  $\Theta_{22}^e$  to  $\Theta_{44}^e$ . If we accept this model, we conclude that the surrogates' proxy reports depend on their true preferences in exactly the same way and to the same degree as their self-reports depend on their true preferences. The second test equates  $\lambda_{31}$  to  $\lambda_{32}$  and  $\lambda_{41}$  to  $\lambda_{42}$ . If we accept this model, we conclude that surrogates' proxy reports depend more on the true preferences of surrogates than on the true preferences of spouses.

*Assessment of research questions.* The research questions were tested through models that equated groups (e.g., male surrogates and their wives to female surrogates and their husbands; spouses who had no discussions, spouses who had discussions with persons other than their surrogates, and spouses who had discussions with their surrogates). In these tests, we first fit the model shown in Figure 1 to each group, allowing all comparable parameters (e.g.,  $\lambda_{42}^{\text{men}} = \lambda_{42}^{\text{women}}$ ) to differ between groups. We then fit the model a second time, constraining all comparable parameters to be equal across groups.<sup>6</sup> If we accept the first model (i.e., prefer it to the second), we conclude that the groups perform differently as surrogates. If we accept the second model, we conclude that the groups do not perform differently as surrogates.

We accepted or rejected models on the basis of fit statistics. In addition to a model's  $\chi^2$  statistic and degrees of freedom, the fit statistics that

concerned us were the Bayesian information criterion (BIC) and the root mean square error of approximation (RMSEA). A difference in BIC, calculated as  $\chi^2 - df \times \ln(N)$ , of 5 or more between models provides evidence for the superior fit of the model with the more negative value (Raftery 1995). An RMSEA, calculated as  $\sqrt{\{[(\chi^2 - df)/(N - 1)]/df\}}$ , of 0.05 or less indicates very good fit (Loehlin 2004).

## Results

### Treatment Preferences, Proxy Reports, and Spouse Characteristics

Descriptive statistics for all variables used in the analysis are presented in Table 1. In the case of physical pain, 78.3% of surrogates and 79.9% of spouses reported that they would want to stop all life-prolonging treatment for themselves, and 80.2% of surrogates reported that their spouses would want all life-prolonging treatment stopped. In the case of cognitive impairment, 91.8% of surrogates and 92.5% of spouses reported that they would want to stop all life-prolonging treatment for themselves, and 90.7% of surrogates reported that their spouses would want all life-prolonging treatment stopped.

The responses to all six items were highly skewed toward ending life-prolonging treatment. This skew partly accounted for the high level of concordance between spouses' self-reports and surrogates' proxy reports of spousal preferences. In the pain scenario, actual agreement was 74.1%, while we would expect agreement of 68.8% by chance. In the cognitive impairment scenario, actual agreement was 87.0%, while we would expect 85.5% agreement by chance. Despite the small percentage of discordant couples, the sample was large enough that we had sufficient statistical power to conduct our analysis.

The average ages of the surrogates' wives and husbands in our sample were 61.5 years ( $SD = 4.2$  years) and 66.9 years ( $SD = 3.9$  years), respectively. The spouses of male and female surrogates were of substantially different ages because of the gender differential in age at marriage in the late 1950s and early 1960s and men's tendency to marry younger women. Male surrogates were overrepresented in our analytic sample, reflecting men's greater likelihood of being married and women's greater likelihood of being widowed or divorced in later life. Spouses had appointed their

**Table 1**  
**Distributions of Variables Used in the Analysis:**  
**Married Participants in the Wisconsin Longitudinal Study**  
**Module on End-of-Life Treatment Preferences, 2004**

Variable	Total Sample
Surrogate in pain: stop treatment	.783
Surrogate with cognitive impairment: stop treatment	.918
Surrogate: stop treatment for spouse in pain	.802
Surrogate: stop treatment for spouse with cognitive impairment	.907
Spouse in pain: stop treatment	.799
Spouse with cognitive impairment: stop treatment	.925
Surrogate is spouse's DPAHC	.297
Other is spouse's DPAHC	.270
Spouse has no DPAHC	.433
Spouse discussed preferences with surrogate	.499
Spouse discussed preferences with other	.244
Spouse did not discuss preferences with anyone	.257
Spouse has diabetes, cancer, heart disease, and/or stroke	.341
<i>n</i>	2,750

Note: Reported prior to listwise deletion. DPAHC = durable power of attorney for health care.

surrogates as DPAHCs in 29.7% of cases and had discussed their end-of-life treatment preferences with their surrogates in 49.9% of cases. A third of spouses reported having been diagnosed with at least one serious illness (diabetes [12.2%], cancer [11.9%], heart disease [16.1%], and/or stroke [3.0%]), either at the time of data collection or in the past.

### Surrogate Characteristics

Our analysis provides little information about the personal characteristics of the surrogates; therefore, we include a brief description here. Nearly all surrogates were born in 1939. Surrogates had appointed their spouses as DPAHCs in 39.0% of cases. One third of surrogates reported having been diagnosed with at least one serious illness (diabetes [11.7%], cancer [10.8%], heart disease [16.0%], and/or stroke [2.8%]), either at the time of data collection or in the past.

### Structural Equation Models: Replication

*Baseline model.* Parameter estimates for the baseline model are presented in Table 2 and Figure 2. The estimates of  $\lambda_{ij}$  are relative slopes; thus,



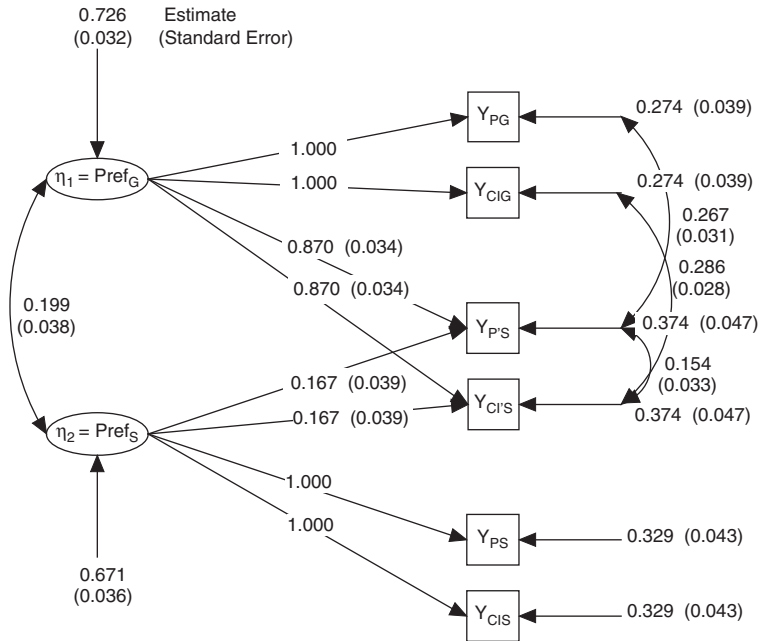
**Table 2**  
**Estimates for Baseline Structural Equation Model: Married**  
**Participants in the Wisconsin Longitudinal Study Module on**  
**End-of-Life Treatment Preferences, 2004**

Parameter	Estimate	SE	Standardized Estimate
$\Psi_{11}$	.726	.032	1.000
$\Psi_{22}$	.671	.036	1.000
$\Psi_{12}$	.199	.038	.285
$\lambda_{11}$	1.000	—	.852
$\lambda_{21}$	1.000	—	.852
$\lambda_{31}$	.870	.034	.742
$\lambda_{41}$	.870	.034	.742
$\lambda_{32}$	.167	.039	.137
$\lambda_{42}$	.167	.039	.137
$\lambda_{52}$	1.000	—	.819
$\lambda_{62}$	1.000	—	.819
$\theta_{11}^e$	.274	.039	.274
$\theta_{22}^e$	.274	.039	.274
$\theta_{33}^e$	.374	.047	.374
$\theta_{44}^e$	.374	.047	.374
$\theta_{55}^e$	.329	.043	.329
$\theta_{66}^e$	.329	.043	.329
$\theta_{13}^e$	.267	.031	.267
$\theta_{24}^e$	.286	.028	.286
$\theta_{34}^e$	.154	.033	.154

the regression of surrogates' proxy reports on their true preferences is .870 times as steep as the regression of their self-reports on their true reports. The correspondence between self-reports and true preferences was less than perfect: The standardized values of  $\lambda_{ij}$  show that the correlation between surrogates' self-reports and their true preferences was .852. The correlation between surrogates' proxy reports and their true preferences was .742 (.870 times as large as the correlation between surrogates' self-reports and their true preferences). That is, the correlation between a surrogate's true preference and his or her report of the spouse's preference was almost as large as that between the surrogate's true preference and his or her expressed self-preference.

*Error:* Fit statistics for all models are presented in Table 3. After taking account of the overall skew in preferences for end-of-life treatment, we found that surrogates' proxy reports of their spouses' end-of-life preferences

**Figure 2**  
**Results of Baseline Structural Equation Model: Married**  
**Participants in the Wisconsin Longitudinal Study Module**  
**on End-of-Life Treatment Preferences, 2004**



Note:  $\text{Pref}_G$  = preferences, surrogate (latent);  $\text{Pref}_S$  = preferences, spouse (latent);  $Y_{PG}$  = surrogate response for self, pain condition;  $Y_{CIG}$  = surrogate response for self, cognitive impairment condition;  $Y_{PS}$  = surrogate report on spouse preference, pain condition;  $Y_{CRS}$  = surrogate report on spouse preference, cognitive impairment condition;  $Y_{PS}$  = spouse response for self, pain condition;  $Y_{CIS}$  = spouse response for self, cognitive impairment condition.

were often erroneous. A model that equated  $\lambda_{52}$  to  $\lambda_{32}$ ,  $\theta_{55}^e$  to  $\theta_{33}^e$ ,  $\lambda_{62}$  to  $\lambda_{42}$ , and  $\theta_{66}^e$  to  $\theta_{44}^e$  fit significantly less well than the baseline model, indicating that surrogates' proxy reports were not as dependent on their spouses' true preferences as were spouses' self-reports of their preferences.<sup>7</sup> In other words, there was error in both self-reports and proxy reports, but there was more error in proxy reports. Future research must be careful not to consider reported attitudes, beliefs, or preferences as "true" scores that lack measurement error, especially when they are reported by proxy.

**Table 3**  
**Fit Statistics for All Structural Equation Models: Married**  
**Participants in the Wisconsin Longitudinal Study Module on**  
**End-of-Life Treatment Preferences, 2004**

Variable	$\chi^2$	df	BIC	RMSEA
Single-group models				
Baseline	12.3	7	-41.1	0.019
Surrogate error ( $\lambda_{32} = \lambda_{32}^e$ , $\theta_{55}^e = \theta_{33}^e$ , $\lambda_{62} = \lambda_{42}^e$ , $\theta_{66}^e = \theta_{44}^e$ )	134.2	11	50.3	0.074
Difference from baseline	121.9	4	91.4	—
Assumed similarity/projection bias test 1 ( $\lambda_{11} = \lambda_{31}$ , $\theta_{11}^e = \theta_{33}^e$ , $\lambda_{21} = \lambda_{41}$ , $\theta_{22}^e = \theta_{44}^e$ )	28.1	10	-48.1	0.030
Difference from baseline	15.8	3	7.0	—
Assumed similarity/projection bias test 1 ( $\lambda_{31} = \lambda_{32}$ , $\lambda_{41} = \lambda_{42}$ )	75.5	8	14.5	0.064
Difference from baseline	12.1	1	55.6	—
Multigroup models				
Parameters $\neq$ by gender, research question 1	26.3	14	-80.4	0.029
Parameters = by gender, research question 1	30.2	28	-183.3	0.009
Difference	3.9	14	102.9	—
Parameters $\neq$ by DPAHC, research question 2	42.5	21	-117.3	0.039
Parameters = by DPAHC, research question 2	61.5	49	-311.5	0.020
Difference	19.0	28	194.2	—
Parameters $\neq$ by discussion, research question 3	21.2	21	-138.8	0.003
Parameters = by discussion, research question 3	34.6	49	-338.8	0.000
Difference	13.4	28	200.0	—
Parameters $\neq$ by illness, research question 4	19.2	14	-87.5	0.019
Parameters = by illness, research question 4	25.6	28	-182.7	0.000
Difference	6.4	14	95.2	—

Note: BIC = Bayesian information criterion; RMSEA = root mean square error of approximation; DPAHC = durable power of attorney for health care.

*Assumed similarity and projection bias.* We found that surrogates' reports of their spouses' end-of-life preferences depended on preferences for their own care, in addition to their spouses' actual preferences. Surrogates did not distinguish well between their own preferences and the preferences of their spouses; they relied strongly on their own preferences when reporting spousal preferences. A model that equated  $\lambda_{11}$  to  $\lambda_{31}$ ,  $\theta_{11}^e$  to  $\theta_{33}^e$ ,  $\lambda_{21}$  to  $\lambda_{41}$ , and  $\theta_{22}^e$  to  $\theta_{44}^e$  fit significantly better than the baseline model, indicating that the proxy reports depended on the surrogates' true preferences in exactly the same way and to the same degree as the surrogates' own reported preferences depended on their true preferences. A model that equated  $\lambda_{31}$  to  $\lambda_{32}$

and  $\lambda_{41}$  to  $\lambda_{42}$  also fit significantly better than the baseline model, indicating that the proxy reports of spouses' preferences depended more on the true preferences of surrogates than on the true preferences of spouses.

## Structural Equation Models: Research Questions

Fit statistics for all models are presented in Table 3. The analyses revealed no subgroup differences: The fit of the model that allowed parameters to vary among groups was not preferred to the fit of the model that constrained parameters to be equal across groups for the groups pertinent to any research question. Male and female surrogates did not differ in their accuracy as surrogates and did rely on their own preferences to the same degree (research question 1). Similarly, surrogates who were their spouses' DPAHCs did not differ from surrogates whose spouses had appointed other persons as DPAHCs or surrogates whose spouses had not appointed DPAHCs in terms of accuracy or reliance on own preferences (research question 2). Spouses who had discussed their end-of-life treatment preferences with their surrogates did not have surrogates whose accuracy or reliance on own preferences differed from the surrogates of spouses who had discussed their end-of-life treatment preferences with others or the surrogates of spouses who had not discussed their end-of-life treatment preferences with anyone (research question 3). Surrogates whose spouses had serious illnesses and surrogates whose spouses did not have serious illnesses did not differ in their accuracy as surrogates and did rely on their own preferences to the same degree (research question 4). Our primary goal was to test whether these four factors are moderators of surrogate reporting errors; we conclude that they are not.

## Discussion

We used SEM to document the accuracy of individuals' assessments of their spouses' end-of-life treatment preferences among 2,750 married couples. When asked to report their spouses' preferences, surrogates made erroneous reports in a sizable minority of cases. Surrogates relied heavily on their own preferences when reporting their spouses' preferences. Similar patterns emerged regardless of the surrogates' gender, their status as their partners' DPAHCs, whether they had discussed with their spouses their end-of-life wishes, and whether their spouses had serious illness. Our results

suggest that, at least among healthy, community-dwelling couples in their mid-60s, the tendency to rely on one's own preferences when reporting spousal preferences is a widespread phenomenon and one that is not affected by health, gender, or two forms of formal end-of-life planning.

### **Moderating Influences on Surrogate Decision Making**

None of the moderating influences we tested in our sample were statistically significant. The processes of assumed similarity and projection bias can offer at least a partial explanation for the lack of statistically significant subgroup differences. When thinking about what end-of-life treatments others would want, surrogates first decide what they would do for themselves and then consider differences between themselves and the targets of their decision (VanBoven and Loewenstein 2003). Projection bias affects the first stage of this process and assumed similarity the second.

*Projection bias, DPAHC appointment, and marital conversations about end-of-life care.* First, we turn our attention to projection bias. We find that neither one's appointment of a DPAHC nor holding discussions with one's spouse improves surrogate judgment, and we speculate that the reason may be the volatility of surrogate preferences for self. Ditto et al. (2003) found that within two years of initially articulating their preferences regarding the receipt of life-sustaining treatment, a quarter of participants, healthy persons in their mid-70s, had altered their preferences. Furthermore, some preferences appeared stable between the baseline and two-year follow-up interviews, but in fact, participants had changed their minds between baseline and one-year follow-up and then reverted back to their initial preferences by the two-year interview. Preferences change as health status declines: As older adults become sicker, their preferences tend to change from treatments that increase the length of life to treatments that enhance the quality of life (Ditto et al. 2006; Fried et al. 2007; Voogt et al. 2005).

In such cases, we suspect that projection bias is occurring: Healthy people are unable to accurately predict what their future ill selves would want, and then carry over or "project" these inaccurate appraisals onto others. One's own preferences may override any information gathered from having been appointed DPAHC and/or having had a discussion. Furthermore, the patient's preferences also may be changing, and information from the time of DPAHC appointment and/or discussion may become less relevant or accurate as time passes.

*Assumed similarity, surrogate gender, and serious spousal illness.* Next, we turn our attention to assumed similarity. We find that neither gender of surrogate nor health status of spouse affects surrogate judgment, and we speculate that the reason may be surrogate failure to take into account key differences between self and spouse. The married couples in our sample were made up of men and women, and spouses often differ with respect to their physical health status. These individual-level differences in partner traits may create differences in their own end-of-life preferences; if differences in preferences do exist, assuming similarity is a poor strategy for achieving substituted judgment.<sup>8</sup>

First, prior research has documented gender differences in end-of-life preferences; men tend to prefer to receive or continue life-sustaining treatment more often than women (Bookwala et al. 2001; Covinsky et al. 2000). Thus, spouses in opposite-sex marriages may differ in their end-of-life preferences, and assuming similarity may result in problematic health care decisions by both male and female surrogates. Our results suggest that male surrogates are as poor at predicting their wives' preferences as female surrogates are at predicting their husbands' preferences.

Second, prior research has documented that end-of-life preferences vary with health status (Ditto et al. 2006; Fried et al. 2007; Voogt et al. 2005). The sicker the patient, the less likely he or she is to prefer continued curative treatment. In the present study, ill spouses did not usually have ill surrogates, and vice versa: In only 11.3% of couples did both partners have serious illnesses. As with gender differences, differences in health status within couples may result in problematic surrogate decisions because of assuming similarity despite the existence of dissimilarity in traits that shape end-of-life preferences.

## **Directions for Future Research**

Our findings raise several important avenues for future research. First, we considered only a limited set of potential moderating variables, and we look forward to exploring a fuller range of potential influences. Individual characteristics such as cognitive functioning or dyadic characteristics such as marital quality may be promising avenues for investigation. For example, cross-sectional data indicate that declines in perspective-taking ability are a part of normal cognitive aging (Bailey and Henry 2008; Ligneau-Hervé and Mullet 2005). Furthermore, persons in high-quality marriages are more likely to report that they try to assume their spouses' perspectives than are persons in low-quality marriages, and spouses in high-quality marriages are likely to perceive their partners' efforts to assume their perspective (Long 1993).

Second, researchers should explore whether individuals can be taught to recognize problematic biases and what potential solutions are for these biases. Although some scholars have concluded that assumed similarity is “ineradicable” (Krueger and Clement 1994), others consider the cognitive process to be persistent yet modifiable (Cronbach 1955; Hoch 1987). In qualitative interviews, Vig et al. (2006) found that surrogates often are aware of their use of assumed similarity. The development and evaluation of educational interventions designed to raise surrogates’ awareness of influences on their decision making may be a fruitful direction for future research.

Third, the consequences of surrogate error should be investigated. If spouses do not hold similar preferences, but one spouse uses assumed similarity or projection bias as a decision-making heuristic, the dying spouse is unlikely to receive the treatment he or she desires. Although some patients want their spouses to make the decisions that they deem best, many patients want their own preferences to be honored and may suffer a poorer quality of life if they are denied control (Kehl 2006; Moorman 2008). Furthermore, if the healthy spouse realizes that he or she has not effectively represented the patient’s preferences at the end of life, the grieving process may be particularly distressing (Prigerson et al. 2003).

## Limitations

Our study has several limitations. First, the WLS is not representative of the overall U.S. population. It tracks a single birth cohort of persons born in 1939; different results may emerge in older or younger populations. All respondents in our analytic sample were married (and most in long-term marriages), and nearly all respondents were non-Hispanic Whites. All surrogates and nearly all spouses were high school graduates, and educational attainment may be associated with the content of end-of-life preferences and/or with the ability to report a spouse’s preferences. Pruchno et al. (2006) found that education affected patients’ preferences, and race affected spouses’ substituted judgments.

Second, the WLS treatment preference scenarios are less precise than the scenarios used in other studies of surrogate response: We did not ask about specific treatments (e.g., antibiotics, chemotherapy) or specific conditions (e.g., coma). Also, the treatment preference scenarios were always administered in the same order (first pain, then cognitive impairment), and we do not know whether this design error affected responses. That our findings on accuracy and assumed similarity replicate those of prior studies

is reassuring (Shalowitz et al. 2006). Our scenarios elicited a general orientation toward end-of-life care; most individuals wanted the same kind of treatment regardless of whether they were dying in physical pain or dying with impaired cognitive functioning.

Our results suggest that dying, rather than specific symptoms or treatments, is the most salient aspect of these questions, and people's answers are essentially statements about values or identity (e.g., "I am the type of person who believes that it is most dignified to accept death by refusing aggressive treatment when my time has come") (Burke 1980). Among a sample of older persons, fully half felt that a living will should contain only general value and goal statements (e.g., religious beliefs, importance of maintaining good cognitive functioning), and an additional 30% felt that it should contain general value and goal statements in addition to directions about specific treatments (Hawkins et al. 2005). New forms of formal end-of-life planning, called combined directives, merge components of the traditional, treatment-and-condition-specific, living will and DPAHC with a values history as a way to obtain a more comprehensive record of a patient's wishes (President's Council on Bioethics 2005). Our broad measures are in line with this current movement in health care practice, whereby general value orientations take precedence over specific treatment preferences that may not be relevant at the actual decision-making moment.

Third, we treated participants who reported that they "did not know" their preferences as if they had not answered the question. However, we believe that "I don't know" is a valid response and is in some ways more interesting than "continue treatment" or "stop treatment." Why do individuals not know? Are they uninformed about end-of-life treatments? When reporting on a spouse, is the answer "I don't know" a reluctance to use one's own preferences as a substitute for spouse preferences? In other work, we found that married persons who have not discussed end-of-life health care with anyone are likely to be uncertain about their preferences or have spousal surrogates who are too uncertain to give proxy reports (Moorman and Carr 2008).

## Conclusions

Despite its limitations, our study has implications for health care practice. We believe that there is a need to train professionals—perhaps nurses, social workers, or chaplains—to facilitate ongoing, in-depth communication between patients and their surrogates. These professionals



would be part of the patient's care team and would attend to issues such as similarities and differences between patient and surrogate, changes in patients' preferences, and surrogates' knowledge of patient preferences. Training and employing such professionals may be financially costly, but at least until researchers identify effective means of moderating surrogate error and problematic bias, we believe that the expense is necessary if substituted judgment is to be the standard for surrogate decision making.

## Notes

1. As described below, our sample consisted of persons who were in relatively good health. When referring to our participants in the remainder of this article, we call the partners who served as the patients the "spouses." The choices surrogates made about treatment for spouses are "proxy reports."

2. This concept has also been referred to as "attributive social projection" (Holmes 1968; Krueger and Clement 1997), "egocentric attribution" (Heider 1958), and "false consensus" (Hoch 1987; Krueger and Clement 1994), although authors differ in their precise definitions and applications of each concept.

3. When a spouse has appointed someone other than the surrogate as DPAHC, the surrogate will not be called on to make decisions should the spouse become incapacitated. We retained this group as an analytic category to shed light on DPAHC choices and surrogate behavior. For example, the retention of this category enabled us to explore whether these surrogates are particularly prone to err.

4. Test scores indicating low cognitive ability, poor grades in high school, and a lack of membership in civic organizations in 1975 predicted nonresponse to the 1993 telephone survey (Hauser 2005).

5. When items are structured to permit such responses, expressed preferences do vary continuously (Libbus and Russell 1995; Principe-Rodriguez et al. 1999; Seckler et al. 1991; Suhl et al. 1994; Sulmasy et al. 1998).

6. For each research question, we tested intermediate models in which some comparable parameters (e.g.,  $\lambda_{ij}$ ) were equated and others (e.g.,  $\psi_j$ ) were not; however, the models with global restrictions were always preferred.

7. We estimated an additional model testing the baseline model under the assumption that respondents' reports of their own preferences were free of error. The fit of this model was significantly worse than the fit of the baseline model we present here ( $\chi^2 = 182.4$ ,  $df = 14$ , BIC = 75.7, RMSEA = 0.077). This is empirical support for our contention that there is error in reports.

8. Often, there are not differences between the surrogate and patient with regard to end-of-life preferences. In our sample, cross-tabulations showed that in the pain scenario, 70.8% of couples had the same preference for self, and in the cognitive impairment scenario, 87.1% wanted the same treatment. In these cases, assumed similarity may pose no problem, and indeed may even be desirable (Fagerlin et al. 2001; Hoch 1987; Kenny and Acitelli 2001). Although this issue is quite interesting, in this article, we are concerned primarily with cases in which surrogates make errors, because these are the cases that are potentially problematic from the standpoint of patients, families, and health care providers.

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**Sara M. Moorman** is a graduate student in the Department of Sociology at the University of Wisconsin–Madison. She conducts research on topics concerning the aging family, including romantic relationships in later life, changes in psychological well-being surrounding widowhood, and spousal participation in end-of-life health care. Her work has recently appeared in the *Journal of Family Issues* and *The Gerontologist*. In fall 2009, she will be an assistant professor of sociology at Boston College.

**Robert M. Hauser** is Vilas Research Professor of Sociology at the University of Wisconsin–Madison, where he directs the Center for Demography of Health and Aging. He has been principal investigator of the Wisconsin Longitudinal Study since 1980. His current research interests include trends in educational progression among American racial and ethnic groups, the uses of educational assessment as a policy tool, and changes in socioeconomic standing, cognition, health, and well-being across the life course. His recent publications include a report of the National Research Council, *Measuring Literacy: Performance Levels for Adults*, and a methodological analysis of scales of psychological well-being.

**Deborah Carr** is an associate professor of sociology at Rutgers University. Her research focuses on the psychological and physical consequences of late-life spousal loss, the causes and consequences of formal end-of-life planning, and psychosocial consequences of body weight. Her work was recently published in the *Journal of Gerontology: Social Sciences*, the *Journal of Health and Social Behavior*, *Social Psychology Quarterly*, and *The Gerontologist*.