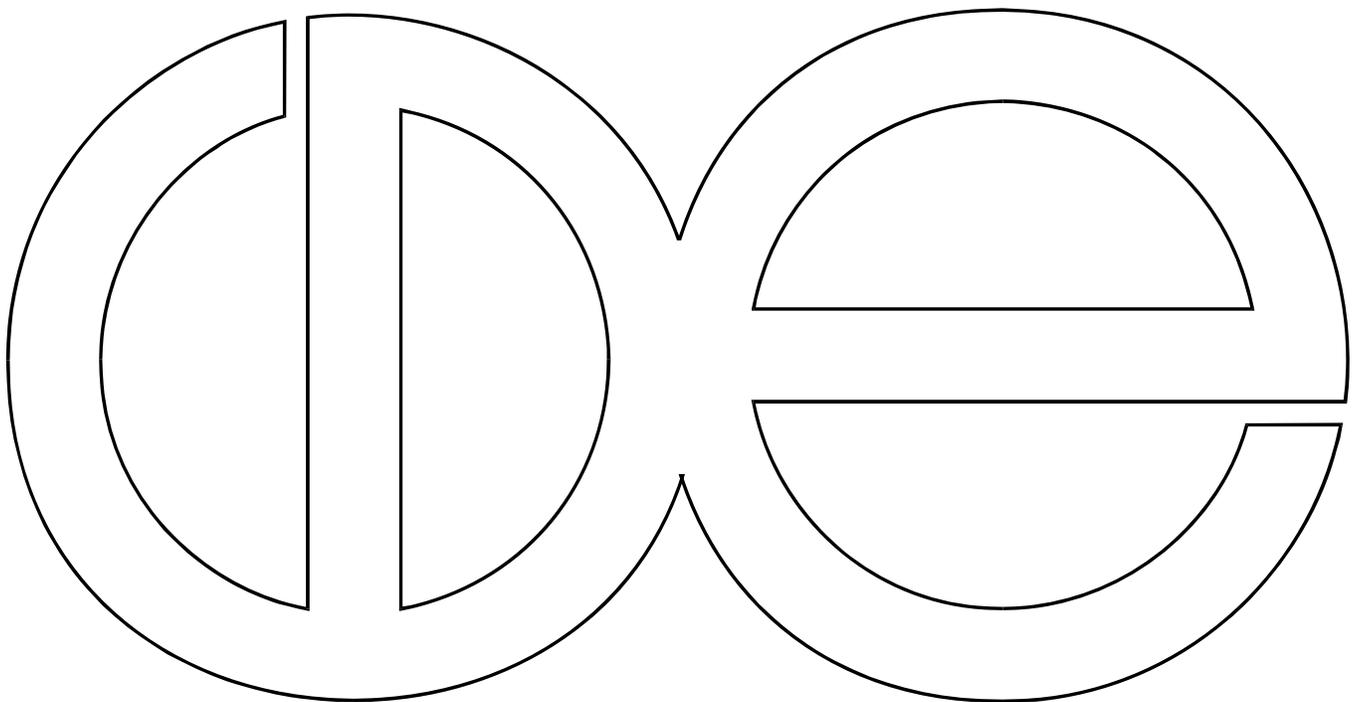


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End-of-Life Treatment Preferences?**

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Running Head: SPOUSAL SURROGACY

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BIOGRAPHICAL NOTES

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 *Journal of Aging and Health*.

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 associate professor in the Department of Sociology and Institute for Health, Health Care Policy and Aging Research at Rutgers University. Her research focuses on end-of-life issues including spousal bereavement; work and family roles over the life course; and psychosocial consequences of obesity. Her work has recently appeared in *Journal of Gerontology; Social Sciences, Journal of Health and Social Behavior*, and *Social Psychology Quarterly*. She is co-editor of *Spousal Bereavement in Late Life* (Springer, 2006).

ABSTRACT

When terminally ill patients become incapacitated, the patient's surrogate often makes treatment decisions in collaboration with health care providers. We examine how surrogates' errors in reporting their spouse's preferences are affected by their gender, status as durable power of attorney for health care (DPAHC), whether the surrogate and spouse held discussions about end-of-life preferences, and the spouse's health status. We apply structural equation models to data from 2,750 married couples in their mid 60s who participated in the 2004 wave of the Wisconsin Longitudinal Study. Individuals reported their spouse's preferences incorrectly 13 and 26 percent of the time in end-of-life scenarios involving cognitive impairment and physical pain, respectively. Individuals projected their own preferences onto the spouse. Similar patterns emerged regardless of surrogate gender, surrogate status as DPAHC, discussions, or spousal health status. We discuss implications for surrogate selection and for the process of surrogate decision-making.

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

As recently as 1970, health care providers had primary control over treatment decisions when a patient was deemed terminal (Christakis 1999; Glaser and Strauss 1965). Following high visibility legal cases in which patients received unwanted or ineffective treatments, attitudes about end-of-life care evolved such that the standard for care is now full disclosure and collaboration among patients, health care providers, and surrogate decision-makers -- should the patient become unable to convey his or her own treatment preferences (American College of Physicians 1992). To ensure that dying people have a greater say in their care, Congress passed the Patient Self-Determination Act (PSDA) in 1990. Under this law, federally funded health care providers are required to give patients information that helps them to execute a living will and to legally appoint a surrogate, known as a durable power of attorney for health care (DPAHC), to oversee their care in the event of decisional incapacitation.

A concern of patients and care providers is that surrogates are effective in accurately conveying the patient's 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 the surrogate makes the medical decision that the patient would have made if he or she were competent to do so. In practice, however, surrogates often do not choose the treatment the dying person 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 percent of the time (Shalowitz, Garrett-Mayer, and Wendler 2006). Surrogates often mistake their own preferences for those of the patient: surrogates' own

preferences account for more of the variance in their surrogate decisions than do the patients' actual preferences (Bar-Tal, Barnoy, and Zisser 2005; Fagerlin et al. 2001; Pruchno et al. 2005).

Study Aims

Our goal is to explore demographic and social factors that affect a surrogate's proneness to error and tendency to rely on their own preferences when attempting to make a substituted judgment for their spouse. The majority of married older adults who name a DPAHC name their spouse (Carr and Khodyakov 2007a, 2007b; Hopp 2000). When individuals do not legally appoint a surrogate, the appointment may occur by default. In most states, if a married patient does not have a DPAHC, then decision-making responsibility falls to the spouse (American Medical Directors Association 2003). We replicate the findings of surrogate error and reliance on own preferences in our full sample of white married surrogates¹ in their mid-60s using structural equation modeling. We then test whether surrogates' gender, surrogates' status as DPAHC, spouses' discussions of preferences with the surrogate, and spouses' health status affect these reporting errors.

Although prior studies have documented the effects of independent variables on surrogate errors, our large sample of surrogate/spouse dyads allows us to examine subgroup differences in surrogate performance. Prior studies have used samples too small to permit statistical detection of moderating effects, and they have lacked variation on characteristics of interest, such as surrogate gender. If surrogates do differ systematically in their ability to accurately convey a spouse's health preferences, this information can aid health care providers. Providers could better advise patients who are choosing surrogates, and know ahead of time which surrogates may need assistance in fulfilling the patient's wishes.

Our study builds on prior research in three additional ways. First, we investigate 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. While some individuals may prefer to articulate their preferences when they are near to death, others may prefer to articulate their preferences while healthy out of concern that fear, depression, or physical discomfort may unduly color preferences articulated while terminally ill (Ditto, Hawkins, and Pizarro 2005). For this reason, 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 a loved one.

Second, participants in our study were recruited by sociologists for involvement in a multi-topic longitudinal study, whereas potential participants in prior studies 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 this knowledge. Ditto and colleagues (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 employ structural equation models (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 is a method uniquely suited to our research question because it allows us to (a) estimate measurement error (i.e., we need not assume that our measures have perfect reliability), and (b) distinguish between effects of

surrogates' own preferences and spouses' own preferences on the surrogates' proxy reports (i.e., estimate the degree to which surrogate reports are 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 suggest that surrogates act on the principle of *assumed similarity* (Cronbach 1955; Kenny and Acitelli 2001).² That is, a surrogate may assume that self and partner hold similar preferences, and thus allow their own preferences to guide assessment of partner preferences. At face value, 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. A recent study of DPAHC appointments among healthy older adults revealed that the vast majority appoint either their spouse or adult child (Carr and Khodyakov 2007b). Indeed, assumed similarity may pose no problem when the surrogate and patient do have the same preferences for care (Fagerlin et al. 2001; Hoch 1987). But although 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 one another (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/she is a good person, that he/she is like the self), 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 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. Those 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 decision for themselves, and then account for differences between self and other (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 a loved one (Loewenstein 2005).

Moderating Influences on Surrogate Decision-Making

Assumed similarity and projection bias are considered to be pervasive, yet not immutable nor universal, cognitive processes (Cronbach 1955). Hoch (1987) found considerable individual differences in how unique or similar 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 explore the extent to which four factors affect one’s tendency to make errors in reporting their 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 marital roles and contact with the health care system.

For example, women are more knowledgeable about illness and treatment than are men, and have more frequent contact with the health care system (Beier and Ackerman 2003; Green and Pope 1999). Women live longer than men, and may expect to see their husbands become incapacitated and ultimately die. Anticipating that they will need to provide care for a dying husband at some point, women may collect information about their husbands' preferences. Further, women traditionally do most of the care work in a family, and may have direct experience with caring for dying relatives. Terry et al. (1999) speculate that men trust female surrogates more than male surrogates. However, the single study to date that found significant gender differences found that female surrogates relied on their own preferences to a *greater* degree than male surrogates did (Bar-Tal et al. 2005). In that study, women's perceived knowledge of the illness (cancer) was greater than men's perceived knowledge, a perception that was probably correct (Beier and Ackerman 2003). Perhaps these women incorrectly decided that their knowledge about the illness meant that they also knew what was best for their husbands. We aim to expand on prior studies by addressing the question:

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 way of reducing the use of assumed similarity and projection bias may be to ensure that surrogates have access to information about patient 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 naming a DPAHC is to have a surrogate who will make decisions that preserve a patient's autonomy and well-being. A rational individual will select the person he or she believes most capable of the job. However, not all individuals value substituted judgment: some individuals do

appoint a DPAHC so that their preferences are followed strictly, but others appoint a DPAHC because they would prefer not to make their own treatment decisions (e.g., Terry et al. 1999).

Therefore, DPAHCs may or may not be better at substituted judgment than others. We address:

Question 2: Are individuals who are their spouse's legally appointed DPAHC accurate surrogates, and do they rely less on their own preferences than either individuals whose spouses have appointed someone else as DPAHC or individuals whose spouses have not appointed a DPAHC?³

Prior studies reveal 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 and colleagues (2001) found that surrogates who participated in a discussion intervention with patients were no better at identifying patient preferences than was a control group of surrogates who did not hold discussions with patients. However, a discussion intervention targeted at patients about to undergo major surgery, facilitated by a health care provider, showed success (Song et al. 2005). We ask:

Question 3: Does discussion of end-of-life treatment preferences with surrogates increase the accuracy of proxy reports or decrease the surrogates' reliance on their own preferences?

Finally, in contexts where 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 a dying spouse. Alternatively, healthy couples may be willing to think about end-of-life issues because they are not immediately threatened, whereas couples facing a serious illness may enter a particularly acute state of death denial. Couples facing an illness 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). We explore:

Question 4: Are individuals who have a spouse with a serious illness more accurate surrogates who rely less on their own preferences than individuals whose spouses have no serious illness?

Our research questions are predicated on the assumption that surrogate error and assumed similarity/projection bias exist in our full sample. They do; we show this replication below. A sizeable minority of our surrogates' reports of their spouses' end-of-life preferences are erroneous, and surrogates' reports of their spouses' end-of-life preferences depend upon 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.⁴ 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 interview. 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 focuses 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. Bureau of the Census 2004). In 2003, 77.3% of American men aged 55 to 64, and 64.4% of American women aged 55 to 64 were married (U. S. Bureau of the Census 2003). In the same year, 72.6% of married American men and 74.5% of married American women aged 55-64 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 are 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.

Gender. Graduates 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 any DPAHC, those who had appointed someone other than the graduate as DPAHC, and those who had appointed the graduate as DPAHC.

Discussed preferences with graduate. 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., graduate and children) with whom they had discussions. Spouses were separated into three groups: those who had discussed with the graduate, those who had discussed with someone other than the graduate, and those who reported no discussions.

Serious illness. Spouses were asked whether a doctor had ever told them that they have 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 a health care provider, we focus on the four major groups of illnesses that are documented as the leading causes of death among older American adults 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 significantly from results obtained using listwise deletion. (Materials sufficient for replicating results reported in this article will be deposited with the ICPSR Publications-Related Archive.)

Statistical approach. We used structural equation modeling (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

are indicators of continuous, bivariate normal variates. Respondents were forced to choose “stop” or “continue,” but we assume that true preferences vary along a continuum reflecting strength of agreement.⁵ Maximum likelihood estimation yields biased estimates and incorrect goodness-of-fit values when ordinal or non-normal 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 are:

$$Y_{PG} = \eta_1 + \varepsilon_1$$

$$Y_{DG} = \eta_1 + \varepsilon_2$$

$$Y_{P'S} = \lambda_{31}\eta_1 + \lambda_{32}\eta_2 + \varepsilon_3$$

$$Y_{D'S} = \lambda_{41}\eta_1 + \lambda_{42}\eta_2 + \varepsilon_4$$

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

$$Y_{DS} = \eta_2 + \varepsilon_6$$

where η_1 = graduate preferences (latent); η_2 = spouse preferences (latent); Y_{PG} = graduate response for self, pain condition; Y_{DIG} = graduate response for self, cognitive impairment condition; $Y_{P'S}$ = graduate report on spouse preference, pain condition; $Y_{D'S}$ = graduate report on spouse preference, cognitive impairment condition; Y_{PS} = spouse response for self, pain condition; Y_{DIS} = spouse response for self, cognitive impairment condition; the λ_{ij} are coefficients to be estimated, and the ε_i are random errors. In addition to the λ_{ij} , the parameters of the model are the variances and covariances of the latent preferences (Ψ_j) and the variances and covariances of the errors in variables (Θ_i^ε).

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

[Figure 1 about here.]

In order 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; this suggests that graduates tend not to distinguish between the pain and cognitive impairment scenarios. The errors in scenario-specific self- and proxy-reports by the graduate also are correlated. That is, graduates’ reports of their own preferences and reports of their spouses’ preferences under each scenario are even more similar than would be expected from the similarity in graduates’ and spouses’ true (latent) preferences and the general tendency of graduates’ proxy reports to resemble their own preferences.

The model equates each of the loadings (λ_{ij}) and error variances (Θ_i^e) pertaining to reports under the two scenarios by the same graduate about the same spouse because there were negligible variations in these parameters when they were allowed to differ. Although there are only two indicators of spouses’ preferences, the parameters of the model are all identified. They would remain identified had we not initially equated selected loadings and error variances.

Our model assumes that preferences may be reported with error. In the clinical setting, one’s stated preference is taken at face value, and is presumed to be an accurate statement of the patient’s own beliefs. In the context of a survey, however, it is plausible to assume that respondents make mistakes when answering questions or that they simply offer an opinion because they have been asked to do so (Schuman and Presser 1980; Schaeffer and Presser 2003).

Even survey respondents' repeated self-reports of clearly objective, unchanging social and economic characteristics, like years of schooling completed, have been found to vary across survey waves (Bielby, Hauser, and Featherman 1977). Thus, we interpret our latent variables simply as referring to what is common in the self-reported preferences of graduates and their spouses under the two hypothetical conditions, leaving the "errors in variables" to refer to the combination of what is specific to each hypothetical condition and reporting error. Our major findings are unchanged under this interpretation, yet we think, based on other evidence, that statements of preference are often unreliable as, for example, in the case of aspirations for post-secondary schooling and occupational choice (Hauser, Tsai, and Sewell 1983). Indeed, in the course of an actual medical decision-making process, patients' expressed preferences are among the factors determining care, but preferences are unstable across time and vary with circumstances (Ditto et al. 2005; Ditto et al. 2006; Kressel and Chapman 2007; Loewenstein 2005).

Replication. Our research questions are predicated on the assumption that surrogate error and assumed similarity/projection bias exist in our full sample. These issues are tested through comparison of the baseline model to models that equate select lambda paths (λ_{ij}) and error variances (Θ_i^e). There is one test for the existence of surrogate error. It equates λ_{52} to λ_{32} , θ_{55}^e to θ_{33}^e , λ_{62} to λ_{42} , and θ_{66}^e to θ_{44}^e . If we accept this model (i.e., prefer it to the baseline model that does not equate lambdas and error variances, we conclude that surrogates' reports of spouses' preferences are not as dependent upon spouses' true (latent) preferences as are spouses' reports of their own preferences. In other words, there is more error in proxy reports than in self reports. There are two tests for assumed similarity/projection bias. The first test equates λ_{11} to λ_{31} , θ_{11}^e to θ_{33}^e , λ_{21} to λ_{41} , and θ_{22}^e to θ_{44}^e . If we accept this model, we conclude that the proxy reports

depend on the graduates' true preferences in exactly the same way and to the same degree as the graduates' own reported preferences depend on their true preferences. The second test equates λ_{31} to λ_{32} and λ_{41} to λ_{42} . If we accept this model, we conclude that the proxy reports of spouses' preferences depend *more* on the true preferences of graduates than on the true preferences of spouses.

Assessment of research questions. The research questions are tested through models that equate groups (e.g., male graduates and female graduates; spouses who had no discussions, spouses who had discussions with someone other than the graduate, and spouses who had discussions with the graduate). 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.⁶ 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 accept or reject models on the basis of fit statistics. In addition to the model's chi-square and degrees of freedom, the fit statistics that concern us are the Bayesian Information Criterion (BIC) and the root mean square error of approximation (RMSEA). A difference in BIC ($\chi^2 - df \times \ln(N)$) of 5 or more between models provides evidence for the superior fit of the model with the more negative value (Raftery 1995). An RMSEA ($\sqrt{((\chi^2 - df) / (N - 1)) / df}$) of 0.05 or less indicates very good fit (Loehlin 2004).

RESULTS

Surrogate Characteristics

Our analysis provides little information about the personal characteristics of the surrogates; therefore, we have included a brief description here. Nearly all graduates were born in 1939. Graduates had appointed the spouse as DPAHC in 39.0% of cases, and had discussed their end-of-life treatment preferences with the spouse in 70.3% of cases. One-third of graduates 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. A quarter of graduates had experienced the death of a parent in the last ten years.

Spouse Characteristics

Descriptive statistics for all variables used in the analysis are presented in Table 1. The average ages of the graduates' wives and husbands in our sample were 61.5 years ($SD = 4.2$ years; interquartile range 60-64 years) and 66.9 years ($SD = 3.9$ years; interquartile range 65-69 years), respectively. Spouses of male and female graduates were of substantially different ages because of the gender differential in age at marriage in the late 1950s and early 1960s. Further, male graduates are 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 the graduate as DPAHC in 29.7% of cases, and had discussed their end-of-life treatment preferences with the graduate 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.

[Table 1 about here.]

Treatment Preferences and Proxy Reports

In the case of physical pain, 78.3% of graduates and 79.9% of spouses reported that they would want to stop all life-prolonging treatment for themselves, and 80.2% of graduates reported that their spouses would want all life-prolonging treatment stopped. In the case of cognitive impairment, 91.8% of graduates and 92.5% of spouses reported that they would want to stop all life-prolonging treatment for themselves, and 90.7% of graduates reported that their spouses would want all life-prolonging treatment stopped.

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

Structural Equation Models: Replication

Baseline model. Parameter estimates for the baseline model are presented in Table 2 and Figure 2. The estimates of λ_{ij} are relative slopes; thus, the regression of graduates' proxy reports on their true preferences is 0.870 times as steep as the regression of their self-reports on their true reports. The correspondence between self-reports and true preferences is less than perfect--the standardized values of the λ_{ij} show that the correlation between graduates' self reports and their true preferences is 0.852. The correlation between graduates' proxy reports and their true preferences is 0.742 (0.870 times as large as the correlation between graduates' self-reports and their true preferences). That is, the correlation between a graduate's true preference and their

expressed self-preference is almost as large as that between their true preference and their report of their spouse's preference.

[Table 2 and Figure 2 about here.]

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' reports of their spouses' end-of-life preferences are often erroneous. A model that equated λ_{52} to λ_{32} , θ_{55}^e to θ_{33}^e , λ_{62} to λ_{42} , and θ_{66}^e to θ_{44}^e fit significantly less well than the baseline model, implying that surrogates' reports of spouses' preferences are not as dependent upon spouses' true preferences as are spouses' reports of their *own* preferences.⁷

In other words, there is more error in proxy reports than in self reports. In the baseline model, true preferences explain between 67% ($0.819^2 = 0.671$) and 73% ($0.852^2 = 0.726$) of the variance in the each self-reported preference. Even when we take the proxy reports to depend both on the true preferences of the graduate and the spouse, the model explains only 63% ($1 - 0.374 = 0.626$) of the variance in the items. Spouses (and graduates) reported their own preferences with error, but surrogates and spouses together predicted proxy reports of spouses' preferences with even more error. 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.

Assumed similarity/projection bias. We found that surrogates' reports of their spouses' end-of-life preferences depended upon preferences for their own care, in addition to their spouses' actual preferences. Graduates 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 λ_{11} to λ_{31} , θ_{11}^e to θ_{33}^e , λ_{21} to λ_{41} , and θ_{22}^e to

θ_{44}^e fit significantly better than the baseline model, implying that the proxy reports depend on the graduates' true preferences in exactly the same way and to the same degree as the graduates' own reported preferences depend on their true preferences. A model that equated λ_{31} to λ_{32} and λ_{41} to λ_{42} also fit significantly better than the baseline model, implying that the proxy reports of spouses' preferences depended more on the true preferences of graduates than on the true preferences of spouses.

[Table 3 about here.]

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 graduates did not behave differently as surrogates (Question 1). Surrogates who were the spouse's DPAHC did not give more accurate proxy reports than surrogates who were not the spouse's DPAHC or who were married to spouses who had no DPAHC, and DPAHC surrogates did not rely less on their own preferences when proxy reporting (Question 2). Discussion of end-of-life treatment preferences with the graduate did not increase the accuracy of proxy reports or decrease the surrogates' reliance on their own preferences (Question 3). Surrogates whose spouses had a serious illness did not give more accurate proxy reports than surrogates whose spouses did not have a serious illness, nor did the former group rely less than the latter group on their own preferences when proxy reporting (Question 4).

DISCUSSION

We used structural equation modeling 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 sizeable minority of cases. Surrogates relied heavily on their own preferences when reporting spousal preferences. Similar patterns emerged among male and female surrogates, surrogates who were and were not their spouse's DPAHC, surrogates whose spouses had and had not discussed their end-of-life wishes with them, and surrogates whose spouses did and did not have a 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.

Social Psychological Perspectives on Surrogate Decision-Making

Our findings indicate that assumed similarity and/or projection bias are occurring in our sample. We do not have sufficient information to ascertain definitively which phenomenon is occurring, but they are not mutually exclusive. VanBoven and Loewenstein (2003) find that surrogates first decide what they would do for themselves, and then consider differences between themselves and the target of the decision. Projection bias affects the first stage of this process; assumed similarity, the second. Therefore, we discuss both phenomena.

Own preferences. We find that DPAHC appointment and preference discussions do not improve surrogate judgment, and we speculate that the reason may be volatility of *surrogate* preferences for self. Ditto and colleagues (2003) found that within two years of initially articulating their preferences regarding receipt of life-sustaining treatment, a full 25 percent of

participants had altered their preferences. Further, some preferences appeared stable after two years, but in fact participants had changed their minds between baseline and one year follow-up and then reverted between one and two years. Preferences change with health status: as older adults become sicker, their preferences tend to change from treatments that increase length of life to treatments that enhance quality of life (Ditto et al. 2006; Fried et al. 2007; Voogt et al. 2005). In such cases projection bias is occurring—healthy people are unable to accurately predict what their future ill selves would want. According to this perspective, if people are wrong about their own preferences, they will be wrong about others' preferences. 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 be out of date.

Differences between surrogate and patient. First, we consider situations in which there *are not* differences between the surrogate and patient with regard to end-of-life preferences. Spouses, especially older spouses in long-term marriages, often share attitudes, values, health behaviors, and social environment (Caspi and Herbener 1990). 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. Vig and collaborators (2006) conducted qualitative interviews and found that surrogates often are aware of their use of assumed similarity, and sometimes prefer it to the information gleaned from conversations or living wills. Fagerlin and colleagues (2001) speculate that assumed similarity might be a preferable strategy to acting on more specific information, such as that gathered from a discussion with the patient, because the heuristic simplifies the cognitive task. In a non-health-related prediction task, Hoch (1987) found that a substantial minority of participants would have

made more accurate predictions if they had only assumed similarity and not tried to account for other information at all.

Second, we consider situations in which there *are* differences between the surrogate and patient with regard to end-of-life preferences. In these cases, assumed similarity can lead to problematic health care decisions. 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 do (Bookwala et al. 2001; Carr and Moorman 2007; Covinsky et al. 2000). In the present study, we are considering heterosexual married couples, which means that surrogate and spouse differ in gender and therefore presumably on end-of-life preferences. We find that this difference results in problematic health care decisions for both men and women: male surrogates are as poor at predicting their wives' preferences as female surrogates are at predicting their husbands' preferences.

As noted above, 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). In the present study, ill spouses did not usually have ill surrogates: in only 11.3% of couples did both partners have a serious illness. As with gender differences, health differences result in problematic health care decisions for unhealthy spouses. However, surrogates were similarly poor at predicting the preferences of healthy spouses—partners of healthy spouses are probably uninformed about their spouses' preferences, and partners of sick spouses probably incorrectly assume similarity.

Moderating Influences on Surrogate Decision-Making

None of the moderating influences we tested in our sample were significant. Perhaps they would be in a different sample—our surrogate/spouse dyads were similar in age, race, educational attainment, and many other characteristics. Moderating influences may help or hurt

surrogates when the surrogate and patient are quite different from one another. Perhaps other moderating influences are at work. For instance, individual level characteristics such as cognitive functioning, or dyadic characteristics such as marital quality, might have conditioned the findings reported here. A third explanation is that the processes reflected here -- assumed similarity and projection bias -- could be psychological “universals,” consistent with the assessment of other cognitive processing strategies, such as the “fundamental attribution error” (Ross 1977). Indeed, Krueger and Clement (1994) conclude that assumed similarity is “ineradicable.” If the latter interpretation is accurate, then it suggests important directions for future research and for health care practice.

First, our study suggests that in order to obtain a correct substituted judgment, a patient should select a surrogate who is as similar to him or her as possible. A person of the same gender, with the same health condition, of the same social background, etc. would be expected to have the same care preferences. Any negative influence of assumed similarity and projection bias would be reduced. Future research can establish whether this course of action results in surrogate accuracy.

Second, there are means of decision-making apart from the standard of substituted judgment. The standard of best interests dictates that the surrogate chooses the treatment he or she believes to be in the patient’s best interests. For some older patients, the latter standard is desirable; they may prefer that their family members’ wishes are followed, and that their own preferences are overruled in case of conflict (Puchalski et al. 2000; Sehgal et al. 1992; Terry et al. 1999). Sulmasy and colleagues (2007) found that terminally ill patients preferred a combination of substituted judgment and best interests—they wished to share decision-making with their loved ones. Under the standard of best interests, assumed similarity and projection bias are less

problematic because accuracy is not the goal. “Best interests” are difficult to define (Kopelman 2007), but substituted judgment is difficult to achieve. The standard of best interests should be given more serious consideration in medical circles, particularly for patients who are not concerned that their wishes be strictly followed.

Limitations

Our study has several limitations. First, the WLS is not representative of the general 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 are married (and most in long-term marriages), and nearly all respondents are non-Hispanic whites. All surrogates (and nearly all spouses) are high school graduates, and educational attainment may be associated with the content of end-of-life preferences and/or with ability to report a spouse’s preferences. Pruchno and colleagues (2006) found that education affected patient preferences, and race affected spouses’ substituted judgments.

Second, the WLS treatment preference scenarios are less specific than the scenarios used in other studies of health care proxies: 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 towards 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 - 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). Many older persons may think about planning in this way. 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).

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? Future studies should further explore the conditions under which respondents say they do not know their own or their spouse’s end-of-life treatment preferences.

Conclusion

If the patterns documented in our study hold true in actual end-of-life situations, the consequences are potentially serious. If spouses do not hold similar preferences yet one spouse uses assumed similarity/projection bias as a decision-making heuristic, the dying spouse is unlikely to receive the treatment he or she desires. If this mistake leads to problematic or unwanted treatments, or if the healthy spouse realizes his or her error, the grieving process may be particularly distressing (Prigerson et al. 2003). Further conceptual and applied work is necessary so that spouses parted by death need not suffer the costs of preventable errors.

FOOTNOTES

¹ As described below, our sample consists of people who are in relatively good health and surrogates who are all high school graduates. When referring to our participants in the remainder of this paper, we call the partner who served as surrogate either “surrogate” or “graduate,” and the partner who served as patient “spouse.” 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 the spouse has appointed someone other than the graduate as DPAHC, the graduate will not be called upon to make decisions should the spouse become incapacitated. We retain this group as an analytic category to shed light on DPAHC choices and surrogate behavior. For example, retention of this category enables us to explore whether these graduates are particularly prone to err.

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

⁵ Where 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., λ_{ij}) were equated and others (e.g., ψ_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 are 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). Thus, we have empirical support from these data for our contention that preferences are reported with error.

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

| Variable | Total Sample |
|---|--------------|
| Graduate in pain: stop treatment | .783 |
| Graduate with cognitive impairment: stop treatment | .918 |
| Graduate: stop treatment for spouse in pain | .802 |
| Graduate: stop treatment for spouse with cognitive impairment | .907 |
| Spouse in pain: stop treatment | .799 |
| Spouse with cognitive impairment: stop treatment | .925 |
| Graduate is spouse's DPAHC | .297 |
| Other is spouse's DPAHC | .270 |
| Spouse has no DPAHC | .433 |
| Spouse discussed preferences with graduate | .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 |
| N | 2750 |

^a Reported prior to listwise deletion.

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

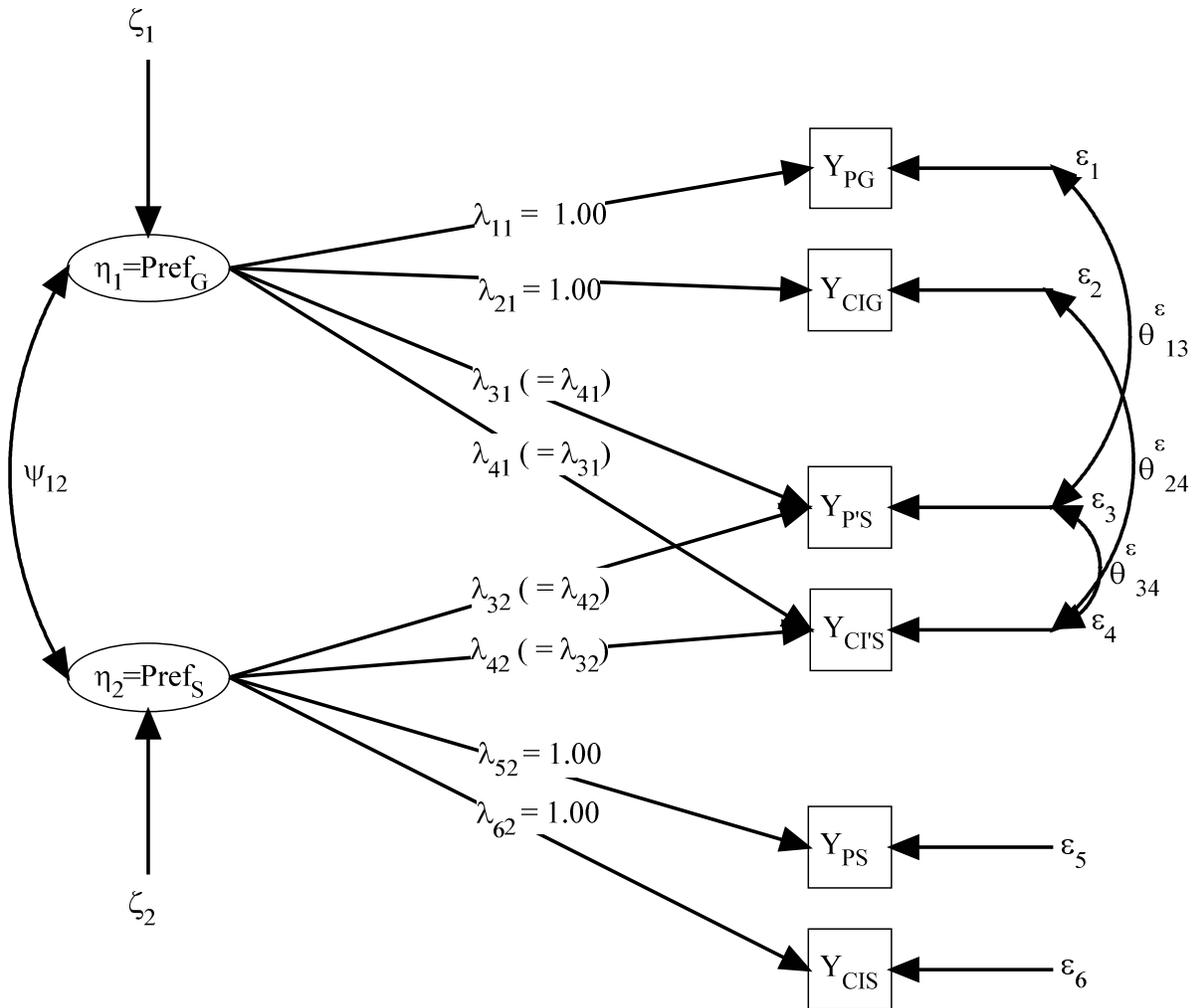
| Parameter | Estimate | Standard Error | Standardized Estimate |
|-----------------|----------|----------------|-----------------------|
| Ψ_{11} | 0.726 | 0.032 | 1.000 |
| Ψ_{22} | 0.671 | 0.036 | 1.000 |
| Ψ_{12} | 0.199 | 0.038 | 0.285 |
| λ_{11} | 1.000 | ----- | 0.852 |
| λ_{21} | 1.000 | ----- | 0.852 |
| λ_{31} | 0.870 | 0.034 | 0.742 |
| λ_{41} | 0.870 | 0.034 | 0.742 |
| λ_{32} | 0.167 | 0.039 | 0.137 |
| λ_{42} | 0.167 | 0.039 | 0.137 |
| λ_{52} | 1.000 | ----- | 0.819 |
| λ_{62} | 1.000 | ----- | 0.819 |
| θ_{11}^e | 0.274 | 0.039 | 0.274 |
| θ_{22}^e | 0.274 | 0.039 | 0.274 |
| θ_{33}^e | 0.374 | 0.047 | 0.374 |
| θ_{44}^e | 0.374 | 0.047 | 0.374 |
| θ_{55}^e | 0.329 | 0.043 | 0.329 |
| θ_{66}^e | 0.329 | 0.043 | 0.329 |
| θ_{13}^e | 0.267 | 0.031 | 0.267 |
| θ_{24}^e | 0.286 | 0.028 | 0.286 |
| θ_{34}^e | 0.154 | 0.033 | 0.154 |

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

| | χ^2 | <i>df</i> | BIC | RMSEA |
|--|----------|-----------|--------|-------|
| <i>Single Group Models</i> | | | | |
| Baseline | 12.3 | 7 | -41.1 | 0.019 |
| Surrogate Error | 134.2 | 11 | 50.3 | 0.074 |
| $(\lambda_{52}=\lambda_{32}, \theta_{55}^e=\theta_{33}^e, \lambda_{62}=\lambda_{42}, \theta_{66}^e=\theta_{44}^e)$ | | | | |
| Difference from Baseline | 121.9 | 4 | 91.4 | ---- |
| Assumed Similarity/Projection Bias Test 1 | 28.1 | 10 | -48.1 | 0.030 |
| $(\lambda_{11}=\lambda_{31}, \theta_{11}^e=\theta_{33}^e, \lambda_{21}=\lambda_{41}, \theta_{22}^e=\theta_{44}^e)$ | | | | |
| Difference from Baseline | 15.8 | 3 | 7.0 | ---- |
| Assumed Similarity/Projection Bias Test 1 | 75.5 | 8 | 14.5 | 0.064 |
| $(\lambda_{31}=\lambda_{32}; \lambda_{41}=\lambda_{42})$ | | | | |
| Difference from Baseline | 12.1 | 1 | 55.6 | ---- |
| <i>Multi-Group Models</i> | | | | |
| 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 | ---- |

| Table 3 (<i>cont'd</i>) | χ^2 | <i>df</i> | BIC | RMSEA |
|--|----------|-----------|--------|-------|
| 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 | ---- |

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



Pref_G : Preferences, graduate (latent)

Pref_S : Preferences, spouse (latent)

Y_{PG} : Graduate response for self, pain condition

Y_{CIG} : Graduate response for self, cognitive impairment condition

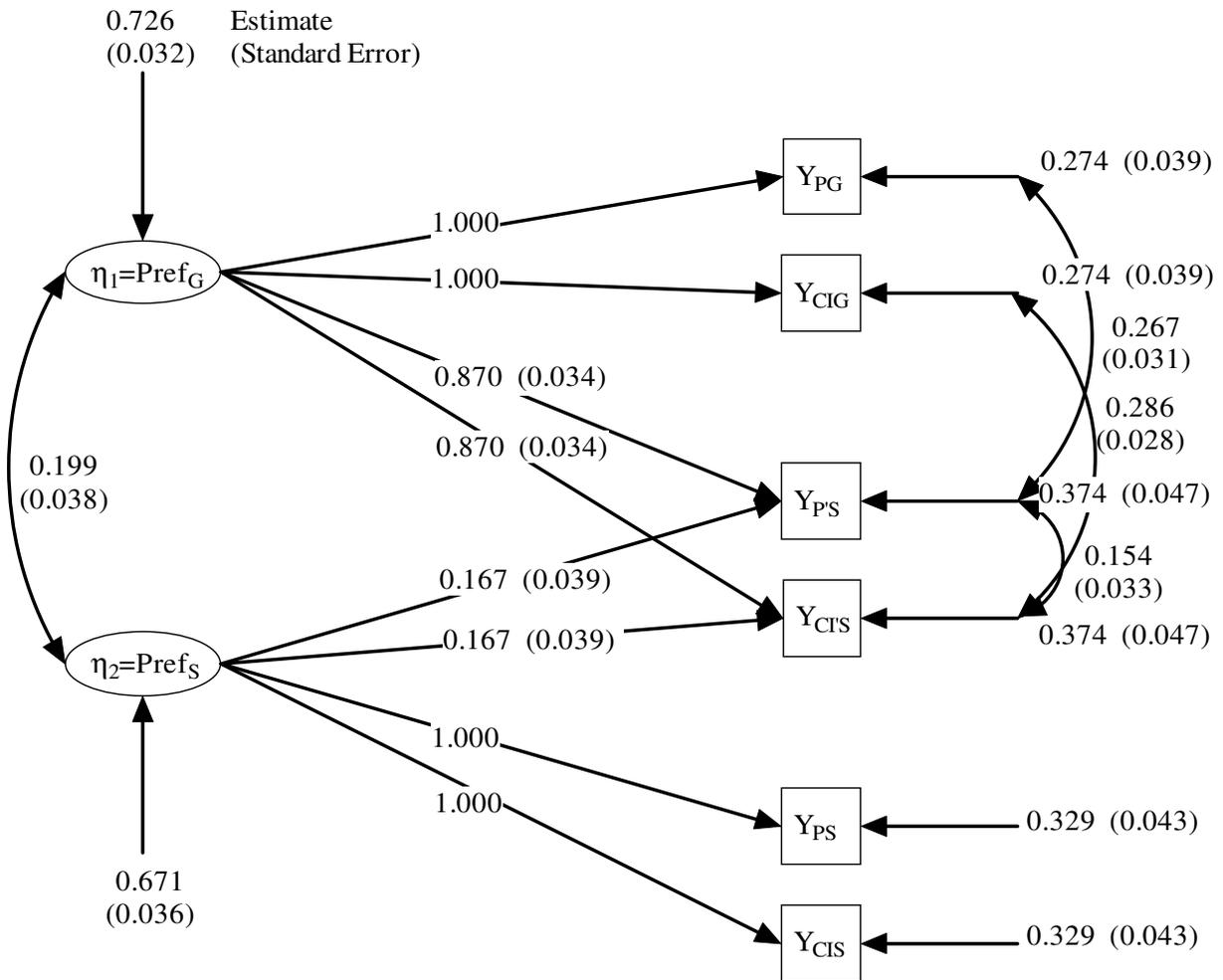
$Y_{P'S}$: Graduate report on spouse preference, pain condition

$Y_{C'I'S}$: Graduate report on spouse preference, cognitive impairment condition

Y_{PS} : Spouse response for self, pain condition

Y_{CIS} : Spouse response for self, cognitive impairment condition

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



Pref_G : Preferences, graduate (latent)

Pref_S : Preferences, spouse (latent)

Y_{PG} : Graduate response for self, pain condition

Y_{CIG} : Graduate response for self, cognitive impairment condition

Y_{PS} : Graduate report on spouse preference, pain condition

Y_{CIS} : Graduate report on spouse preference, cognitive impairment condition

Y_{PS} : Spouse response for self, pain condition

Y_{CIS} : Spouse response for self, cognitive impairment condition

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