Journal of Gerontology: SOCIAL SCIENCES
2008, Vol. 63B, No. 2, S81–S91

Stability and Change in Patient Preferences and Spouse Substituted Judgments Regarding Dialysis Continuation

Rachel A. Pruchno,[1] Michael J. Rovine,[2] Francine Cartwright,[1] and Maureen Wilson-Genderson[1]

[1]New Jersey Institute for Successful Aging, University of Medicine & Dentistry of New Jersey, Stratford.
[2]Department of Human Development and Family Studies, Pennsylvania State University, University Park.

Objectives. The objective of this study was to examine whether some treatment preferences are more stable than others, how patient preferences and substituted judgments change over time, and whether some people's decisions are more stable than others'.

Methods. Hypothetical scenarios elicited preferences for dialysis continuation under various health conditions at two points in time. Predictors included initial treatment preference, age, gender, race, education, length of time on dialysis, presence of a living will, and change in patient's health.

Results. Some treatment preferences were more stable than others, and the cause of this stability varied across treatment preferences. Similarity between patient preferences and spouse substituted judgments within couples was low and varied as a function of hypothetical condition. The strongest predictor of treatment preferences at follow-up was initial preference. Age, gender, race, education, length of time on dialysis, presence of a living will, and change in patient's health had limited effects on changes to treatment preferences.

Discussion. There is a great deal more stability than change in patient preferences and substituted judgments regarding continuation of dialysis over the course of 1 year. This suggests that if patients have previously expressed preferences it is possible for this to maintain their voice in end-of-life decisions when the patients themselves are unable to express their wishes.

***Key Words*:** Dialysis—Patient preferences.

MAINTAINING the patient's voice when his or her capacity to participate in end-of-life decisions is compromised is the driving force guiding policies regarding advance directives and substituted judgment. Effective advance directives and accurate substituted judgments assume that a proxy is accurately able to represent the patient's most recent preferences, that previously stated preferences do not change as a function of time or change in health condition, and that patient preferences shift in predictable ways. There is little information, however, regarding the extent to which patient preferences change over time, and even less is known about the extent to which substituted judgments change. This article examines whether the preferences for continuing dialysis treatment of patients with end-stage renal disease (ESRD) and the substituted judgments of their spouses change over a 1-year period, questions whether patient preferences and substituted judgments change in similar ways over time, and identifies whether some people's treatment preferences are more stable than other's.

When patients lose decision-making capacity and there are no clear advance directives, health care providers typically rely on surrogate decision makers to make health care decisions. The President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (1983) endorsed the principle of *substituted judgment*, which calls for surrogates to make decisions in a manner that approximates the patient's wishes. The principle of substituted judgment assumes that surrogates understand patient preferences and correctly represent the wishes of the patient. Underlying accurate substituted judgment, however, is the assumption either that patient preferences are stable over time or that surrogates understand the most recent and salient preferences of the patient.

Research is clear, however, that, when faced with hypothetical decisions about life-sustaining medical care, family members are not able to predict a patient's preferences at levels of accuracy beyond those expected by chance alone (Ditto et al., 2001; Fried, Bradley, & Towle, 2003; Gerety, Chiodo, Kanten, Tuley, & Cornell, 1993; Hare, Pratt, & Nelson, 1992; Suhl, Simons, Reedy, & Garrick, 1994; Sulmasy et al., 1998; Terry et al., 1999). Although a recent meta-analysis of the accuracy of surrogate decision makers by Shalowitz, Garrett-Mayer, and Wendler (2006) concluded that overall surrogates predicted patients' treatment preferences with 68% accuracy, this average figure is confounded by a host of salient design issues. Family surrogates consistently overestimate the frequency with which patients would like to receive treatment (Uhlmann, Pearlman, & Kain, 1988). They also project their own end-of-life preferences onto the patient. As such, the decisions that family members make often bear little resemblance to those that the patient would make (Ditto et al., 2001; Pruchno, Lemay, Feild, & Levinsky, 2005, 2006).

Empirical evidence for the stability of patient preferences is mixed, with stability varying as a function of the health conditions of people participating, the medical treatment of interest, and the time interval between assessments (Blank, Robison, Prigerson, & Schwartz, 2001; Danis, Garrett, Harris, & Patrick, 1994; Ditto et al., 2003; Emanuel, Emanuel, Stoeckle, Hummel, & Barry, 1994; Everhart & Pearlman, 1990; Fried et al., 2006; Kohut et al., 1997; Rosenfeld et al., 1996; Weissman et al., 1999). Everhart and Pearlman, for example, in a study of Veteran's Affairs patients, found no significant differences in the life-sustaining treatment preferences expressed by patients at the time of transfer from the intensive care unit and 1 month later, leading them to conclude that patient preferences are stable over 1 month despite change in health and mood. Similarly, Emanuel and colleagues found that stability of preferences was moderately high among patients as well as members of the public. However, in a study of preference for treatment desired among persons with AIDS, Weissman and associates found that approximately 25% of the respondents changed their minds about life-sustaining care during a 4-month period.

Factors that increase the likelihood that patient preferences remain stable include greater education (Emanuel et al., 1994; Weissman et al., 1999) and the presence of an advance directive (Danis et al., 1994; Emanuel et al., 1994; Weissman et al., 1999). Initial treatment preference also affects stability, as Danis and colleagues found that the choice to forgo treatment was twice as stable over a 2-year period as was the choice to receive treatment. Similarly, Rosenfeld and associates (1996) found that hypothetical preference for cardiopulmonary resuscitation was more stable over a 2-month period for patients who initially preferred cardiopulmonary resuscitation than for those who initially did not chose it. In a study of the stability of preferences for treatment among nursing home residents, Berger and Majerovitz (1998) reported that although most preferences were stable, when preference changes occurred they were toward less intervention. Weissman and colleagues found that of patients who initially desired cardiac resuscitation, 23% indicated the desire to forgo this treatment 4 months later. Of those who initially said they would decline cardiac resuscitation, 34% later said they would accept it.

Although researchers have examined the effects of changed health status on treatment preferences, empirical evidence regarding its impact is not clear. Danis and colleagues (1994), for example, found that people were more likely to want increased treatment at a later time if they had been hospitalized, had an accident, become more immobile, become more depressed, or had less social support. Weissman and associates (1999) found that patients whose desire for cardiac resuscitation increased over time had significantly lower functional ability and pain scores at baseline than other patients. They also had greater improvements in functional abilities over time than other patients.

Together these data suggest that the extent to which patient preferences for treatment remain stable is unclear, and that there are a host of factors responsible for whether preferences for treatment increase, decrease, or remain stable. The combination of questionable stability regarding preferences among patients and the inability of family members to render substitute judgments that accurately mirror the preferences of patients leaves unclear the way in which decisions should be made regarding end-of-life care. This issue is particularly salient for the approximately 300,000 people in the United States with ESRD who are treated with hemodialysis each year (U.S. Renal Data System, 2002). More than 90% of dialysis patients develop significant comorbid conditions, including diabetes, congestive heart failure, ischemic heart disease, peripheral vascular disease, and cerebrovascular disease (Merkus et al., 1999; Shidler, 1998; Valderrabano, Jofre, & Lopez-Gomez, 2001), and close to half of dialysis patients lose decision-making capacity near the end of life due to dementia or other organic brain syndromes (Neu & Kjellstrand, 1986). Moreover decisions to withdraw dialysis precede 25% of the deaths of patients with ESRD (Cohen, Germain, & Poppel, 2003). Despite this, little information exists about the extent to which preferences to continue dialysis change over time (Holley, 2004; Holley et al., 1999; Sehgal et al., 1992; Sekkarie & Moss, 1998).

Although theory identifying variables that explain change and stability of end-of-life preferences is virtually nonexistent, the analyses that follow build on research by Ditto and colleagues (2003), who sought to explain the psychology behind treatment preference stability. Observing that much of the literature regarding treatment preferences had been conducted outside the field of psychology, Ditto and colleagues suggested that the focus on characterizing absolute stability (i.e., the probability of an individual stating the same preferences at two different points in time) and on drawing broad conclusions regarding the stability of preferences as a whole may not provide a wholly accurate perspective on treatment preferences. They suggested both the importance of examining directional trends in the desire for life-sustaining treatments over time and the salience of identifying characteristics of situations and of people that may moderate treatment preference stabilities. The analyses that follow focus on stability and change in patient preferences and spouse substituted judgments over time as they examine the extent to which individual and situational characteristics affect whether preferences for continuing dialysis increase, decrease, or remain stable over time. More specifically, our analyses addressed the following three major questions: (a) Are preferences to continue treatment more stable when some hypothetical health conditions are considered than when others are considered? (b) How do patient preferences and spouse substituted judgments change over time in relationship to one another? and (c) Are some people's treatment preferences more stable than other's?

Methods

A national sample of hemodialysis patients and their spouses was recruited primarily through advertisements in newspapers and newsletters, referral from staff at dialysis centers, and a one-time mailing to a random sample of patients receiving financial assistance for dialysis treatment from the Centers for Medicare & Medicaid Services. Participants came from 39 states, including those in the Northeast (29.4%), Midwest (28.4%), South (23.5%), and West (18.6%). More detailed information regarding recruitment is available in Feild, Pruchno, Bewley, Lemay, and Levinsky (2006). Samples obtained from various recruitment strategies did not significantly differ on any of the focal variables in the current research. Couples were eligible to participate if patients (a) were diagnosed with ESRD, (b) had

been treated with hemodialysis for at least 6 months, (c) were aged 55 or older, and (d) were married or partnered and had been living together for at least 5 years. English-language proficiency, intact cognitive function, and verbal communication abilities were additional inclusion criteria for both patients and spouses. Written individual informed consent was a prerequisite to enrollment.

Recruitment efforts yielded a sample of 315 couples. Patients and spouses participated in baseline individual structured telephone interviews. One year later 204 couples participated in a follow-up telephone interview. The 111 couples who did not participate in the follow-up interview included those in which the patient died (62.2%) or either the patient or spouse did not participate in the follow-up study because of lack of interest, health-related issues, or the fact that the couple was unable to be reached (37.8%). Analyses contrasting couples who completed the 1-year follow-up interview, those in which the patient died, and those who dropped out of the study revealed that there were no differences between the groups at baseline on patient age, $F(2) = 0.90$, $p = .41$; gender, $\chi^2(2) = 3.07$, $p = .22$; or time on hemodialysis, $F(2) = 0.02$, $p = .98$. Patients who dropped out of the study had lower levels of education than either those who continued in the study or those who died, $F(2) = 5.29$, $p = .01$. A significant race difference, $\chi^2(2) = 6.04$, $p = .05$, revealed that Black respondents were more likely to drop out of the study for reasons other than death than White respondents (26% vs 12%, respectively) and that Black patients were less likely to die (15% vs 23%) than White patients. Patients completing both interviews (61.1%) and those who died (73%) were more likely than those who dropped out (48%) to have completed a living will, $\chi^2(2) = 6.96$, $p = .05$.

The average age at baseline was 69.7 years for patients and 67.5 years for spouses. Most (75.0%) of the patients were male. Based on self-report, the patient sample included 86.8% Whites, 9.8% Blacks, and 3.5% who indicated other or mixed race. Spouses' race distribution was nearly identical. At the time of the baseline interview, patients had been receiving treatment for ESRD for a mean of 78.7 months ($SD = 70.5$). Patients had an average of 14.3 years of education (range 3–20). Couples had been married/partnered for an average of 41.8 years ($SD = 13.4$). The majority of patients (61.1%) indicated that they had a signed living will indicating their preferences for medical treatment should they become seriously ill and unable to speak for themselves.

Measures

Preferences for continuing dialysis treatment.—Researchers assessed patient preferences for dialysis continuation and spouse substituted judgments at both baseline and follow-up by presenting respondents with nine hypothetical medical conditions and then asking them about the likelihood that they (or the patient) would continue on dialysis given each situation. The scenarios included mild, moderate, and severe stroke; mild, moderate, and severe dementia; permanent coma; and terminal illness, both with and without pain. To ensure a common understanding of each condition, interviewers read descriptions developed by Singer and colleagues (1995) to the respondents prior to asking questions about their preferences for continuing dialysis. These descriptions emphasized the impact of the condition on the patient's functional abilities. For example, for the severe stroke scenario, patients were told the following:

> A stroke means that you would have damage to the brain causing permanent physical disability such as paralysis. You would have severe paralysis on one side of your body, be unable to walk and would need to be in a chair or bed. You would not have meaningful conversations, be unable to carry out routine daily activities, need a feeding tube for nourishment, and would be able to live at home with someone caring for you day and night; otherwise you would probably need to be cared for in a chronic care hospital.

Respondents were told to assume, for the purposes of the research study, that these problems would stay the same for the rest of their lives. After they heard each description, patients were asked the following question: "If you had [condition], how likely would you be to want to continue your dialysis treatments? Would you say: very likely (5), somewhat likely (4), not sure (3), somewhat unlikely (2), or very unlikely (1)?" Spouses were asked, "If patient had [condition], how likely do you believe he/she would be to want his/her dialysis treatments continued?" An identical response scale was used.

Independent variables.—Gender was coded as 0 for men, 1 for women. Race was coded as 0 for White, 1 for Black. People who had signed a living were coded as 1; those who had not signed a living will as 0. Age, education, and length of time on dialysis were continuous variables. Change in patient's health was assessed in the follow-up interview with the patient by asking him or her the following: "Compared to one year ago, how would you rate your health in general now? Would you say it is much better now (5), somewhat better now (4), about the same (3), somewhat worse now (2), or much worse now (1)?" Approximately half of the patients (52.4%) reported stable health, 6.4% reported that their health became much worse, 22.1% somewhat worse, 13.2% somewhat better, and 5.9% much better over time.

Analysis Plan

We addressed the first research question, examining the extent to which preferences to continue treatment are more stable for some hypothetical health conditions than for others, by using chi-square analysis and kappa statistics. We examined each treatment condition separately for patients and for spouses by crossing initial response with follow-up response. To more validly represent decisions made in clinical contexts (continue treatment, not sure, terminate treatment), for these analyses we collapsed very likely and somewhat likely scores (1), maintained not sure as a second category (0.5), and collapsed somewhat unlikely and very unlikely as a third category (0). We considered individual stable if responses at both times of measurement were on the same side of the want/don't want dichotomy at each interview. Although some researchers have chosen to group "unsure" responses with "want" responses (Ditto et al., 2003; Uhlmann et al., 1988) because the clinical default is to provide treatment unless it is specifically refused, we kept unsure as a distinct category in order to more closely monitor stability and change in these as well as other perceptions.

Table 1. Stability and Change in Preferences of Patients and Substituted Judgments of Spouses

	Stability				Change				
Condition	Unlikely	Not sure	Likely	Total No Change	More Likely	Less Likely	Total Change	$\chi^2(df = 4)$	κ
Mild stroke									
Patient ($N = 196$)	4.1	1.5	78.1	83.7	8.2	8.2	16.4	76.80***	.39***
Spouse ($N = 195$)	0.5	1.5	81.5	83.5	8.2	8.2	16.4	16.28**	.20***
Moderate stroke									
Patient ($N = 195$)	14.9	9.7	34.9	59.5	23.1	17.4	40.5	62.35***	.35***
Spouse ($N = 195$)	9.7	8.2	52.3	70.2	17.4	12.4	29.8	78.43***	.44***
Severe stroke									
Patient ($N = 195$)	60.0	5.1	4.6	69.7	10.8	19.5	30.3	39.88***	.31***
Spouse ($N = 193$)	40.9	10.9	12.4	64.2	22.3	13.4	35.7	74.68***	.41***
Mild dementia									
Patient ($N = 194$)	6.2	3.6	55.7	65.5	13.3	21.2	34.5	27.45***	.25***
Spouse ($N = 194$)	0.5	3.6	69.6	73.7	12.4	13.9	26.3	14.15**	.18***
Moderate dementia									
Patient ($N = 195$)	29.7	6.7	18.5	54.9	23.6	21.6	45.2	37.92***	.30***
Spouse ($N = 195$)	12.8	10.8	33.8	57.4	20.1	22.5	42.6	55.07***	.33***
Severe dementia									
Patient ($N = 195$)	71.8	4.1	3.6	79.5	9.3	11.4	20.7	59.38***	.38***
Spouse ($N = 195$)	52.6	7.7	6.7	67.0	15.0	18.1	33.1	58.08***	.36***
Permanent coma									
Patient ($N = 196$)	83.2	2.0	1.0	86.2	5.6	8.2	13.8	33.26***	.32***
Spouse ($N = 194$)	72.7	3.6	3.6	79.9	9.8	10.3	20.1	89.57***	.43***
Terminal (comfortable)									
Patient ($N = 195$)	15.9	5.1	29.7	50.7	22.1	27.2	49.3	17.97***	.21***
Spouse ($N = 194$)	11.9	9.3	39.2	60.4	19.6	20.0	39.6	43.59***	.34***
Terminal (pain)									
Patient ($N = 195$)	35.9	5.1	14.9	55.9	19.4	24.7	44.1	39.69***	.28***
Spouse ($N = 193$)	33.7	9.8	14.0	57.5	20.3	22.3	42.6	46.19***	.33***

Notes: Data are percentages, except where indicated.
$^{**}p < .01$; $^{***}p < .001$.

We examined the extent to which patient preferences and substituted judgments change over time in relationship to one another (the second research question) using bivariate correlations. Because these analyses examined mean levels of responses, we maintained the 5-point interval level nature of the preference variables (ranging from very likely [5] to very unlikely [1]). We contrasted the significance of each pair of correlations (between patient and spouse stability for each condition, and between patient and spouse baseline preference and patient and spouse follow-up preference for each condition) using the Fisher *r*-to-*z* transformation.

Finally, we addressed the third research question using multinomial regression analysis for each hypothetical condition separately for patients and spouses. For these analyses we trichotomized the outcome variable as described previously to reflect people who indicated that they were less likely to continue on dialysis at follow-up than at baseline, those whose responses were similar at both baseline and follow-up, and those who were more likely to indicate a preference to continue dialysis at follow-up than at baseline. We used the stable group as reference category in each analysis. Reported statistics include the adjusted odds ratios, pseudo-R^2 (Nagelkerke, Cox and Snell), and classification results.

Results

Are Preferences to Continue Treatment More Stable When Some Hypothetical Health Conditions Are Considered Than When Others Are Considered?

Table 1 shows results from kappa statistics and chi-square analyses testing the extent to which baseline and follow-up preferences are similar. The kappa statistics for patient preferences ranged from .21 (terminal but comfortable) to .39 (mild stroke); those for substituted judgment ranged from .18 (mild dementia) to .44 (moderate stroke). According to Landis and Koch (1977), these kappa statistics ranged from slight to moderate. As indicated in Table 1, not only were some treatment preferences more stable than others (mild stroke, permanent coma vs moderate stroke, terminal with pain), but it was clear that some of the stabilities ensued from consistent preferences that people had to continue dialysis, whereas other stabilities were the result of consistent preferences to discontinue dialysis. In the context of mild stroke, for example, the preferences of 83.7% of patients and the substituted judgments of 83.5% of spouses were stable, with most of this stability deriving from people indicating that the patient would be likely to continue dialysis. Responses to the condition of

Table 2. Stability of Patient Preferences and Spouse Substituted Judgments by Condition

Condition	Patient Stability	Spouse Stability	z
Mild stroke	.56**	.38**	2.31*
Moderate stroke	.52**	.67**	−2.30*
Severe stroke	.49**	.59**	−1.38
Mild dementia	.31**	.26**	0.53
Moderate dementia	.44**	.55**	−1.43
Severe dementia	.47**	.57**	−1.34
Permanent coma	.40**	.67**	−3.79***
Terminal (comfortable)	.35**	.50**	−1.8
Terminal (pain)	.46**	.54**	−1.04

Note: *$p < .05$; **$p < .01$; ***$p < .001$.

Table 3. Correlation Between Patient Preferences and Spouse Substituted Judgments at Baseline and at Follow-Up (by Condition)

Condition	Patient–Spouse Baseline	Patient–Spouse Follow-Up	z
Mild stroke	.35**	.21**	1.50
Moderate stroke	.28**	.26**	0.21
Severe stroke	.25**	.28**	−0.32
Mild dementia	.13	−.07	1.98*
Moderate dementia	.27**	.06	2.14*
Severe dementia	.20**	.37**	−1.83
Permanent coma	.20**	.26**	−0.62
Terminal (comfortable)	.08	−.02	0.99
Terminal (pain)	.15*	.12	0.30

Note: *$p < .05$; **$p < .01$.

mild dementia were similar to those for mild stroke, with both patients and spouses indicating a strong likelihood that the patient would choose to continue dialysis (65.5% patients; 73.7% spouses). Responses regarding permanent coma, although of similar overall stability (86.2% patients; 79.9% spouses), varied in direction, with the overwhelming majority of both patients (83.2%) and spouses (72.7%) indicating that the patient would be unlikely to continue treatment under this condition. Of particular note are responses to the scenarios of moderate stroke, moderate dementia, terminal but comfortable, and terminal with pain. These conditions witnessed both lower overall levels of stabilities as well as differences in cause of stability, with some of the stability being associated with people whose stable preferences were to discontinue dialysis and some of it being associated with people who had stable preferences to continue dialysis.

Turning attention to people whose preferences changed over time (Table 1 "Change" columns) revealed that there were people who increased as well as who decreased their likelihood of continuing dialysis over time. As indicated in Table 1, for example, in the case of moderate stroke, 23.1% of patients and 17.4% of spouses indicated that the patient would become more likely to want to pursue dialysis treatments over time, whereas 17.4% of patients and 12.4% of spouses indicated that the patient would become more unlikely to want to do so. Similarly, in the case of moderate dementia, 23.6% of patients and 20.1% of spouses indicated that the patient would be more likely to want to continue dialysis treatments over time, whereas 21.6% of patients and 22.5% of spouses indicated that the patient would be less likely to want to continue dialysis over time.

How Do Patient Preferences and Substituted Judgments Change Over Time in Relationship to One Another?

Examination of bivariate correlations (see Table 2) indicated that there were varying levels of stability in the responses of both patients (ranging from .31 for mild dementia to .56 for mild stroke) and spouses (ranging from .26 for mild dementia to .67 for both moderate stroke and permanent coma) as a function of health condition. The overall pattern was for spouse stabilities to be higher (average correlation of .53) than patient stabilities (average of .44). As indicated by the z statistic, only three of the stabilities differed significantly from one another, with spouses having significantly higher stabilities for moderate stroke and permanent coma and patients having higher stability for mild stroke.

Although these individual stabilities were typically high and significant, levels of within-couple similarity at both baseline and follow-up were somewhat lower. Bivariate correlations of patient and spouse pairs at both baseline and follow-up reported in Table 3 varied as a function of hypothetical patient condition. Whereas relationships were positive and significant at both baseline and follow-up for mild stroke, moderate stroke, severe stroke, severe dementia, and permanent coma, correlations between patients and their spouses were not significant at either baseline or follow-up for mild dementia and terminal but comfortable. The z statistics indicated no significant differences between baseline and follow-up correlations for these conditions. For mild dementia, although both baseline and follow-up correlations were not significant, the z statistic indicated that there was a significant difference in the magnitude of these correlations. For moderate dementia, the z statistic indicated that baseline and follow-up correlations between patients and spouses were statistically different, with the baseline correlation significant and the follow-up correlation not significant. Important to note is that regardless of significance level, the magnitudes of these relationships were relatively small (range = −.02 to .37).

Are Some People's Treatment Preferences More Stable Than Others'?

Table 4 reports results from multinomial logistic regression analyses predicting change in patient preferences. Across all hypothetical conditions, pseudo-R^2 Nagelkerke values ranged from .30 (terminal with pain) to .58 (permanent coma). Examination of adjusted odds ratios and confidence intervals for adjusted odds ratios revealed that the best predictor of whether preference to continue dialysis decreased, was stable, or increased over the course of a year was initial treatment preference. The way in which initial preference affected preference at follow-up varied, however, as a function of severity of the hypothetical health condition.

Focusing first on the mildest health conditions (e.g., mild stroke) indicated that a greater desire to continue dialysis at baseline reduced the probability that the patient would change (either increase or decrease) his or her preference over time. For the more severe conditions (severe stroke, severe dementia, coma), a greater desire to continue dialysis at baseline increased

Table 4. Multinomial Logistic Regression Analyses Predicting Change in Patient Preferences for Treatment (Reference = Stability)

	Mild Stroke (N = 193)				Moderate Stroke (N = 192)			
	Less Likely to Continue		More Likely to Continue		Less Likely to Continue		More Likely to Continue	
Variable	AOR	95% CI	AOR	95% CI	AOR	95% CI	AOR	95% CI
Patient age	1.078	0.995–1.167	1.041	0.942–1.150	0.985	0.933–1.041	0.991	0.941–1.043
Patient (1 = male)	2.940	0.785–11.009	2.948	0.584–14.879	0.425	0.147–1.226	1.296	0.512–3.278
Education	1.153	0.938–1.416	1.101	0.880–1.379	0.862*	0.743–1.001	0.916	0.793–1.057
Time in treatment	1.003	0.995–1.011	1.003	0.995–1.012	0.992	0.983–1.002	0.995	0.988–1.001
Race (1 = Black)	10.201**	2.246–46.324	7.287*	1.050–50.565	0.549	0.115–2.617	0.353	0.069–1.811
Living will (1 = yes)	1.146	0.325–4.035	0.623	0.141–2.745	0.818	0.347–1.928	0.814	0.365–1.820
Health change	1.291	0.662–2.517	1.501	0.653–3.449	0.942	0.589–1.509	1.415	0.909–2.202
Time 1 preference	0.568*	0.350–0.922	0.256***	0.156–0.419	1.763**	1.172–2.653	0.483***	0.356–0.655
Number in category		15		16	33		45	
Nagelkerke			.402			.331		
Cox and Snell			.268			.282		
% correctly classified	Less likely (0%), stable (95.7%), more likely (43.8%)				Less likely (18.2%), stable (84.2%), more likely (31.1%)			

	Severe Stroke (N = 192)				Mild Dementia (N = 191)			
	Less Likely to Continue		More Likely to Continue		Less Likely to Continue		More Likely to Continue	
Variable	AOR	95% CI	AOR	95% CI	AOR	95% CI	AOR	95% CI
Patient age	1.054	0.981–1.133	1.066	0.995–1.142	1.028	0.981–1.078	0.965	0.886–1.051
Patient (1 = male)	2.020	0.615–6.637	1.014	0.291–3.535	0.798	0.336–1.898	0.209	0.028–1.575
Education	1.087	0.898–1.316	0.878	0.740–1.043	0.942	0.828–1.071	1.033	0.840–1.271
Time in treatment	0.999	0.991–1.007	0.992	0.981–1.004	1.001	0.996–1.006	0.993	0.983–1.003
Race (1 = Black)	0.913	0.158–5.261	1.221	0.209–7.133	1.352	0.414–4.418	0.656	0.054–7.924
Living will (1 = yes)	0.771	0.256–2.320	0.650	0.239–1.774	0.816	0.384–1.736	1.805	0.472–6.897
Health change	0.667	0.351–1.267	0.868	0.496–1.517	1.163	0.768–1.761	1.389	0.740–2.607
Time 1 preference	4.456***	2.793–7.111	1.200	0.736–1.959	1.121	0.766–1.642	0.258***	0.163–0.410
Number in category	37		20			39		26
Nagelkerke		.509					.400	
Cox and Snell		.406					.330	
% correctly classified	Less likely (59.5%), stable (93.3%), more likely (0%)				Less likely (0%), stable (93.7%), more likely (57.7%)			

	Moderate Dementia (N = 192)				Severe Dementia (N = 192)			
	Less Likely to Continue		More Likely to Continue		Less Likely to Continue		More Likely to Continue	
Variable	AOR	95% CI	AOR	95% CI	AOR	95% CI	AOR	95% CI
Patient age	1.063*	1.003–1.127	0.975	0.929–1.023	1.009	0.922–1.104	0.945	0.884–1.001
Patient (1 = male)	0.385	0.128–1.153	1.132	0.479–2.677–2.719	0.911	0.222–3.729	0.472	0.121–1.838
Education	0.784**	0.661–0.930	0.863*	0.756–0.985	0.852	0.674–1.077	1.001	0.839–1.196
Time in treatment	1.006*	1.000–1.012	1.001	0.996–1.006	0.997	0.986–1.009	1.000	0.993–1.007
Race (1 = Black)	0.116*	0.015–0.917	0.502	0.121–2.083	0.396	0.035–4.495	1.185	0.216–6.487
Living will (1 = yes)	0.895	0.374–2.139	1.216	0.551–2.683	0.791	0.222–2.823	0.512	0.180–1.455
Health change	1.001	0.636–1.575	0.906	0.588–1.395	0.740	0.347–1.576	0.645	0.347–1.196
Time 1 preference	2.215***	1.596–3.074	0.616**	0.448–1.395	3.956***	2.437–6.422	1.003	0.505–1.993
Number in category		41		45		22		17
Nagelkerke			.361				.418	
Cox and Snell			.312				.303	
% correctly classified	Less likely (43.9%), stable (77.4%), more likely (11.1%)				Less likely (40.9%), stable (95.4%), more likely (0%)			

	Terminal, Comfortable (N = 192)				Terminal, Pain (N = 192)			
	Less Likely to Continue		More Likely to Continue		Less Likely to Continue		More Likely to Continue	
Variable	AOR	95% CI	AOR	95% CI	AOR	95% CI	AOR	95% CI
Patient age	0.988	0.943–1.034	1.001	0.941–1.065	1.024	0.973–1.077	1.006	0.955–1.061
Patient (1 = male)	0.866	0.380–1.973	0.889	0.313–2.521	1.238	0.501–3.056	0.926	0.362–2.369
Education	0.866*	0.763–0.983	0.862	0.735–1.010	1.028	0.891–1.185	1.024	0.895–1.171
Time in treatment	0.999	0.994–1.005	0.997	0.991–1.003	1.003	0.998–1.009	0.999	0.994–1.005
Race (1 = Black)	0.813	0.249–2.656	0.142	0.016–1.280	0.833	0.212–3.271	0.909	0.226–3.662
Living will (1 = yes)	1.187	0.571–2.465	1.290	0.508–3.273	0.584	0.258–1.320	0.954	0.425–2.141
Health change	0.977	0.659–1.447	0.863	0.524–1.422	0.821	0.528–1.276	0.956	0.617–1.480
Time 1 preference	1.422*	1.066–1.898	0.400***	0.285–0.562	2.367***	1.741–3.216	0.745	0.538–1.032
Number in category		52		42		48		37
Nagelkerke			.373				.300	
Cox and Snell			.326				.259	
% correctly classified	Less likely (17.3%), stable (68.4%), more likely (59.5%)				Less likely (37.5%), stable (82.2%), more likely (0%)			

(*Table 4 continues*)

Table 4. Multinomial Logistic Regression Analyses Predicting Change in Patient Preferences for Treatment (Reference = Stability) (*Continued*)

	Permanent Coma ($N = 193$)			
	Less Likely to Continue		More Likely to Continue	
Variable	AOR	95% CI	AOR	95% CI
Patient age	1.133	0.937–1.370	1.007	0.924–1.097
Patient (1 = male)	2.306	0.167–31.904	1.547	0.353–6.783
Education	0.950	0.602–1.498	0.966	0.769–1.215
Time in treatment	0.978	0.953–1.003	1.001	0.992–1.010
Race (1 = Black)	0.112	0.001–18.809	2.511	0.401–15.715
Living will (1 = yes)	0.305	0.022–4.167	1.888	0.417–8.541
Health change	2.065	0.434–9.824	1.414	0.673–2.969
Time 1 preference	14.371***	3.934–52.499	1.449	0.647–3.242
Number in category		16		10
Nagelkerke			.581	
Cox and Snell			.361	
% correctly classified	Less likely (81.3%), stable (98.8%), more likely (0%)			

Notes: AOR = adjusted odds ratio; CI = confidence interval.
*$p < .05$; **$p < .01$; ***$p < .001$.

the probability that the patient would change his or her preference in the direction of becoming less likely to continue dialysis as opposed to having preferences that remain stable. For the conditions of moderate stroke, moderate dementia, terminal (comfortable), and terminal (pain), the pattern of findings was more complex. For these conditions, as desire to continue treatment at baseline increased, the probability of being in the group that was less likely to want to continue dialysis at follow-up increased compared with the likelihood of being in the stable group, whereas the probability of being in the group indicating that they were more likely to want to continue dialysis decreased relative to the group whose preferences remained stable.

Although we examined seven other independent variables, only education had a consistent effect on patient preferences. For the conditions of mild stroke, moderate dementia, and terminal but comfortable, patients with greater education were more likely to have stable preferences as opposed to preferences that changed toward being less likely to continue on dialysis. The other independent variables examined (age, gender, race, length of time in treatment, presence of a living will, change in patient's health) had relatively insignificant effects on determining whether patient preferences for dialysis increased, decreased, or remained stable. Moreover, these variables had inconsistent relationships across the hypothetical health outcome variables. To more formally test the strength of these predictors, we ran separate analyses using only baseline preference as predictor. These analyses indicated nearly identical results both in terms of pseudo-R^2 values and percentage of cases correctly classified as did the analyses that included age, gender, education, race, length of time in treatment, and presence of a living will, confirming that these variables contributed little to our understanding of changes in treatment preferences in this sample of ESRD patients.

Classification results indicated that the most accurately predicted group included patients whose preferences remained stable. Across all hypothetical conditions the model correctly identified an average of 87.6% of the cases in which patient preferences remained stable. The model was much less effective in identifying patients who changed their preferences. It identified an average of 33.2% of patients correctly who became less likely to want to continue treatments and an average of 22.6% of patients correctly who became more likely to want to continue dialysis treatments. These classification analyses also indicated that when errors of classification were made they were between adjacent sequential categories (either between decreasing desire for dialysis and stability, or between stability and increasing desire for dialysis). No classification errors were made between decreasing desire for dialysis and increasing desire for dialysis.

Results for the substituted judgments of spouses, depicted in Table 5, revealed that initial substituted judgment played a role similar to that of patient preferences, with baseline responses having the greatest effect on follow-up assessments. Moreover, as was true for the patient data, the nature of the effect varied as a function of the severity of the hypothetical health condition. For the most mild conditions (mild stroke, mild dementia), spouses whose substituted judgments remained stable were those who indicated at baseline that the patient would be more likely to continue dialysis treatments. For the most severe conditions (severe stroke, severe dementia, coma) spouses whose substituted judgments indicated a greater likelihood that the patient would want continue dialysis were more likely to fall in the group whose desire for dialysis decreased over time than the group whose substituted judgments remained stable. For the more moderate conditions (moderate stroke, moderate dementia, terminal but comfortable), results were less consistent. For both moderate stroke and moderate dementia, initial preference was not a significant predictor of whether substituted judgments remained stable or decreased. Initial preference was a significant predictor of whether desire to continue dialysis increased (as opposed to remained stable), with spouses who indicated greater likelihood of the patient continuing on dialysis at baseline being more likely to be in the group that remained stable than in the group whose preferences for dialysis increased over time. For the condition of terminal but comfortable, initial substituted judgment was a significant predictor of both whether desire

Table 5. Multinomial Logistic Regression Analyses Predicting Change in Substituted Judgment (Reference = Stability)

	Mild Stroke (N = 192)				Moderate Stroke (N = 192)			
	Less Likely to Continue		More Likely to Continue		Less Likely to Continue		More Likely to Continue	
Variable	AOR	95% CI	AOR	95% CI	AOR	95% CI	AOR	95% CI
Patient age	0.999	0.929–1.073	0.927	0.773–1.111	0.999	0.942–1.060	0.973	0.917–1.032
Patient (1 = male)	1.574	0.470–5.270	0.194	0.003–14.174	0.822	0.273–2.473	1.826	0.641–5.202
Education	1.043	0.851–1.278	0.981	0.597–1.614	0.970	0.816–1.153	1.053	0.889–1.247
Time in treatment	1.000	0.992–1.009	0.991	0.956–1.028	1.000	0.993–1.006	0.992*	0.917–1.032
Race (1 = Black)	0.524	0.050–5.467	0.157	0.001–20.633	1.40E–009	1.40E–009	1.531	0.342–6.852
Living will (1 = yes)	4.731*	1.007–22.223	0.891	0.074–10.668	1.358	0.527–3.499	1.874	0.658–5.336
Health change	1.152	0.618–2.148	0.308	0.040–2.373	1.235	0.766–1.993	1.142	0.665–1.960
Time 1 preference	0.347*	0.147–0.820	0.014***	0.001–0.154	1.137	0.753–1.715	0.357***	0.247–0.516
Number in category		16		16		24		33
Nagelkerke			.600				.340	
Cox and Snell			.406				.273	
% correctly classified	Less likely (0%), stable 98.1%), more likely (100%)				Less likely (0%), stable (90.4%), more likely (33.3%)			

	Severe Stroke (N = 190)				Mild Dementia (N = 191)			
	Less Likely to Continue		More Likely to Continue		Less Likely to Continue		More Likely to Continue	
Variable	AOR	95% CI	AOR	95% CI	AOR	95% CI	AOR	95% CI
Patient age	0.940	0.870–1.015	1.000	0.956–1.047	1.041	0.980–1.105	0.989	0.862–1.134
Patient (1 = male)	0.539	0.152–1.903	0.721	0.302–1.718	1.708	0.644–4.529	0.877	0.134–5.751
Education	0.879	0.712–1.086	1.011	0.892–1.146	1.109	0.938–1.311	1.312	0.900–1.912
Time in treatment	1.004	0.997–1.012	1.000	0.995–1.005	1.003	0.998–1.009	0.999	0.979–1.018
Race (1 = Black)	0.026**	0.002–0.439	0.622	0.164–2.359	0.318	0.307–2.724	0.534	0.029–9.983
Living will (1 = yes)	0.749	0.262–2.139	0.720	0.332–1.563	0.598	0.240–1.491	0.257	0.041–1.628
Health change	1.126	0.619–2.047	0.888	0.592–1.331	1.263	0.787–2.028	1.424	0.468–4.333
Time 1 preference	3.127***	1.975–4.951	0.751	0.524–1.052	0.523*	0.277–0.985	0.033***	0.008–0.137
Number in category		25		43		27		24
Nagelkerke			.306				.585	
Cox and Snell			.254				.459	
% correctly classified	Less likely (40.0%), stable (95.1%), more likely (0%)				Less likely (3.7%), stable (96.4%), more likely (83.3%)			

	Moderate Dementia (N = 192)				Severe Dementia (N = 191)			
	Less Likely to Continue		More Likely to Continue		Less Likely to Continue		More Likely to Continue	
Variable	AOR	95% CI	AOR	95% CI	AOR	95% CI	AOR	95% CI
Patient age	1.009	0.960–1.060	1.049	0.991–1.110	1.018	0.951–1.090	1.027	0.973–1.085
Patient (1 = male)	1.191	0.511–2.777	0.580	0.202–1.664	0.825	0.263–2.589	0.945	0.356–2.507
Education	0.932	0.814–1.067	0.913	0.786–1.061	1.094	0.911–1.313	0.918	0.788–1.068
Time in treatment	1.002	0.997–1.007	0.991	0.982–1.000	1.002	0.995–1.010	1.002	0.996–1.008
Race (1 = Black)	0.339	0.068–1.690	0.913	0.200–4.164	0.919	0.194–4.359	0.976	0.232–4.107
Living will (1 = yes)	2.512*	1.114–5.666	1.278	0.514–3.178	0.364*	0.133–1.000	0.242**	0.099–0.593
Health change	1.172	0.770–1.784	1.375	0.852–2.219	0.756	0.429–1.335	0.807	0.490–1.329
Time 1 preference	1.296	0.951–1.767	0.440***	0.313–0.620	3.399***	2.283–5.060	0.847	0.539–1.330
Number in category		43		39		34		29
Nagelkerke			.317				.419	
Cox and Snell			.272				.344	
% correctly classified	Less likely (7.0%), stable (89.1%), more likely (38.5%)				Less likely (50.0%), stable (89.8%), more likely (3.4%)			

	Terminal, Comfortable (N = 191)				Terminal, Pain (N = 190)			
	Less Likely to Continue		More Likely to Continue		Less Likely to Continue		More Likely to Continue	
Variable	AOR	95% CI	AOR	95% CI	AOR	95% CI	AOR	95% CI
Patient age	1.068*	1.012–1.128	1.019	0.960–1.081	0.983	0.930–1.038	0.999	0.950–1.051
Patient (1 = male)	1.335	0.562–3.174	1.168	0.392–3.482	0.683	0.264–1.769	0.549	0.198–1.523
Education	0.899	0.787–1.027	1.172	0.983–1.397	1.058	0.917–1.222	1.046	0.902–1.214
Time in treatment	1.000	0.995–1.006	1.000	0.993–1.007	1.001	0.995–1.006	1.000	0.995–1.006
Race (1 = Black)	1.329	0.411–4.300	0.264	0.026–2.689	0.338	0.085–1.337	1.52E–009	1.52E–009
Living will (1 = yes)	0.839	0.376–1.876	0.256**	0.094–0.696	0.491	0.212–1.139	0.649	0.284–1.485
Health change	0.986	0.641–1.518	1.170	0.703–1.947	0.998	0.620–1.605	1.371	0.877–2.142
Time 1 preference	1.395*	0.998–1.951	0.356***	0.246–.514	2.453***	1.744–3.449	0.795	0.574–1.099
Number in category		39		38		43		38
Nagelkerke			.387				.357	
Cox and Snell			.329				.306	
% correctly classified	Less likely (5.1%), stable (88.6%), more likely (50.0%)				Less likely (46.5%), stable (83.5%), more likely 2.6%)			

(*Table 5 continues*)

Table 5. Multinomial Logistic Regression Analyses Predicting Change in Substituted Judgment (Reference = Stability) (*Continued*)

	Permanent Coma ($N = 191$)			
	Less Likely to Continue		More Likely to Continue	
Variable	AOR	95% CI	AOR	95% CI
Patient age	0.962	0.865–1.070	0.999	0.933–1.069
Patient (1 = male)	0.225	0.022–2.331	1.229	0.395–3.826
Education	0.913	0.669–1.248	1.146	0.940–1.396
Time in treatment	0.993	0.978–1.008	0.984*	0.968–1.000
Race (1 = Black)	0.007**	0.000–0.192	0.530	0.072–3.885
Living will (1 = yes)	0.111*	0.018–0.693	0.368	0.128–1.053
Health change	0.536	0.223–1.288	0.916	0.514–1.634
Time 1 preference	9.028***	3.984–20.462	1.817*	1.070–3.088
Number in category		19		19
Nagelkerke			.540	
Cox and Snell			.389	
% correctly classified	Less likely (78.9%), stable (96.7%), more likely (5.3%)			

Notes: AOR = adjusted odds ratio; CI = confidence interval.
*$p < .05$; **$p < .01$; ***$p < .001$.

for dialysis increased or decreased. The odds ratio greater than 1 between initial substituted judgment and less desire for dialysis indicated that spouses indicating that the patient would be more likely to want to continue dialysis at baseline had a greater probability of being in the group whose desire for dialysis continuation decreased over time than in the group that remained stable. The odds ratio less than 1 between initial substituted judgment and greater desire for dialysis indicated that spouses indicating that patient would be more likely to want to continue dialysis had a greater probability of being in the group whose desire for dialysis continuation remained stable than the group desiring more dialysis over time. Similar to findings for change in patient preferences, the demographic variables, length of time patient was in treatment, presence of a living will, and change in patient's health had inconsistent, nonsignificant effects for change in substituted judgments. As was true for patient preferences, the most accurately predicted group of spouse substituted judgments was that in which preferences remained stable. On average, across all hypothetical conditions the model correctly identified 92.0% of spouses whose preferences remained stable. The model was much less effective at correctly identifying spouses who believed that the patient would either decrease (average of 25.7%) or increase (35.2%) his or her preferences over time.

Discussion

These analyses suggest that there is a great deal more stability than change in patient preferences regarding continuation of dialysis over the course of 1 year, supporting findings described by Everhart and Pearlman (1990), Emanuel and colleagues (1994), and Ditto and associates (2003). Treatment preferences, however, are not devoid of change, as these data suggest that over the period of 1 year significant numbers of patients indicate both an increase and a decrease in their desire to continue dialysis treatments. Depending on the hypothetical health condition that patients are asked to consider, between 13.8% and 49.3% of patients indicate that their preferences regarding continuing dialysis would change over the course of a year. Similarly the data indicate that although there is greater stability than change in spouse substituted judgments, these preferences change as well for some people.

Stability of Treatment Preferences Varies as a Function of Hypothetical Condition

Stability levels are highest for patients and spouses when they are asked to consider whether the patient would continue dialysis under hypothetical conditions at the extremes of the continuum. In the case of mild stroke (for which the overwhelming majority of both patients and spouses indicate that the patient would be very likely to continue dialysis) or permanent coma (for which both patients and spouses indicate that the patient would be very unlikely to continue dialysis), stability levels are much higher than they are for hypothetical conditions that are more moderate. These findings, although consistent with those described by Gready and colleagues (2000) and Ditto and associates (2003), extend the knowledge base because they suggest that even for respondents who have a chronic condition such as ESRD that requires them to make end-of-life decisions on a daily basis, the stability of treatment preferences varies as a function of the hypothetical health condition that is presented.

Patient and Spouse Preferences Do Not Change in Consistent Ways

The moderate levels of within-person stability combined with the low level of within-couple similarity suggest that patient and spouse preferences change in ways that are different from one another. Although the data are marked by higher within-person stabilities for patients than for spouses under the conditions of mild stroke and mild dementia, these stabilities are higher for spouses than for patients under all other conditions. These findings, combined with the relatively low magnitude of correlations between preferences expressed by patients and their spouses both at baseline and follow-up, are consistent with previous research that has found that substituted judgments are no better than chance. These data add to that literature, however, as they reveal that levels of similarity in

responses between patients and spouses do not consistently either improve or decline over time.

The Stability of Treatment Preferences Is Dependent Largely on Initial Preference

Across all of the hypothetical health conditions, initial preference is the variable most likely to distinguish patients and spouses whose preferences and substituted judgments for dialysis decreased, stayed the same, and increased. The direction of this relationship varies, however, depending on the nature of the hypothetical situation that respondents are asked to contemplate. Decisions to continue treatment are more stable when respondents are asked to imagine experiencing mild health conditions such as mild stroke or dementia, whereas decisions to terminate dialysis are more stable when respondents are asked to consider whether they would continue dialysis under more serious health conditions such as severe dementia or coma.

Although there is evidence in the literature that patients who have an advance directive have more stable preferences than patients who do not (Danis et al., 1994; Emanuel et al., 1994; Weissman et al., 1999), our analyses did not support this finding. Similarly, whereas others have found that the changing health of the patient is associated with changed preferences (Danis et al., 1994; Weissman et al., 1999), our data did not support this trend. Although it is possible that these factors lacked prominence because of the relative homogeneity of our sample or because of the duration of time over which we studied preferences, this is unclear and awaits further research.

There is evidence, both in our findings as well as in the work of others (Emanuel et al., 1994; Weissman et al., 1999), that greater stability of preferences is associated with higher levels of education. The knowledge that the tendency is for better educated people to have more stable preferences should be helpful to surrogates faced with making end-of-life decisions for these people.

Findings from these analyses add to conceptual knowledge regarding end-of-life preference by indicating the importance of considering specific hypothetical situations. Both patient preferences and substituted judgments vary as a function of the health condition respondents are asked to consider. These findings also have salience for clinical practice, as they indicate the importance of asking surrogate decision makers to consider not only the general values of the patient for whom they are providing substituted judgments, but also the patient's values given specific contexts. The stability of patient preferences suggests that it is possible to maintain patients' voices in end-of-life decisions when patients themselves are unable to express their wishes if they have previously expressed their preferences. When a patient is unable to express current wishes, previously stated preferences can serve as a useful starting point for family members who are faced with the daunting task of deciding whether the patient should continue on dialysis. These findings, however, highlight the importance of encouraging patients to discuss their preferences with spouses and other decision makers and strongly suggest that these discussions revolve around the different potential health conditions that could ensue over time rather than on general beliefs or feelings. Furthermore, these types of discussions should ideally be revisited over time to ensure that the surrogate has an understanding of the patient's most current wishes.

Although this study provides important new information about the end-of-life decision-making process, it has some limitations that we must note. First, it is not clear whether actual preferences on the part of patients and spouses would mimic responses to the hypothetical scenarios. Many social–psychological studies have suggested that people are generally poor at predicting their future preferences and behavior (Osberg & Shrauger, 1986). Second, we based these analyses on patients who were available and both cognitively and physically able to participate in the interview at two points in time. It is unknown whether results would generalize to those situations in which the patient is not intact. The relatively small number of people in this study who changed to being either more or less likely to continue dialysis may have affected statistical results. Moreover, the voluntary nature of the sample and the inability to calculate response rates makes it difficult to estimate the extent to which findings from this sample would generalize to other samples of patients with ESRD. Third, although the opportunity to measure patient preferences and spouse substituted judgments at two points in time represents a significant addition to a literature that is largely cross-sectional, because the research design was limited to two time points spaced 1 year apart, these data can only hint at how preferences function over time. Fourth, we must note the study's reliance on a single item to measure each preference (and substituted judgment). It is plausible that the wording of these questions may have altered responses. Further work on establishing measures with valid and reliable psychometric properties is needed. Finally, results are limited to an understanding of the conditions under which patients would continue dialysis. They provide no information about preferences for other life-sustaining treatments such as feeding tubes or ventilators.

Investigators should design future research to remedy some of the limitations of this study and also to test the extent to which these findings generalize to other populations of patients making end-of-life decisions. The finding that there is both a great deal of stability to the preferences of patients and spouses to continue dialysis, but also predictable change, suggests that the patient's voice can be maintained at the end of life. These data add to a host of other research studies that have raised serious questions about whether the principle of substituted judgment is the best way to maintain the voice of the patient. As research in this area continues to develop, it will be critical to examine the ethical and moral principles that guide the preferences for end-of-life care.

Acknowledgments

This study was funded by Grant RO1 NR-05237 from the National Institute of Nursing Research. We gratefully acknowledge helpful comments on this manuscript from Lucy Feild, PhD; Edward Lemay, MS; and Richard McConaughy, PhD.

Correspondence

Correspondence concerning this article should be addressed to Rachel Pruchno, PhD, New Jersey Institute for Successful Aging, University of Medicine & Dentistry of New Jersey, 42 East Laurel Rd., Suite 2300, Stratford, NJ 08084. E-mail: pruchnra@umdnj.edu

References

Berger, J. T., & Majerovitz, D. (1998). Stability of preferences for treatment among nursing home residents. *The Gerontologist, 38*, 217–223.

Blank, K., Robison, J., Prigerson, H., & Schwartz, H. I. (2001). Instability of attitudes about euthanasia and physician assisted suicide in depressed older hospitalized patients. *General Hospital Psychiatry, 23*, 326–332.

Cohen, L., Germain, M., & Poppel, D. (2003). Practical considerations in dialysis withdrawal: To have that option is a blessing. *Journal of the American Medical Association, 289*, 2113–2119.

Danis, M., Garrett, J., Harris, R., & Patrick, D. L. (1994). Stability of choices about life-sustaining treatments. *Annals of Internal Medicine, 120*, 567–573.

Ditto, P. H., Danks, J. H., Smucker, W. D., Bookwala, J., Coppola, K. M., Dresser, R., et al. (2001). Advance directives as acts of communication: A randomized, controlled trial. *Archives of Internal Medicine, 161*, 421–430.

Ditto, P. H., Smucker, W. D., Danks, J. H., Jacobson, J. A., Houts, R. M., Fagerlin, A., et al. (2003). Stability of older adults' preferences for life-sustaining medical treatment. *Health Psychology, 22*, 605–615.

Emanuel, L. L., Emanuel, E. J., Stoeckle, J. D., Hummel, L. R., & Barry, M. J. (1994). Advance directives: Stability of patients' treatment choices. *Archives of Internal Medicine, 154*, 209–217.

Everhart, M., & Pearlman, R. (1990). Stability of patient preferences regarding life-sustaining treatments. *Chest, 97*, 159–164.

Feild, L., Pruchno, R. A., Bewley, J., Lemay, E. P., & Levinsky, N. G. (2006). Using probability vs. non-probability sampling to identify hard-to-access participants for health-related research: Costs and contrasts. *Journal of Aging & Health, 18*, 565–583.

Fried, T. R., Bradley, E. H., & Towle, V. R. (2003). Valuing the outcomes of treatment: Do patients and their caregivers agree? *Archives of Internal Medicine, 163*, 2073–2078.

Fried, T. R., Byers, A. L., Gallo, W. T., Van Ness, P. H., Towle, V. R., O'Leary, J. R., et al. (2006). Prospective study of health status preferences and changes in preferences over time in older adults. *Archives of Internal Medicine, 166*, 890–895.

Gerety, M. B., Chiodo, L. K., Kanten, D. N., Tuley, M. R., & Cornell, J. E. (1993). Medical treatment preferences of nursing home residents: Relationship to function and concordance with surrogate decision-makers. *Journal of the American Geriatrics Society, 41*, 953–960.

Gready, R. M., Ditto, P. H., Danks, J. H., Coppola, K. M., Lockhart, L. K., & Smucker, W. D. (2000). Perceived versus actual stability of life-sustaining treatment preferences. *Journal of Clinical Ethics, 11*, 334–346.

Hare, J., Pratt, C., & Nelson, C. (1992). Agreement between patients and their self-selected surrogates on difficult medical decisions. *Archives of Internal Medicine, 152*, 1049–1054.

Holley, J. L. (2004). Advance care planning in elderly chronic dialysis patients. *International Urology and Nephrology, 35*, 565–568.

Holley, J. L., Hines, S. C., Glover, J. J., Babrow, A. S., Badzek, L. A., & Moss, A. H. (1999). Failure of advance care planning to elicit patients' preferences for withdrawal from dialysis. *American Journal of Kidney Disease, 33*, 688–693.

Kohut, N., Sam, M., O'Rourke, K., MacFadden, D. K., Salit, I., & Singer, P. A. (1997). Stability of treatment preferences: Although most preferences do not change, most people change some of their preferences. *Journal of Clinical Ethics, 8*, 124–135.

Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics, 33*, 159–174.

Merkus, M. P., Jager, K. J., Dekker, F. W., de Haan, R. J., Boeschoten, E., & Krediet, R. (1999). Physical symptoms and quality of life in patients on chronic dialysis: Results of The Netherlands Cooperative Study on Adequacy of Dialysis (NECOSAD). *Nephrology Dialysis Transplantation, 14*, 1163–1170.

Neu, S., & Kjellstrand, C. M. (1986). Stopping long-term dialysis: An empirical study of withdrawal of life-supporting treatment. *New England Journal of Medicine, 314*, 14–20.

Osberg, T. M., & Shrauger, J. S. (1986). Retrospective versus prospective causal judgments of self and others behavior. *Journal of Social Psychology, 126*, 169–178.

President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research. (1983). *Deciding to forgo life-sustaining treatment: A report on the ethical, medical, and legal issues in treatment decisions* (Gov. Doc. No. Pr 40.8: Et 3/L 62/2). Washington, DC: U.S. Government Printing Office.

Pruchno, R. A., Lemay, E. P., Feild, L., & Levinsky, N. G. (2005). Spouse as health care proxy for dialysis patients: Whose preferences matter? *The Gerontologist, 45*, 812–819.

Pruchno, R. A., Lemay, E. P., Feild, L., & Levinsky, N. G. (2006). Predictors of patient treatment preferences and spouse substituted judgments: The case of dialysis continuation. *Medical Decision Making, 26*, 112–121.

Rosenfeld, K. E., Wenger, N. S., Phillips, R. S., Connors, A. F., Dawson, N. V., Layde, P., et al. (1996). Factors associated with change in resuscitation preference of seriously ill patients: The SUPPORT investigators Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *Archives of Internal Medicine, 156*, 1558–1564.

Sehgal, A., Galbraith, A., Chesney, M., Schoenfeld, P., Charles, G., & Lo, B. (1992). How strictly do dialysis patients want their advance directives followed? *Journal of the American Medical Association, 267*, 59–63.

Sekkarie, M. A., & Moss, A. H. (1998). Withholding and withdrawing dialysis: The role of physician specialty and education and patient functional status. *American Journal of Kidney Disease, 31*, 464–472.

Shalowitz, D. I., Garrett-Mayer, E., & Wendler D. (2006). The accuracy of surrogate decision makers: A systematic review. *Archives of Internal Medicine, 166*, 493–497.

Shidler, S. (1998). Participation of chronically ill older adults in their life-prolonging treatment decisions: Rights and opportunity. *Canadian Journal on Aging, 17*, 1–23.

Singer, P. A., Thiel, E. C., Naylor, C. D., Richardson, R. M., Llewellyn-Thomas, H., Goldstein, M., et al. (1995). Life-sustaining treatment preferences of hemodialysis patients: Implications for advance directives. *Journal of American Society of Nephrology, 6*, 1410–1417.

Suhl, J., Simons, P., Reedy, T., & Garrick, T. (1994). Myth of substituted judgment: Surrogate decision making regarding life support is unreliable. *Archives of Internal Medicine, 154*, 90–94.

Sulmasy, D. P., Terry, P. B., Weisman, C. S., Miller, D. J., Stallings, R. Y., Vettese, M. A., et al. (1998). The accuracy of substituted judgments in patients with terminal diagnoses. *Annals of Internal Medicine, 128*, 621–629.

Terry, P. B., Vettese, M., Song, J., Forman, J., Haller, K. B., Miller, D. J., et al. (1999). End-of-life decision making: When patients and surrogates disagree. *Journal of Clinical Ethics, 10*, 286–293.

Uhlmann, R. F., Pearlman, R. A., & Kain, K. C. (1988). Physicians' and spouses' predictions of elderly patients' resuscitation preferences. *Journal of Gerontology: Medical Sciences, 43*, M115–M121.

U.S. Renal Data System, USRDS 2002 annual data report: Atlas of end-stage renal disease in the United States [Data file]. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive Kidney Diseases.

Valderrabano, F., Jofre, R., & Lopez-Gomez, J. M. (2001). Quality of life in end-stage renal disease patients. *American Journal of Kidney Disease, 38*, 443–464.

Weissman, J. S., Haas, J. S., Fowler, F. J., Gatsonis, C., Massagli, M. P., Seage, G. R., III, et al. (1999). The stability of preferences for life-sustaining care among persons with AIDS in the Boston Health Study. *Medical Decision Making, 19*, 16–26.

Received June 11, 2007
Accepted December 13, 2007
Decision Editor: Kenneth F. Ferraro, PhD