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Improving Advance Care Planning by Accommodating Family Preferences

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ABSTRACT

Context: **Family members often lack the knowledge of patients' values and preferences needed to function well as surrogate decision-makers.**

Objective: **To determine whether differences in values and preferences for the advance care planning process may be reasons family members are inadequately informed to act as surrogates.**

Design: **Face-to-face and telephone surveys using structured questionnaires.**

Participants: **Two hundred forty-two pairs of dialysis patients and their designated surrogates.**

Main Outcome Measures: **Content and number of end-of-life care discussions; patient and surrogate attitudes toward having patients express preferences explicitly; factors most important to surrogates in decision making; and within-pair agreement about the values of suffering and certainty.**

Results: **Ninety percent of patients designated a family member as their surrogate. In most cases, having more conversations about end-of-life issues did not increase surrogate knowledge of patients' values or preferences. Surrogates wanted written and oral instructions more often than patients wanted to provide them (62% vs. 39%, $p < 0.001$). Knowing the patient's wish to stop treatment in the present condition was more important to most surrogates than the physician's recommendation to stop treatment (62% vs. 45 %, $p < 0.001$). Compared to patients, surrogates were less likely to want to prolong the patient's life if it entailed suffering (12% vs. 23%, $p < 0.01$) and were more concerned about being certain before stopping life-sustaining treatments (85% vs. 77%, $p < 0.02$).**

Conclusions: **Differences in preferences for the advance care planning process between patients and their surrogates and failure to discuss specific end-of-life values and preferences may explain why surrogates often lack information needed to serve as surrogate decision-makers.**

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INTRODUCTION

Many patients prefer to have their family members make end-of-life (EOL) care decisions for them should they become incapacitated, believing that their families will make the best decisions even if the family's decisions override the patient's expressed preferences.[1–3] Legislation in all states empowers patients to designate medical power of attorney representatives, and 28 states currently authorize judges and/or health care providers to appoint surrogates for incapacitated persons who did not select one for themselves.[4] These legal policies formalize the historical practice of turning to the next of kin for decision making and have resulted in family members being selected to function as surrogates for incapacitated patients.[5–8] Recent studies have shown that most patients support these policies, want to involve family members in EOL discussions, and are comfortable allowing them to function as surrogates if the patient's decision-making capacity is lost.[9–15]

Despite patients' extensive reliance on family member surrogates to make EOL decisions, surrogates often lack knowledge of the patient's values and preferences[16–19] and frequently provide answers about how they would respond in hypothetical EOL situations that differ from those of the patient.[17,20–28] Because patients normally talk infrequently and in generalities with their family members about the EOL decisions they would make,[12,18] it is not surprising that surrogates lack information they need to function well in their role.

Efforts to improve surrogate performance require a clearer understanding of the reasons surrogates are poorly informed and why their EOL treatment preferences often do not match those of the patient. One explanation may be that patients overestimate the degree of autonomy that their surrogates want to exercise and underestimate the importance of assuring that their surrogates have the information needed to make informed choices. Another potential reason that surrogates often differ from patients in their specific EOL treatment decisions is that they may use different values when making choices for EOL care. While the body of research that has examined how patients want EOL decisions to be made for them is now substantial, no studies have examined patients and their self-designated surrogates to determine the degree to which they concur about the advance care planning process, the amount of information surrogates want, or the core values that guide EOL decision making. The purpose of this study was to examine these issues.

METHODS

Subjects

We studied a stratified random sample of adult hemodialysis patients from two regions. The first region included all nine dialysis units in metropolitan Rochester, New York, a city with a population of 232,000 that was selected for its ethnic diversity and range of socioeconomic strata. The second region included all six dialysis units located within 75 miles of Morgantown, West Virginia. This region includes northern West Virginia and southwestern Pennsylvania and has a combined population of 873,000. Eligible patients were English-speaking persons, 18 years old or older, who did not have physical or mental impairments that prevented oral communication. A random numbers table was used to select patients for interviews on each shift at each dialysis unit. The number of persons selected on each shift was predetermined to ensure that each dialysis patient in the two regions had an equal probability of being selected for the study. Interviewers asked patients for permission to contact the person they would want to function as their surrogate if they lost decision-making capacity. If permission was granted, multiple attempts were made to contact each designated surrogate for an interview.

Study design

The interview questionnaire was drafted by two investigators with expertise in communication (S.C.H. and A.S.B.) and reviewed for face and content validity by a philosopher-ethicist (J.J.G.), a nurse-attorney (L.A.B.), and two physicians with research experience in advance care planning (J.L.H. and A.H.M.). The questionnaire was pretested with 12 dialysis patients. Questions were modified to reduce misunderstandings and simplify response categories.

Face-to-face interviews of 400 patients were conducted during routine hemodialysis treatments in the dialysis units. Interviews of designated surrogates were conducted by telephone (n = 206) or in person in a private room at a dialysis unit (n = 36). Interviews were conducted by trained research assistants. All questions were asked orally. Interviewers used placards with possible answer categories to assist patients in selecting responses. The data from this study regarding patients' desires to include their families more than physicians in the advance care planning process have been previously reported.[12] The data from this study regarding the association between advance directive completion and communication of life-sustaining treatment preferences between patients and surrogates have also been previously reported.[29]

Measures of communication in the advance care planning process

Patients and surrogates were asked if the patient had informed the surrogate of their role as designated decision maker for the patient. They were also asked the number of conversations they had with each other, the reason for the conversations, and how well they thought the surrogate understood the patient's preferences for treatment. Patients and surrogates were also asked if they had discussed the use of tube feedings, mechanical ventilation, dialysis, and cardiopulmonary resuscitation (CPR) in the event of permanent coma.

Measures of preferences for the advance care planning process

Patients and their surrogates reported what they believed was the best way to prepare surrogates for their role. Surrogates who wanted patients to "both tell and write out what is wanted" were classified as wanting more information. Additional questions dealt with the importance patients and surrogates placed on discussions of location of death, worst case scenarios, and the option of ending treatment and dying. Each was also asked the importance they placed on involving physicians in advance care planning discussions. Surrogates were asked the importance of five factors in making a decision for the patient to stop a life-sustaining treatment: terminal illness, permanent loss of ability to relate to others, permanent unconsciousness, patient said they did not want to be kept alive in the condition they were in, and the doctor said patient should not be kept alive in the patient's condition.

Measures of EOL treatment values

Respondents were asked questions to determine the value placed on avoiding suffering by forgoing life-sustaining treatments and on reducing uncertainty by continuing treatment.

Statistical analysis

Comparisons of the sample regions to each other and to the national end-stage renal disease (ESRD) population were examined with χ^2 analyses and independent t tests. Comparisons of differences between patients and their surrogates were made using McNemar's test and paired t tests. Two-tailed 0.05 probability levels were used to identify significant relationships between variables. Patient-surrogate agreement was assessed using Cohen's κ. Ninety-five percent confidence intervals around percentage estimates for the patient and surrogate groups were ±6%.

The protocol was approved by the Institutional Review Boards for the Protection of Human Subjects of West Virginia University, the University of Rochester, and each dialysis unit.

RESULTS

Patient and surrogate demographics

Completed interviews were obtained from 400 of the 518 (78%) randomly selected patients who met the inclusion criteria. Of these 400, 242 (61%) had designated surrogates who also completed interviews. Of the 158 patients whose surrogates were not interviewed, 10 (6%) could not identify a person they would want to make decisions for them if they lost decision-making capacity, 52 (33%) refused permission to contact their surrogate, 19 (12%) had surrogates who refused to participate, and 77 (49%) had surrogates who could not be contacted after a minimum of four efforts. There were no statistically significant differences between the patients whose surrogates were interviewed and those who were not with respect to their age, gender, race, marital status, education level, or time on dialysis.

Table 1 shows the demographics of the patient and surrogate samples. Ninety percent of patients designated a family member as their surrogate. The patient sample was slightly older than the ESRD population,[30] but did not differ from this population on any other demographics for which comparisons were possible.

Communication in the advance care planning process

In 63% of the patient-surrogate pairs, both the patient and the surrogate agreed that the patient

TABLE 1. PATIENT AND SURROGATE DEMOGRAPHICS

	USRDS[a] national Patient Data[30] 242)	Patient sample (n = 242)	Surrogate sample (n =
Mean age, years	56	59[b]	51[c]
(range)	(0–85)	(20–87)	(23–85)
Women (%)	46	46	66[c]
Race (%)			
White	62	69	69
Black	32	27	28
Other	6	4	3
Mean education, year	N/A	11.9	12.8[c]
(range)		(5–19)	(4–20)
Married (%)	N/A	48	
Family income (%)	N/A		
0–10,000		28	
10,001–20,000		38	
20,001–30,000		14	
30,001–40,000		6	
40,001–50,000		7	
50,000 or more		7	
Mean dialysis time, months	N/A	44	
(range)		(1–277)	
Relationship to Patient (%)			
Spouse			38
Child			33
Parent			10
Sibling			9
Other			10

[a]USRDS, United States Renal Data System.
[b]$p < 0.01$ for USRDS patient age compared to patient sample.
[c]$p < 0.001$ for surrogate sample compared to patient sample.
N/A, USRDS data is not available for these variables.

had informed the surrogate of the patient's preference for the surrogate to play this role. If the patient had told the surrogate that the patient wanted the surrogate to make decisions for the patient when the patient became ill, the surrogate was more likely to report understanding well or very well the treatment the patient wanted (97% vs. 82%, $p < 0.001$). Thirty-six percent of patients reported having more than five conversations with their surrogate about EOL treatment. If the patient had more than five conversations with the surrogate about EOL treatment, the surrogate was more likely to report understanding the patient's wishes well (91% vs. 79%, $p = 0.028$). With the same frequency (35% vs. 41%, $p =$ NS), patients and surrogates identified the patient's getting sick or being hospitalized as the most common reason that led them to talk about EOL treatment. There was no association between the reason for talking about EOL treatment and the number of conversations about EOL treatment. Although 85% of patients agreed that it was important to discuss worst case scenarios, there was no difference between those who held this belief and those who did not with regard to having discussed the use of tube feedings, mechanical ventilation, dialysis, and CPR in permanent coma with their surrogates. The number of conversations patients had with their surrogates about end-of-life care was not consistently associated with an increased likelihood that patients had discussed their preferences regarding use of life-sustaining treatments in the event of permanent coma (Table 2). The majority of patients having

Table 2. Relationship Between Number of Conversations and Discussion of Preferences[a] ($n = 242$ Patient-Surrogate Pairs)

	Tube feedings	*Mechanical ventilation*	*CPR*[b]	*Dialysis*
Patient conversations with surrogate				
≤5	37	35	11	19
>5	48	63[c]	26[d]	37[e]
Surrogate conversations with patient				
≤5	36	49	25	33
>5	52[f]	69[g]	37	50[f]

[a] Numbers indicate the percentage of respondents who reported a conversation with the other member of the patient-surrogate pair regarding use of tube feedings, mechanical ventilation, CPR, or dialysis in the event of permanent coma.

[b] CPR indicates cardiopulmonary resuscitation.

[c] $p < 0.001$ compared to value for ≤5 patient conversations with surrogate.

[d] $p < 0.01$ compared to value for ≤5 patient conversations with surrogate.

[e] $p < 0.05$ compared to value for ≤5 surrogate conversations with patient.

[f] $p < 0.01$ compared to value for ≤5 surrogate conversations with patient.

more than five conversations with their surrogates still had not discussed their preferences for being kept alive with tube feedings, CPR, and dialysis in this circumstance.

Preferences for the advance care planning process

Surrogates were more likely than patients to believe that the patient should express both orally and in writing how the patient would want to be treated if they became too sick to make decisions for themself (62% vs. 39%, $p < 0.001$). Surrogates were less likely than patients to prefer that the patient let someone else make EOL decisions for him or her (8% vs. 20%, $p < 0.001$). More surrogates than patients believed it was important to discuss all three EOL-specific issues—location of death, worst case scenarios, and the option of stopping treatment—(78% vs. 64%, $p < 0.001$). As shown in Table 3, the most common factor that surrogates identified as extremely important to know when deciding to stop a life-sustaining treatment was that the patient had told them that they did not want to be kept alive in the condition they were in.

Compared to patients, surrogates had more interest in including doctors in discussions of how the patient should be treated if they became very ill (51% vs. 37%, $p < 0.001$) and in having doctors lead these discussions (21% vs. 8%, $p < 0.001$). Within-pair agreement about whether the patient's preferences were understood and whether doctors should lead or be included in discussions did not exceed what would be expected by chance.

Differences in EOL treatment values

As shown in Table 4, most patients and their surrogates wanted to avoid suffering even if it meant living a shorter period of time. However, more patients than surrogates reported wanting to live as long as possible despite suffering and the need for life support. Surrogates were more likely to accept a trial treatment period for the patient if they were uncertain the patient would recover; they were also more concerned about knowing the patient would not recover before stopping a life-sustaining treatment. Within-pair agreement did not exceed what would be expected by chance. There was no association between the number of conversations the patient reported having with the surrogate and within-pair agreement on the values of avoiding suffering or uncertainty.

COMMENT

In addition to corroborating the growing body of research that challenges the assumption that surrogates will know the patients' values and treatment preferences,[16,17,20–25] we found that patients and surrogates tended to overestimate surrogates' knowledge of patients' wishes. Although having more conversations was associated with surrogates believing that they had a better understanding of the patient's wishes, the number of conversations addressing EOL care between patients and surrogates was weakly or totally un-

TABLE 3. COMPARATIVE IMPORTANCE OF FACTORS IN DECIDING TO STOP LIFE-SUSTAINING TREATMENT[a]

	Younger surrogates (age ≤51) (n = 127)	*Older surrogates (age >51) (n = 111)*	*All surrogates (n = 238)*
Knowing the patient had told them that they didn't want to be kept alive in this condition (%)	70	52[b]	62[c]
Knowing that the patient was permanently unconscious (%)	65	45[b]	57
Knowing that the patient had a terminal illness (%)	63	44[b]	54
Knowing that the patient had terminal illness (%)	60	41[b]	54
Knowing that the patient had lost the ability to relate to others (%)	60	41[b]	51
Being told by the doctor that the patient shouldn't be kept alive in the condition they were in (%)	49	39	45

[a] Numbers indicate the percentage of respondents who rated each factor as "extremely important" in a decision to stop a life-sustaining treatment.

[b] $p < 0.01$ for older surrogates compared to younger surrogates.

[c] 95% confidence intervals around reported percentages for all respondents are ±6%.

related to surrogate knowledge of specific patient preferences or to the extent of agreement on treatment values. As a whole, our results suggest that successful efforts to develop patient-centered and family-based advance care planning[11,15–18] will require physicians or other health care professionals to take a more active role in assuring that surrogates are prepared to fulfill their responsibilities. Our data strongly suggest that physicians cannot assume that patients who report having talked with their family will have adequately prepared them for surrogate decision making. To facilitate this goal, new strategies are needed.

One such strategy may be to encourage pa-

TABLE 4. DIFFERENCES IN PREFERENCES FOR END-OF-LIFE CARE[a]

Preference	*Patients (n = 242)*	*Surrogates (n = 242)*	*Patient & surrogate both agreed (%)*	*Patient & surrogate both disagreed (%)*
Live as long as possible even though suffering (%)	18	10[b]	3	75
Avoid suffering even if living shorter (%)	64	64	44	16
Choose being kept alive as long as possible over avoiding suffering (%)	23	12[b]	6	71
Attempt a 2-week trial if unsure recovery is possible (%)	65	75[b]	49	10
Be sure patient won't recover before stopping life-sustaining treatment (%)	77	85[b]	68	6

[a] Numbers in Patients and Surrogates columns indicate the percentages of respondents who agreed with the preference statement. The numbers in the third and fourth columns indicate within-pair concurrence with the preference statement, either both in agreement or disagreement. The rows in the table are not meant to add up to 100%.

[b] $p < 0.03$ for surrogates compared to patients.

tients and their surrogates to discuss the amount of freedom the surrogate ought to exercise in decision making. In general, patients want to allow their surrogates more freedom to make decisions than surrogates desire. Surrogates were more likely to believe that the best way to prepare for decision making was through written and oral instructions from the patient. More surrogates than patients believed that it was important to discuss specific EOL issues. Such discussions may convince patients that their surrogates want and need more information than they have received. These discussions may also reassure surrogates that they may make choices that go beyond those explicitly communicated by the patient.

A second possible strategy is for physicians to obtain patients' permission to directly discuss with surrogates the amount and kinds of information that they need to be prepared to fulfill their responsibilities as a decision-maker. Because surrogates were more likely than patients to believe that physicians should be included in discussions of EOL decision making, direct physician communication with surrogates is needed to assure that surrogates' needs are met.

Our results also indicate that physicians should encourage patients and their surrogates to discuss two basic value conflicts that often arise in EOL choices: suffering and uncertainty. Patients were more likely than surrogates to choose to prolong life despite suffering, and patients were less concerned than their surrogates about certainty before stopping a life-sustaining treatment. Encouraging patients to discuss specific situations they consider to entail suffering may assist surrogates in understanding patients' preferences regarding prolongation of life versus ending suffering.

Finally, our results indicate that physicians may want to recommend that advance care planning be conducted in stages whenever possible. Initially, physicians may be most helpful and supportive when they encourage discussions about more general issues, including who the patient wants to function as surrogate, how the patient and surrogate prefer to have the patient express EOL preferences (i.e., writing a formal advance directive, orally, or both), and who the patient (and surrogate) want to include in advance care planning discussions. These topics are comparatively nonthreatening and can establish a foundation for subsequent discussions.

At a later stage, physicians should encourage discussions between the patient and surrogate of the values guiding EOL choices and the specific choices that the patient or their surrogate may need to make. We recommend such specific discussions because the factor surrogates most frequently regarded as extremely important in making a decision to stop a life-sustaining treatment was being told by the patient that the patient would not want to live in a specific condition. Even though we interviewed dialysis patients with long histories of illness, our results indicate that discussions of specifics such as use of feeding tubes, dialysis, and CPR in permanent coma were still relatively uncommon among patients and surrogates.

Limitations

This study has two major limitations with regard to generalizability: we studied patients with surrogates who could be contacted in only two regions of the country and we studied only one subset of patients with chronic illness, those with ESRD undergoing hemodialysis. Despite these limitations, these results may be generalizable to those with other chronic illnesses. Except for lower education levels than have been reported in some other studies, the demographics of our sample closely matched those of the ESRD population nationwide,[29] and the EOL preferences of hemodialysis patients are very similar to those of patients with other chronic conditions.[31] Because we obtained very similar results in two very dissimilar regions and patient populations, our generalizability is enhanced. Our generalizability also is strengthened by our replication of the findings of researchers studying other patient populations in other geographic regions, including one nationwide EOL care study,[32] a study of 140 patients with human immunodeficiency virus (HIV),[33] and a statewide study in Vermont.[34] Although our study is the first to have examined the preferences of patient-surrogate pairs for the decision making process, the patients we studied shared attitudes towards doctor and family involvement in EOL decisions that were very similar to each of these other studies.[12] Because many dialysis patients have been hospitalized and experienced other serious health problems, they are more likely to have discussed EOL issues with their families. This fact has led others to suggest that dialysis patients are an ideal population in which to study advance care planning.[35]

Advance care planning is a complex process involving multiple parties who have different preferences and needs. Standard approaches to advance care planning have focused almost exclusively on the concerns of patients and physicians.[36,37] Surrogate understanding of the situations in which the patient would not want to live is critical to surrogates confronted with such decisions. Because of this, patients and surrogates should be urged to discuss these situations. Advance care planning that encourages both patients and physicians to communicate more frequently and extensively with surrogates has the potential for obtaining better information about the patient's values and preferences, developing more trust between families and physicians, and fostering EOL care that is more respectful of patients' wishes.

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