

Dialysis Patients' Preferences for Family-Based Advance Care Planning

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Background: Most patients do not participate in advance care planning with physicians.

Objective: To examine patients' preferences for involving their physicians and families in advance care planning.

Design: Face-to-face interviews with randomly selected patients.

Setting: Community-based dialysis units in one rural and one urban region.

Participants: 400 hemodialysis patients.

Measurements: Questions about whom patients involve in advance care planning, whom patients would like to include in this planning, and patients' reactions to state legislation on surrogate decision makers in end-of-life care.

Results: Patients more frequently discussed preferences for end-of-life care with family members than with physicians (50% compared with 6%; $P < 0.001$). More patients wanted to include family members in future discussions of advance care planning than wanted to include physicians (91% compared with 36%; $P < 0.001$). Patients were most comfortable with legislation that granted their family end-of-life decision-making authority in the event of their own incapacity ($P < 0.001$).

Conclusion: Most patients want to include their families more than their physicians in advance care planning.

To date, studies do not show widespread patient acceptance of the current model of advance care planning (1–3). One flaw in this model may be the assumption that physicians should play a major role and families should play a minor one in the advance care planning process (4–6). Studies have shown that patients who specify their preferences for future treatment usually do so more often to their families than to their physicians (7–10). Most states have also passed legislation that presumes that families are the best surrogate decision makers if a written advance directive is not available (11, 12). Thus, patients' communication practices and recent changes in legislation that provide families with a greater role in end-of-life decision making may be incompatible with the current advance care planning model.

In this study, we examine hemodialysis patients' preferences for involving physicians and family members in advance care planning. We also explore patients' reactions to state laws that provide varying degrees of decision-making authority to family members who act as surrogates.

Methods

Patients

A stratified random sample of adult hemodialysis patients located in one rural region and one metropolitan region was studied. The first region included all six dialysis units in a rural area that encompassed northern West Virginia and southwestern Pennsylvania. The second region included all nine dialysis units in the city of Rochester, New York. Approximately 30 nephrologists treat the patients in these regions. Eligible patients were at least 18 years of age, spoke English, and were capable of oral communication. Informed consent was obtained from each patient before the interview.

Study Design

Face-to-face patient interviews were conducted in the dialysis units during hemodialysis treatments. Patients were asked whether they had completed an advance directive and whom they would want to be their surrogate for medical decisions if they became incapacitated. Patients also indicated whether they had discussed end-of-life preferences for cardiopulmonary resuscitation, mechanical ventilation, tube feeding, and dialysis with their surrogate, other family members, or physicians. Patients who had not discussed these issues with other family members or their physicians were asked whether they wanted to do so in the future. Patients were also asked whether they would be comfortable talking about

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Table 1. Patient Characteristics

Characteristics	U.S. Renal Data System National Patient Data	Total Patient Sample (n = 400)	Patients from West Virginia and Pennsylvania (n = 153)	Patients from New York (n = 247)
Mean age (range), y	56* (0-85)	59 (20-89)	62 (24-87)†	57 (20-89)
Women, %	46	45	51	41
Ethnicity, %				
White	62	67	90‡	52
Black	32	29	9‡	41
Other	6	5	1	7
Mean education (range), y		11.9 (1-20)	11.5 (3-20)	12.1 (1-19)
Married, %		45	51§	41
Selected family member as surrogate, %		93	95	91
Mean duration of dialysis (range), mo		41.6 (1-277)	36.3 (1-277)	44.8 (1-259)

* $P < 0.05$ for age of patients in the U.S. Renal Data System compared with age of the total patient sample.

† $P < 0.05$ for patient ages.

‡ $P < 0.001$ for ethnic differences between patients.

§ $P = 0.05$ for percentage of patients living with a family member.

important questions that should be discussed “with those they are close to about how they would want to be treated if they got very sick.” If patients responded that they would be comfortable, they were asked whom they would like to include in such a conversation and whom they would like to lead the discussion.

West Virginia has a health care surrogate law that authorizes surrogate decision making in the absence of written advance directives. New York and Pennsylvania do not have such a law. After listening to brief summaries of the relevant legislation, which had been reviewed by external experts for accuracy, respondents in New York and West Virginia reported their level of comfort with the laws of those two states and respondents in Pennsylvania evaluated the laws of Pennsylvania and West Virginia.

The research protocol was approved by the institutional review boards of West Virginia University, the University of Rochester, and each dialysis unit.

Table 2. Patients' Desire for Family and Physician Involvement in Advance Care Planning*

Form of Involvement	Surrogate†	Other Family Member	Physician
	←-----%-----→		
Person with whom specific treatment preferences are discussed	50 (45-55)	46 (41-51)†	6 (4-8)
Person with whom, besides surrogate, patient wants to discuss specific preferences in the future	-	23 (19-27)†	2 (1-3)
Person whom patient wants to include in conversation about desired treatment if he or she is very ill	91 (87-91)	88 (84-92)†	36 (31-41)
Person whom patient wants to lead conversation about desired treatment if he or she is very ill‡	45 (40-50)	6 (4-8)	9 (6-12)

* $n = 400$. Values in parentheses are 95% CIs.

† $P < 0.001$ for differences with the percentage of patients who wanted to include the physician.

‡ Twenty-five percent of patients wanted to lead such a conversation themselves. The remainder did not want to have such a conversation or wanted a different person, such as a social worker or a member of the clergy, to lead it.

Statistical Analysis

Comparisons of demographic characteristics and of preferences for the involvement of family members and physicians in advance care planning were examined by using the *t*-test, the Pearson chi-square statistic, and the McNemar test. A two-tailed *P* value of 0.05 was considered statistically significant.

Results

Completed interviews were obtained from 400 (77%) of the 518 randomly selected patients who met the inclusion criteria; interviews lasted for a mean of 30 minutes. As shown in **Table 1**, the average age of our sample was 3 years greater than that of the U.S. population with end-stage renal disease (which includes patients <18 years of age) (13) but was comparable in other respects. Of the 390 patients who identified a surrogate decision maker, 93% selected a family member.

Patients were more likely to report comfort discussing end-of-life care with their family than they were to complete an advance directive (79% compared with 51%; $P < 0.001$). As shown in **Table 2**, patients were much more likely to have discussed specific treatment preferences with their surrogates and with other family members than with their physicians. Although 23% of patients expressed a desire to tell family members whom they had not yet informed about these specific preferences, only 2% of patients wanted to inform a physician they had not yet told ($P < 0.001$). When asked whom they would want to include in a discussion of how they wished to be treated if they became critically ill and whom they would want to lead this discussion, substantially fewer patients expressed a desire for the involvement of their physician than for the involvement of their surrogate or other family members (**Table 2**).

Eighty-five percent of patients (95% CI, 81% to

89%) expressed comfort with the West Virginia state law that allows family members a greater role in decision making and does not require families to go to court to have treatment withheld or stopped. Significantly fewer patients reported comfort with the state laws of New York (26% [CI, 21% to 31%]) and Pennsylvania (18% [CI, 7% to 29%]) ($P < 0.001$). These differences persisted regardless of age, sex, ethnicity, geographic region, or marital status (all $P < 0.01$).

Discussion

We found that patients' preferences do not support the current model of advance care planning, which assumes that such planning should occur in the context of the patient-physician relationship. Patients talk much more frequently about specific end-of-life issues with their surrogates and with other family members than they do with their physicians. Although only 36% of patients wanted to include a physician in discussions of advance care planning, 91% of patients wanted to include their surrogate and 88% of patients wanted to include additional family members.

Although study participants were not asked why they did not want to talk to their physicians about advance care planning, other qualitative studies of persons' opinions about end-of-life care—including a nationwide study (14), a statewide study in Vermont (15), a study of 140 patients with HIV (16), and a study of dialysis patients (17)—have found that patients do not trust their physicians to honor their wishes. Instead, they trust their families and prefer that their families speak for them.

These results suggest that most patients do not want a physician-oriented approach to advance care planning (4) and that the current model is not sufficient. The development of a patient-centered, family-based model for advance care planning is supported by our research, the research of others (14–17), and the evolving role of the patient in U.S. medicine (18).

A patient-centered, family-based model is also supported by patients' preferences for the legal role of families in end-of-life decision making. Patients were much more comfortable with legislation that allows family members to be appointed as surrogates and make decisions to withhold or withdraw life-sustaining treatment without judicial involvement.

The major limitations of our study relate to its generalizability. Because we studied only hemodialysis patients, we lack data on the preferences of other patient populations. However, similar findings in qualitative studies (14–17) and in a recent comparative study of the end-of-life values of dialysis

patients, HIV patients, and residents of long-term care facilities (19) suggest that many patient populations prefer to conduct advance care planning within their families and with limited physician involvement. In addition, because dialysis patients have a chronic condition that requires frequent contact with their physicians, dialysis patients may be an ideal population in which to study advance care planning (20). Another generalizability concern relates to our focus on only two geographic regions. Although regional biases about advance care planning may exist, we observed few differences and obtained results similar to the findings of a qualitative study of dialysis patients in another region (17). We recognize these limitations, but generalizability is not necessarily an all-or-none phenomenon (16). We expect that the desire for physician involvement in advance care planning may be even less among persons who have less extensive contact with physicians. Further research is necessary in other patient populations to assess the extent to which our findings are generalizable.

Because most of the hemodialysis patients we studied wanted to have conversations about end-of-life issues with close family members rather than with physicians, additional advance care planning options are needed. In a patient-centered, family-based model, physicians would have a new but important role in which they would provide information about advance care planning and encourage the process within the context of the family. Physicians would also need to inquire about the results of patient-family deliberations to be able to respect their patients' preferences. In addition, our data indicate that when end-of-life decisions need to be made, patients want their family members to have the legal authority to make them. If the practice of medicine is to become truly patient-centered, patients' preferences in decision making and treatment should guide the changes we make in medicine and the law.

Disclaimer: The opinions expressed are those of the authors and do not necessarily represent those of the supporting foundation.

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But Zingara never tired of humanity or found it a nuisance. She enjoyed telling fortunes and truly thought she did good by it. "Most people have nobody to talk to," she said to me many times. "Wives and husbands don't talk; friends don't really talk because people don't want to get mixed up in anything that might cost them something in the end. Nobody truly wants to hear anybody else's worries and troubles. But everybody has worries and troubles and they don't cover a big range of subjects. People are much more like one another than they are unlike. Did you ever think of that? Well? So I am someone to talk to . . . I don't look like the doctor or preacher, always judging, always tired. Flatter everybody. Is it crooked? Most people are starved to death for a kind word."

Robertson Davies
World of Wonders
Viking Pr; 1976

Submitted by:
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