

Chronic In-Center Hemodialysis Patients' Attitudes, Knowledge, and Behavior Towards Advance Directives¹

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ABSTRACT

Forty-three chronic in-center hemodialysis patients were asked about their knowledge, attitudes, and behavior towards advance directives. The survey collected patient demographic data and assessed attitudes, knowledge, and behavior towards advance directives by agreement or disagreement with statements. Sixty-six percent of patients did not know what a health care proxy was, and 42% did not know the legal status of a living will. However, 90% of older patients (≥ 60 yr of age) understood living wills. Although 77% of the patients had discussed their wishes about life-sustaining care with someone close to them, only 17% had had such discussions with their doctor. Twenty-one percent had completed an advance directive. Fifty percent of patients agreed with the statement that a potential problem with advance directives was that patients could change their minds about heroic treatments; 51% agreed that advance directives might interfere with a doctor's judgment. Only 26% agreed that a dialysis unit's promotion of the use of advance directives might lead to undertreatment. Patient age, race, marital status, and time on dialysis did not affect responses. A prior failed transplant and the educational level completed by the patient influenced some specific responses. Despite some concern, 79% of patients agreed that a dialysis unit policy asking patients whether they had completed an advance directive was a good idea.

Key Words: Living wills, health care proxy, medical ethics

With the enactment of the Patient Self-Determination Act in November 1991, Medicare and Medicaid provider organizations were required to

develop written policies and provide patients with information about advance directives (1). Documents such as a living will or health care proxy are examples of advance directives that outline a patient's wishes for future medical care. The provider organizations specified by the Patient Self-Determination Act include hospitals, hospices, nursing homes, home health agencies, and health maintenance organizations. Although dialysis units were not specifically noted, they also come under the Medicare provider organizations. The knowledge and attitudes of chronic dialysis patients about the use and implementation of advance directives are not well known. A survey of chronic in-center hemodialysis patients was therefore done to assess these patients' attitudes, knowledge, and behavior towards advance directives. Specifically, we wanted to know: (1) if patients understand what a health care proxy is and the legal status of living wills; (2) if patients had had discussions about advance directives and/or completed an advance directive; (3) what patients perceive as barriers to the implementation of advance directives, and (4) what are patients' attitudes towards advance directives and programs to promote their use?

METHODS

All in-center chronic hemodialysis patients were asked to complete the survey during one of their routine dialysis treatments. The surveys were administered during September 1991 by the nurse practitioner working in the dialysis unit. After granting informed consent, 43 patients completed the survey; 12 patients refused to participate.

The dialysis center is a free-standing unit administered through the University of Pittsburgh. One nephrologist is primarily responsible for outpatient care and is identified by the patients as their doctor (R. Rault). Renal fellows and other nephrologists (J.L. Holley) spend 1 to 3 months/yr "rounding" in the unit. At the time of the study, no formal policy about advance directives or cardiopulmonary resuscitation and no routine discussions about these topics were held with the patients, as was the rule in most dialysis units at that time (2). When hospitalization is required, patients are admitted to Presbyterian University Hospital. The hospital's policy of providing information about advance directives (mandated by the Patient Self-Determination Act) took effect December 1, 1991.

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The survey consisted of patient demographic data including age, sex, race, marital status, educational level attained, time on dialysis, and history of kidney transplantation. Patients were also asked to define their current state of health (excellent, good, fair, or poor) and how religious they were. Apart from their ESRD, patients also indicated whether or not they or any family member had ever been seriously ill.

The remainder of the survey was composed of statements related to advance directives to which the patient agreed or disagreed by circling a number from 1 to 5. The categories of responses corresponding to the numbers circled were as follows: 1, agree strongly; 2, agree; 3, not sure; 4, disagree; 5, disagree strongly. Only three category titles were listed on the questionnaire (agree strongly, unsure, disagree strongly). For data presentation, agree is the total of responses numbered 1 and 2 and disagree is the total of the responses numbered 4 and 5. Because not all patients responded to each statement, the percentage of patients agreeing with a statement was calculated as the total number agreeing divided by the total number responding to that statement. The first page of the questionnaire contained a definition of an advance directive, including examples of a living will and a proxy.

The survey was approved by the University of Pittsburgh Institutional Review Board. Statistical analysis was performed by unpaired *t* test and the Mann-Whitney *U* test for nonparametric data where appropriate. A *P* value less than 0.05 was considered significant.

RESULTS

The patient demographic data are given in Table 1. Forty-one of the 43 patients had been hospitalized overnight at least once. Forty-seven percent of patients (20 of 43) said that they had an illness, besides kidney failure, that was potentially life threatening. Thirteen patients (30%) said that there had been a time during which they were too sick to participate fully in their own medical care, and 49% (21 of 43) reported such an experience involving an adult family member or someone close to them.

Thirty-three percent of the patients understood what a health care proxy was, and 42% understood the legal status of a living will in Pennsylvania. More elderly patients (≥ 60 yr of age; $N = 11$) understood the status of living wills (median response, 1 [strongly agree]), versus patients < 60 yr of age (median response, 3 [not sure]; $P = 0.02$). Thirty-three patients (77%) had discussed wishes about life-sustaining care with someone close to them, but only 7 (17%) had had such discussions with their doctor. Only nine patients (21%) had completed an advance directive.

TABLE 1. Patient demographic data^a

Mean Age (yr)	48 ± 15 (range, 24–74)
Men (%)	20 (47%)
White	22 (51%)
African-American	20 (47%)
Asian	1 (2%)
Marital Status	
Single	16 (37%)
Married	13 (30%)
Separated/divorced	8 (19%)
Widowed	6 (14%)
Education	
≤12 yr	22 (51%)
>12 yr	21 (49%)
How Religious	
Very	15 (35%)
Somewhat	16 (37%)
Not very	9 (21%)
Not at all	3 (7%)
Prior Transplant	15 (35%)
Time on Dialysis	
≤3 yr	11 (26%)
>3 yr	32 (74%)
Health in General	
Excellent	0
Good	20 (47%)
Fair	19 (44%)
Poor	4 (9%)

^a $N = 43$.

Table 2 shows the patients' responses to statements about the perceived barriers to the implementation of advance directives. Patients with 12 yr of formal education or fewer were more likely to agree that a potential problem with advance directives was that patients could change their minds (median response of 2 versus median response of 3 in those with more than 12 yr of education; $P = 0.04$). Patients with a prior, failed transplant disagreed with the statement that patients and physicians had more important things than advance directives to discuss during clinic visits (median response of 4 [disagree] versus median response of 2 [agree] in patients without a prior transplant; $P = 0.03$). Patients with a prior transplant were unsure if the use of advance directives could interfere with a doctor's judgment about medical care (median response of 3 [not sure] versus median response of 2 [agree] in nontransplanted patients; $P = 0.04$). Patients who were somewhat religious (median response of 3 [not sure]) differed from those who were not very religious (median response of 4 [disagree]; $P = 0.03$) in agreement that a dialysis unit's promotion of the use of advance directives could lead to undertreatment. No other patient demographic feature, patient-reported health status, or

previous personal or family experience with life-threatening illness affected the responses.

Table 3 shows the patients' attitudes about advance directives and ways to promote their use. Patients generally agreed that discussion and education about advance directives were good ideas.

TABLE 2. Patients' perceived barriers to implementation of advance directives

	Agree	Not Sure	Disagree
A major barrier to discussing advance directives with the doctor is a lack of time	27 (65%)	9 (21%)	7 (16%)
Advance directives can cause problems because they may interfere with a doctor's judgment about how to care for a patient	22 (51%)	9 (21%)	12 (28%)
A potential problem with advance directives is that patients could change their minds about heroic treatments after becoming terminally ill	20 (50%)	9 (23%)	11 (28%)
During clinic visits, patients and doctors have more important things to discuss than advance directives	20 (47%)	5 (12%)	18 (42%)
If a dialysis unit strongly promotes the use of advance directives, I would worry that this might lead to undertreatment of patients	11 (26%)	10 (23%)	22 (51%)

DISCUSSION

Thirty-three percent of our patients understood a health care proxy. Fifty-eight percent understood the status of living wills in Pennsylvania, with age (≥ 60 yr) predicting the understanding of living wills. Thus, although 77% of the patients had discussed their wishes about life-sustaining care with someone close to them, formal knowledge about advance directives was less secure. This could be because only 17% of the patients had discussed such issues with their doctor. As previously reported in both dialysis (3,4) and nondialysis populations (5,6), patients are quite willing to engage in discussions about life-sustaining care and desire some form of advance directive (7). They do, however, expect physicians to initiate such discussions (6).

Before the passage of the Patient Self-Determination Act, only 8% of chronic hemodialysis units had policies for obtaining advance directives from their patients (2). It is not unusual, then, that only a small proportion of chronic hemodialysis patients would have completed an advance directive (21% in this study). The instrument used to assess patient knowledge and behavior towards advance directives in this study was not optimal and conceivably biased our results. Furthermore, our study group consisted of mostly long-term dialysis patients who were relatively young and well educated. Thus, they may represent a selected population. The characteristics of the 12 patients who refused to participate are not known, and therefore, it may be unwise to generalize these results to all chronic dialysis patients. However, others have found that a minority of dialysis (8) and nondialysis patients (1) have completed advance directives, results similar to ours.

TABLE 3. Patient attitudes about advance directives and programs to promote their use

	Agree	Not Sure	Disagree
Attitudes About Advance Directives			
Feel prepared and comfortable to discuss advance directives with my doctor	32 (78%)	5 (22%)	4 (10%)
Advance directives should help avoid wasteful use of expensive hospital treatments	27 (63%)	9 (21%)	7 (16%)
Advance directives are irrelevant or unnecessary for most dialysis patients	2 (5%)	9 (21%)	32 (74%)
Attitudes About Programs Promoting the Use of Advance Directives			
Doctors should encourage patients to talk about advance directives with their family and/or close friends	39 (93%)	3 (7%)	0
A policy of asking all dialysis patients whether they have prepared an advance directive is a good idea	33 (79%)	8 (19%)	1 (2%)
Dialysis units should conduct educational programs about advance directives	34 (70%)	6 (14%)	3 (7%)

Our results are also subject to a desirability bias (patients gave the responses they thought we wanted to hear) and may merely reflect the patients' projections based on the survey instrument's inherent bias. However, the concern that an advance directive may not allow for specific clinical situations that would abrogate a strict interpretation of the directive has previously been raised (9). Moreover, a recent study reported that only 39% of chronic hemodialysis patients granted surrogates or physicians no leeway to override an advance directive (10). In another study of nursing home patients, 25% of the time the care rendered was inconsistent with written advance directives (11). Inattention to the document and decisions to place priority on considerations other than the advance directive accounted for the limited effectiveness of written advance directives in this study (11). Thus, although our survey questions introduced bias regarding patients' perceived barriers to the implementation of advance directives, our patients' attitudes may reflect some observed practices and the concerns of some in medical practice.

A prior transplant was the only patient factor that affected patient attitudes about the implementation of advance directives. Patients with a prior transplant were less likely to agree that an advance directive could interfere with a doctor's judgment and were also less likely to agree that the patient and doctor had more important things than advance directives to discuss. Those with a prior transplant therefore seemed to approach advance directives more favorably. The reason for this is unclear. Past hospital experiences may have influenced the responses, but further study is needed to elucidate this finding.

Ninety-three percent of the patients agreed that doctors should encourage patients to discuss advance directives with family and/or close friends. Over 70% of the patients agreed with dialysis unit policies asking all patients about advance directives. Thus, as in the nondialysis population (7), most dialysis patients welcome the opportunity to complete advance directives. Seventy percent of the patients agreed that dialysis units should conduct educational programs about advance directives. Little has been written about formal programs on advance directives sponsored by dialysis units. One unit reported that 53% of the patients who completed a videotape and workbook-centered program on advance directives subsequently completed an advance directive (8). We are currently engaged in a formal educational program on advance directives in our dialysis unit that should provide more information about the success and problems with such programs.

When an incompetent dialysis patient's family requests that dialysis be discontinued, the patient's prior wishes were found to be a significant factor in the nephrologist's response: 90% of nephrologists

would stop dialysis in the case of clear prior wishes, but only 63% would stop in the absence of the patient's clear prior wishes (12). Thus, dialysis-directed programs to educate dialysis patients about advance directives would seem to benefit both patient and physician. Such programs should include discussions of particular circumstances in which an advance directive should be followed or ignored (10). Discussion of these issues, rather than establishment of a formal written advance directive (9,10), may be preferred.

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