Life-Sustaining Treatment Preferences of Hemodialysis Patients: Implications for Advance Directives[1]

Peter A. Singer,[2] Elaine C. Thiel, C. David Naylor, Robert M.A. Richardson, Hilary Llewellyn-Thomas, Marc Goldstein, Carl Saiphoo, P. Robert Uldall,[3] Donald Kim, and David C. Mendelssohn

P.A. Singer, Centre for Bioethics, University of Toronto, Toronto, Canada

P.A. Singer, C.D. Naylor, R.M.A. Richardson, M. Goldstein, C. Saiphoo, P.R. Uldall, D. Kim, D.C. Mendelssohn, Department of Medicine, University of Toronto, Toronto, Canada

H. Llewellyn-Thomas, Department of Nursing Science, University of Toronto, Toronto, Canada

P.A. Singer, R.M.A. Richardson, D.C. Mendelssohn, Toronto Hospital, Toronto, Canada

M. Goldstein, St. Michael's Hospital, Toronto, Canada

C. Saiphoo, C.D. Naylor, Sunnybrook Health Science Centre, North York, Canada

P.R. Uldall, Wellesley Hospital, Toronto, Canada

D. Kim, Credit Valley Hospital, Mississauga, Canada

E.C. Thiel, C.D. Naylor, H. Llewellyn-Thomas, Institute for Clinical Evaluative Sciences in Ontario, North York, Canada

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ABSTRACT

The purpose of this study was to describe the life-sustaining treatment preferences of dialysis patients and to compare the acceptability of two generic and a disease-specific advance directive (AD). Of 532 potentially eligible hemodialysis patients, 95 (17.9%) participated in the study. These patients completed two generic (the Centre for Bioethics Living Will and the Medical Directive) and one disease-specific (the Dialysis Living Will) AD in a randomized cross-over trial. Treatment preferences were measured by using the Centre for Bioethics Living Will. Acceptability of the AD was measured by using a 13-item advance directive acceptability questionnaire (ADAQ) for each AD, and the advance directive choice questionnaire (ADCQ) to elicit participants' preferred AD. Twenty-five percent of the participants wanted to continue dialysis in case of severe stroke, 19% in severe dementia, and 14% in permanent coma. Averaged across treatments, proportions of participants wanting treatment in various health states were: current health (86%), mild stroke (84%), moderate stroke (60%), severe stroke (21%), mild dementia (78%), moderate dementia (51%), severe dementia (14%), terminal illness (41%), and permanent coma (10%). Averaged across health states, proportions of participants wanting various types of treatment were: dialysis (58%), antibiotics (53%), transfusion (53%), surgery (48%), cardiopulmonary resuscitation (48%), respirator (47%), and tube feeding (41%). Mean ADAQ scores were: Dialysis Living Will, 71%; Centre for Bioethics Living Will, 70%; and Medical Directive, 60% ($F = 8.27$, $P < 0.001$ (repeat measures analysis of variance); the Dialysis Living Will and Centre for Bioethics Living Will scored significantly higher than the Medical Directive). The proportion of participants who said they would choose to complete each AD was: Dialysis Living Will, 28%; Centre for Bioethics Living Will, 38%; Medical Directive, 31%; and unsure, 3% ($\chi^2 = 1.465$, df = 2, $P = 0.48$). In conclusion, twenty-five percent or less of hemodialysis patients want to continue dialysis in three specific health states: severe stroke, severe dementia, and permanent coma. Health states and illness severity, far more than treatment descriptions, influence preferences. Dialysis patients should be offered a generic AD, and some generic AD are more acceptable than others. Only a minority of dialysis patients will complete any AD, but the completion of written AD forms is only one element in the process of advance care planning.

Key Words: *Advance directives, ethics-medical*

Withdrawal from dialysis is the third most common cause of death in dialysis patients (1). About half of the time, patients who are withdrawn from dialysis are mentally incompetent (2). Knowledge of the life-sustaining treatment preferences of these patients would be extremely helpful to substitute decision-makers and nephrologists in deciding whether to continue or stop dialysis. Such knowledge is obtained through advance care planning, a "process of communication among patients, their health care providers, their families, and important others regarding the kind of care that will be considered appropriate when the patient cannot make decisions." (3,4) Advance care planning may incorporate the completion of written advance directives (AD).

Decisions to forgo treatment and AD have received considerable empirical attention in the context of dialysis (1,2,5–10). Therefore, it is surprising that,

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[2] Correspondence to Dr. P.A. Singer, Centre for Bioethics, University of Toronto, 88 College St., Toronto, Ontario, Canada, M5G-1L4.

[3] Deceased. This article is dedicated to Dr. Uldall's memory.

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although previous studies have examined the treatment preferences of dialysis patients (11–14), none has done so in as comprehensive a manner as might be recorded in a typical AD. Moreover, because an AD developed specifically for dialysis patients might be more acceptable than a generic AD, we developed a dialysis-specific AD on the theory that the choice to continue or stop dialysis would serve as a surrogate for other life-sustaining treatment choices (15,16). The purpose of this study was to describe the treatment preferences of dialysis patients and to compare the acceptability of the dialysis AD with that of two generic AD.

METHODS

Study Design

This randomized cross-over trial involved a total of five interviews, conducted during a period of about 3 wk during the patients' regular dialysis visits. The randomization scheme was stratified by dialysis unit and sequence of presentation of AD by using a 3 × 3 latin square design. At the first visit, patients completed a brief demographic questionnaire and viewed a 20-min videotape on AD for dialysis patients, entitled "If I Only Knew" (17). During each of Visits 2 to 4, participants received one of the three study AD in random order; at each visit, they completed the AD and rated its acceptability by using the Advance Directive Acceptability Questionnaire (ADAQ; see below). At the fifth visit, participants reviewed all three completed AD and stated which they would choose to complete using the AD choice questionnaire (ADCQ; see below).

Participants

We included patients receiving hemodialysis at all six units serving adults in Metropolitan Toronto. Patients were excluded if they were less than 18 yr of age, were unable to understand written English, were incapable of completing an AD, would experience undue emotional distress from completing one, had received dialysis for less than 3 months, or refused to participate in the research. The determination of whether potential participants fit these exclusion criteria was made by the patient's dialysis nurse or by the research assistant.

Interventions

Three AD were used in this study: the Medical Directive, (18), the Centre for Bioethics Living Will, and the Dialysis Living Will. All three AD are combined proxy and instruction directives. The Medical Directive and the Centre for Bioethics Living Will are generic AD; the Dialysis Living Will is a disease-specific AD developed specifically for patients on dialysis. There are marked differences in design between the two generic AD, including the background information provided regarding AD, the taxonomy and description of health states and treatments, and the format of the AD. The Dialysis Living Will is similar in design to the Centre for Bioethics Living Will, on which it is based, except that the specific treatments are reduced to just two, cardiopulmonary resuscitation (CPR) and dialysis, based on the assumption that the choice to continue or stop dialysis is an adequate surrogate for other treatment choices. The Centre for Bioethics Living Will and Dialysis Living Will are available upon request from the authors.

Outcome Measures

Treatment preferences were measured by using the Centre for Bioethics Living Will. Descriptions of health states and treatments used to elicit these preferences are contained in the Appendix. Acceptability of the AD was measured by using the ADAQ, which contains 13 items rated on a five-point ordinal scale ranging from excellent to poor. The ADAQ had been previously evaluated for face and content validity by an interdisciplinary panel with expertise in AD and, in the current study, internal consistency reliability coefficient (Cronbach's α) for the ADAQ was 0.93. Choice of AD was measured by using the ADCQ. The ADCQ asked respondents, "We are interested in which of the 3 living wills you liked best. If you were going to complete a living will, which one would you choose to complete?" There was also space for patients to provide open-ended comments about why they chose that AD over the others, what they liked about it, and what they disliked about the others.

Data Analysis

Demographic characteristics, treatment preferences, and the proportions of subjects who would use a particular AD were analyzed by using simple descriptive statistics. ADAQ items were scored as follows: 0 = poor, 1 = fair, 2 = good, 3 = very good, and 4 = excellent. The total score on the ADAQ was calculated by the addition of scores on each individual item, division by the highest possible total score, and multiplication by 100, to yield a percent value. Total ADAQ scores for the three AD were compared by using repeated measures analysis of variance. To evaluate their potential confounding effect, dialysis unit (N = 6) and sequence of AD presentation (N = 3) were included as between-subjects factors in the analysis. The least-squares means procedure was used to correct the total ADAQ scores for possible confounders and to analyze differences between acceptability scores for the three AD. The χ^2 test was used to test the hypothesis that the proportion of participants who would choose to complete each AD on the ADCQ would be equal, *i.e.*, 0.33. Responses to the open-ended question on the ADCQ about why respondents preferred their chosen AD over the others were analyzed by content analysis.

Sample Size

A priori, we based our sample size primarily on grounds of feasibility. We planned to approach all 540 patients receiving hemodialysis in Metropolitan Toronto's six hemodialysis units. Based on an estimated 15% participation rate, we expected to enroll 81 subjects. We estimated that this sample would yield a 95% confidence interval (CI) at a difference in ADAQ scores of ±3.3%, which was relatively small compared with a clinically important difference on the ADAQ in a previous study of 12 to 14% (19). The clinically important difference in ADAQ score in the current study, calculated with the mean difference in ADAQ score between participants' chosen and nonchosen AD according to the ADCQ, was 9.3% (95% CI 6.7%, 11.9%).

Research Ethics

The study was approved by the Review Committee on the Use of Human Subjects at the University of Toronto and by the research ethics committees at each of the participating hospitals.

RESULTS

Respondent Characteristics

There were 532 patients (215 women and 317 men) receiving hemodialysis as outpatients at the six dialysis units during the study period. Of these, 310 patients were excluded (275 by the dialysis staff and 35 by the research assistants) for the following reasons: 169 were unable to understand written English, 19 had poor vision, 94 were considered psychologically or physically unable to participate, 13 patients had been on dialysis for less than 3 months, 1 was less than 18 yr of age, and 14 were away during the study period. Of the remaining 222 eligible subjects, 95 completed the study, 20 began the study but withdrew before completing all five visits (eight due to illness), 26 were not approached because our required sample size had been exceeded, and 81 chose not to participate. Of the 81 patients who chose not to participate, the reasons given were "not interested" (N = 32); "not now/working," "too sleepy," "feel ill," or "other concerns while being dialyzed" (N = 29); "no" without further explanation (N = 10); "in other studies" (N = 7); and "already have a living will or proxy" (N = 3).

Of the 95 participants, 34% were women, 44% were married, 74% were Caucasian, 30% were employed, and 77% had finished high school. The mean age of participants was 47.7 yr (range, 20–81 yr). Current health was described by 6% as excellent, 19% as very good, 36% as good, 32% as fair, and 7% as poor. Eighty-five percent of the participants had been hospitalized during the past 2 yr, 44% had other illnesses, 11% had received CPR, and 65% had been in an intensive care unit. Sixty-two percent had heard of living wills before the study and 7% had completed one.

Treatment Preferences

Treatment preferences elicited by using the Centre for Bioethics Living Will are shown in Figure 1. Twenty-five percent of participants wanted to continue dialysis in case of severe stroke, 19% in case of severe dementia, and 14% in case of permanent coma. Averaged across treatments, proportions of participants wanting treatment in various health states were: current health (86%), mild stroke (84%), moderate stroke (60%), severe stroke (21%), mild dementia (78%), moderate dementia (51%), severe dementia (14%), terminal illness (41%), and permanent coma (10%). Averaged across health states, proportions of participants wanting various types of treatment were: dialysis (58%), antibiotics (53%), transfusion (53%), surgery (48%), cardiopulmonary resuscitation (48%), respirator (47%), and tube feeding (41%). As shown in Figure 2A, less than 10% of participants who refused dialysis chose to receive any of the other life-sustaining treatments in any health situation. By contrast, as shown in Figure 2B, up to 46% of participants who chose dialysis in a particular health state refused one of the other treatments in that health state.

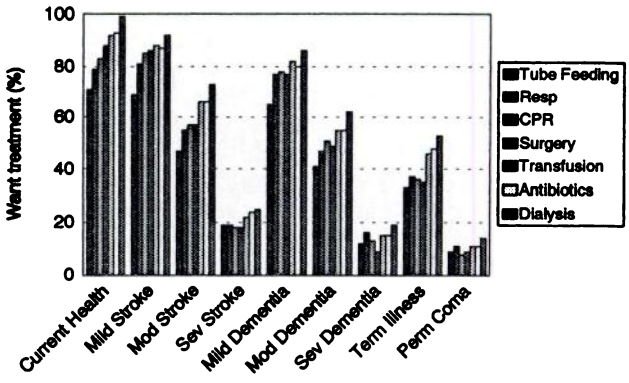

Figure 1. The proportion of patients wanting various treatments in various health states (N = 95). Health states are on the x-axis: current health; mild, moderate, and severe stroke; mild, moderate, and severe dementia; terminal illness; and permanent coma. Treatments are clustered within health states: tube feeding, respirator, CPR, surgery, transfusion, antibiotics, and dialysis.

Advance Directive Acceptability Scores

Mean scores on the ADAQ were: Dialysis Living Will, 71%; Centre for Bioethics Living Will, 70%; and Medical Directive, 60% (F = 8.27, df = 2, $P < 0.001$). The Dialysis Living Will and Centre for Bioethics Living Will scored significantly higher than the Medical Directive (P = 0.0003 and P = 0.0009, respectively), but there was no significant difference between the Dialysis Living Will and Centre for Bioethics Living Will (P = 0.78). Scores for individual ADAQ items for the three AD are shown in Table 1. There were significant differences favoring the Dialysis Living Will and Centre for Bioethics Living Will over the Medical Directive in general information provided, simplicity of language, amount of detail, length, description of situations, description of treatments, and ease of giving instructions about treatment.

Advance Directive Choices

At the final visit, after reviewing the AD together, proportions of subjects who said on the ADCQ that they would choose to complete each AD were: Dialysis Living Will, 28%; Centre for Bioethics Living Will, 38%; Medical Directive, 31%; and unsure, 3% (χ^2 = 1.46, df = 2, P = 0.48). On the ADCQ, participants were also asked to provide their reasons for choosing their preferred AD over the other two. Those who chose the Dialysis Living Will said they did so because it was more concise, simpler to read and understand, easier to complete, and suited their personal needs better than the other two AD. Those who chose the Centre for Bioethics Living Will said they did so because it offered more treatment choices, and the explanations of health situations and treatments were better than in the other two AD. Those who chose the Medical Directive said they did so because it offered more treatment

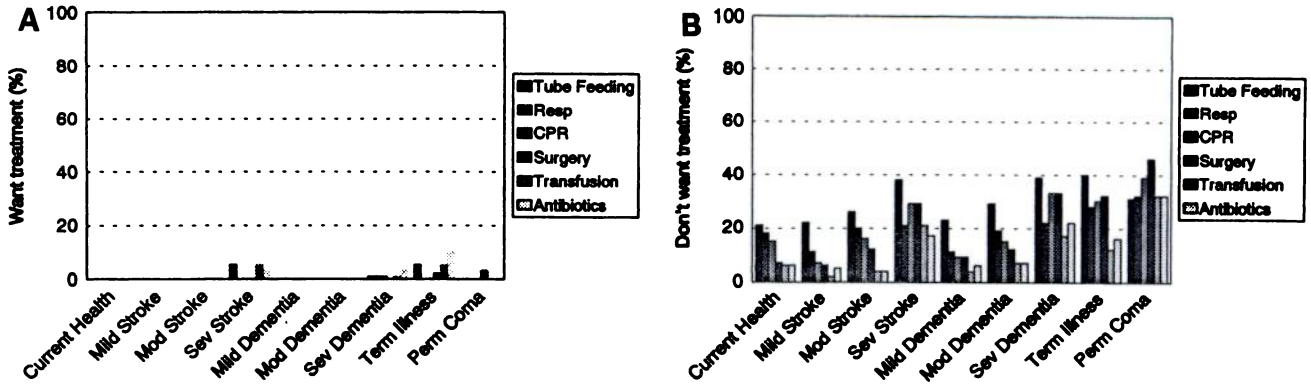

Figure 2. (A) Proportion of participants who don't want dialysis but want other life-sustaining treatments in a particular health state. (B) Proportion of participants who want dialysis but don't want other life-sustaining treatments in a particular health state.

TABLE 1. Acceptability scores of the three advance directives

Item	ADAQ Score (mean (SD))[a]		
	DLW[b]	CFBLW[b]	MD[b]
General Information	2.97 (0.82)	3.01 (0.75)	2.55 (1.00)[c]
Simplicity of Language	3.00 (0.91)	3.06 (0.86)	2.45 (1.04)[c]
Amount of Detail	2.63 (0.89)	2.80 (0.95)	2.43 (1.12)[c]
Length	2.67 (0.99)	2.48 (0.94)	2.09 (1.11)[c]
Design or Layout	2.65 (1.04)	2.38 (1.09)	2.30 (1.18)
Description of Situations	2.93 (0.88)	2.77 (0.93)	2.32 (1.18)[c]
Description of Treatments	2.81 (0.86)	2.87 (0.91)	2.41 (1.03)[c]
Easy-to-Give Instructions	2.70 (0.99)	2.65 (1.03)	2.26 (1.18)[c]
Easy-to-Appoint Proxy	2.98 (1.02)	3.07 (0.95)	2.67 (1.11)
Raised Disturbing Issues	2.73 (1.05)	2.64 (0.90)	2.53 (1.07)
Express Wishes	2.62 (1.04)	2.72 (1.08)	2.41 (1.11)
Control over Medical Care	2.78 (0.95)	2.76 (0.96)	2.53 (1.15)
Overall	2.74 (0.90)	2.75 (0.88)	2.38 (1.07)

[a] ADAQ: Items have been scored so that 0 = poor, 1 = fair, 2 = good, 3 = very good, and 4 = excellent.
[b] DLW, Dialysis Living Will; CFBLW, Centre for Bioethics Living Will; MD, Medical Directive (see text).
[c] ADAQ score for MD significantly lower ($P < 0.05$) than DLW and CFBLW with repeated measures analysis of variance.

choices, and the format or layout was preferred to that of the other two AD.

DISCUSSION

This study provides new information regarding four aspects of dialysis patient care: (*1*) life-sustaining treatment preferences; (*2*) the influence of health states and illness severity on the treatment preferences; (*3*) the acceptability of various types of written AD forms to dialysis patients; and (*4*) the low likelihood of widespread completion of any written AD form in the dialysis population.

Life-Sustaining Treatment Preferences

Previous studies of dialysis patients' life-sustaining treatment preferences have shown that 74% would stop dialysis if they became demented (11), and 58% would choose to stop dialysis in case of permanent coma (12). Our study provides a comprehensive view of hemodialysis patients' life-sustaining treatment preferences in various health states. Twenty-five percent or less of the hemodialysis patients would want to continue dialysis in three health states: severe stroke, severe dementia, and permanent coma.

There is some discrepancy between the preferences of patients and the reported behaviors of nephrologists. Moss *et al.* have reported that 68% of dialysis unit medical directors would continue dialysis with a patient who becomes severely demented (7). However, Singer *et al.* have shown that knowledge of a patient's prior wishes to stop dialysis strongly influence nephrologists to stop dialysis if that patient should become incompetent (6). Therefore, the gap between hemodialysis patients' treatment preferences and nephrologists' reported behaviors could be closed through advance care planning.

Influence of Health States and Illness Severity on Treatment Preferences

Health states have a greater influence on preferences than do treatments. Preferences across health states vary widely from 86% of participants wanting to continue treatment if needed while in their current health state to 10% wanting treatment in case of permanent coma. By contrast, preferences across treatments are much less variable, from 58% of participants wanting dialysis to 41% wanting tube feeding. Therefore, to elicit a full set of preferences, advance directives should focus on descriptions of a spectrum of health states from current health, with an acute, potentially reversible illness, to permanent coma. The descriptions of these health states should be at least as comprehensive as the description of treatments. By implication, in discussions with patients about future treatment choices, such as discussions about "Do Not Resuscitate" orders, physicians should focus on not only the treatments proposed, but also the resultant health states.

Within a particular health state, illness severity strongly influences preferences. Eighty-four percent of participants would want treatment in case of a mild stroke, 60% in moderate stroke, and 21% in severe stroke. Similar results were found for mild, moderate, and severe dementia. An AD or discussion that does not probe for differences in illness severity within health states will fail to identify major variations in preferences.

Acceptability of Various Written AD Forms

Our data show that dialysis patients should be offered a generic AD. Participants gave the Dialysis Living Will and Centre for Bioethics Living Will virtually identical ratings on the ADAQ (71% *versus* 70%). Moreover, a lower proportion of participants would choose to complete the Dialysis Living Will than the Centre for Bioethics Living Will (28% *versus* 38%). Therefore, our initial hypothesis that dialysis patients would find the Dialysis Living Will more acceptable than a generic AD was not supported.

Why did the Dialysis Living Will fail? The Dialysis Living Will was developed on the theory that the choice to continue dialysis was an adequate surrogate for other treatment choices. The data on treatment preferences show that this theory is incorrect. Generally, preferences regarding dialysis were an inadequate surrogate for treatment preferences. When participants refused dialysis, they were unlikely to choose any of the other life-sustaining treatments in any of the health situations. However, among participants who chose dialysis, about one-third would refuse other life-sustaining treatments in particular situations. Therefore, a patient's choice regarding dialysis is an adequate surrogate for other life-sustaining treatment choices only if the patient refuses dialysis. If the patient chooses dialysis, it cannot be assumed that he or she necessarily wants other life-sustaining treatments. These results build on the finding of Holley *et al.* that dialysis patients are more willing to refuse ventilation than to discontinue dialysis (12).

Nevertheless, some generic AD may be more acceptable than others. The dialysis patients in our study found the Centre for Bioethics Living Will more acceptable than the Medical Directive. Participants gave the Centre for Bioethics Living Will a significantly higher rating on the ADAQ (70% *versus* 60%). Moreover, a higher proportion of participants (38% *versus* 31%) said they would choose to complete the Centre for Bioethics Living Will than the Medical Directive (this difference was not statistically significant). In a previous study with similar methods, we compared the acceptability of the Medical Directive with another generic AD, the Let Me Decide directive, to family medicine outpatients and found them to be equally acceptable (19). As far as we are aware, the current study is the first to show that any AD is more acceptable to patients than any other AD.

Low Likelihood of Widespread Completion of Written AD Forms in Dialysis Population

It appears that only a minority of dialysis patients will complete any written AD (5,8,10). Of 532 potentially eligible hemodialysis patients, only 95 (17.9%) completed the study. The reasons for nonparticipation provide important insights for advance directive program-planning in dialysis units. Three reasons accounted for nonparticipation of two-thirds (64.7%) of the initial cohort of dialysis patients. The most important reason for nonparticipation was the inability to understand written English (169 patients, or 31.8% of the initial cohort). Unless serious attention is paid to the development of culturally sensitive advance directives in other languages, the potential benefits of advance care planning will be denied to almost one-third of dialysis patients. The second most important reason for nonparticipation was that a number of patients were considered psychologically or physically unable to participate by the nursing staff or research assistant (94 patients, or 17.7% of the initial cohort). Generally, these patients were cognitively impaired or too ill to participate in the study. This group underlines the importance of beginning advance care planning before it is too late to be effective. The third most important reason for nonparticipation was the refusal by the patient (81 patients, or 15.2% of the initial cohort). It is not clear whether these patients refused to participate because they did not want to consider an advance directive or did not want to participate in a research study. Nevertheless, it is noteworthy that patient refusal, traditionally regarded as the main limiting factor on advance directive education programs, is only the third most important reason for nonparticipation by dialysis patients.

Regardless of the reasons for nonparticipation, our study underlines the findings of others that there is a low likelihood of widespread completion of written AD forms in the dialysis population. For instance, Holley and colleagues found that 13% of hemodialysis patients completed a written AD before receiving educational material on AD, 48% shortly after, and 37% 6 months after (9). There are two possible conclusions from our data and from those of Holley *et al.* Either AD programs are doomed to failure in dialysis units, or simply counting completed, written AD forms is an inadequate measure of the benefits of advance care planning. Although we cannot confirm one conclusion or the other based on our current data, we favor the latter view. Advance care planning is a process in which AD forms are embedded (3,4). It is possible that many of the goals of advance care planning can be met through discussions between patients and their health providers or substitute decision-makers. Using qualitative methods, we are currently investigating the process of advance care planning in dialysis.

Limitations

The main limitations of this study occur because only 95 of the 532 patients (17.9%) receiving dialysis in the six units completed the study. Although the point estimates for treatment preference for a given treatment in a particular health state should be generalized with caution, there is no reason to believe that the pattern of variation in preferences across health states and treatments should be different in nonparticipants compared with participants. Moreover, our findings about acceptability of various AD are not undermined, because the patients included in our study sample likely approximate those who would complete an AD in practice, precisely the group whose views about the acceptability of any particular AD form are important to elicit.

Conclusions

Twenty-five percent or less of hemodialysis patients want to continue dialysis in three specific health states: severe stroke, severe dementia, and permanent coma. Health states and illness severity, far more than treatment descriptions, influence preferences. Dialysis patients should be offered a generic AD, and some generic AD are more acceptable than others. Only a minority of dialysis patients will complete any AD, but the completion of written AD forms is only one element in the process of advance care planning.

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APPENDIX: HEALTH STATE AND TREATMENT DESCRIPTIONS IN THE CENTRE FOR BIOETHICS LIVING WILL

Health States

Current Health. This describes the way your health is now.

Stroke. This means you would have damage to the brain causing permanent physical disability such as paralysis. You might also have trouble communicating because of impaired speech. These problems stay the same for the rest of your life. They do not get worse with time unless there is another injury to the brain, such as another stroke. Stroke can be described as:

- *Mild*: You would have mild paralysis on one side of the body. You could walk with a cane or walker. You would be able to have meaningful conversations, but might have trouble finding words. You could carry out most routine daily activities, such as work and household duties, dressing, eating, bathing, and using the toilet. You would have bowel and bladder control. You could live at home with someone caring for you for a few hours each day.
- *Moderate*: You would have moderate paralysis on one side of the body. You would be unable to walk and would need a wheelchair. You could carry out conversations, but you might not always make sense. You would need help with routine daily activities. You may have bowel and bladder control. You could live at home with someone caring for you throughout the daytime; otherwise you would probably need to live in a nursing home.
- *Severe*: You would have severe paralysis on one side of the body. You would be unable to walk and would need to be in a wheelchair or bed. You would not have meaningful conversations. You would be unable to carry out routine daily activities. You would need a feeding tube for nourishment. You would not have bowel or bladder control. You could live at home with someone caring for you all day and night; otherwise you would probably need to be cared for in a chronic care hospital.

Dementia. This means you would have a progressive and irreversible deterioration in brain function. You would be awake and aware, but you would have trouble thinking clearly, recognizing people, and communicating. The most common cause of dementia is Alzheimer's disease. Dementia gradually gets worse over months or years. Dementia can be described as:

- *Mild*: You could have meaningful conversations, but would be forgetful and have poor short-term memory. You could carry out most routine daily activities, such as work and household duties, dressing, eating, bathing, and using the toilet. You would have bowel and bladder control. You could live at home with someone caring for you for a few hours each day.
- *Moderate*: You would not always recognize family and friends. You could carry out conversations but you might not always make sense. You would need help with routine daily activities. You may have bowel and bladder control. You could live at home with someone caring for you throughout the daytime; otherwise you would probably need to live in a nursing home.
- *Severe*: You would not recognize family and friends, and would be unable to have meaningful conversations. You would be unable to carry out routine daily activities. You would need a feeding tube for nourishment. You would not have bowel and bladder control. You could live at home with someone caring for you all day and night; otherwise you would

probably need to be cared for in a chronic care hospital.

Terminal Illness. This means you would have an illness for which there is no known cure, such as some types of cancer. It is likely that you would die within six months even if you received treatment.

Permanent Coma. This means you would be permanently unconscious. Permanent coma is usually caused by decreased blood flow to the brain, for example, from the heart stopping. You would be unable to eat or drink and would need a feeding tube for nourishment. You would not have bowel or bladder control. You would need to be in bed and you would never regain consciousness. You could live at home with someone caring for you all day and night; otherwise you would probably need to be cared for in a chronic care hospital.

Treatment

Dialysis (kidney machine) replaces the normal functions of the kidney. Dialysis removes excess potassium, water, and other waste products from the blood. Without dialysis, the potassium in the blood would build up and cause the heart to stop. Dialysis is needed as long as the person's kidneys are not working. Without dialysis, a person with kidney failure will die within 7 to 14 days. With dialysis, the chance that a person will live depends on the cause of the kidney failure and the seriousness of the person's other illnesses.

Cardiopulmonary Resuscitation (CPR) is used to try to restart the heart if it has stopped beating. CPR involves applying pressure and electrical shocks to the chest, assisted breathing with a respirator (breathing machine) through a tube inserted down the throat and into the lungs, and giving drugs through a needle into a vein. It is usually followed by unconsciousness and several days of treatment in an intensive care unit. Without CPR, immediate death is certain. On average, when hospitalized patients are given CPR, it is successful at restarting the heart in about 41% of the patients (41 patients out of 100). However, about 14% (14 patients out of 100) will live to be discharged from hospital. Patients whose hearts are successfully restarted but who do not survive to hospital discharge spend several days in an intensive care unit before death. The chance that a person will live depends on the cause of the heart stopping and the seriousness of the person's other illnesses.

Respirator (breathing machine) is used when a person cannot breathe; for example, because of emphysema or a serious pneumonia. A tube is put down the person's throat into the lungs. The respirator is needed as long as the person's lungs are not working. Without the respirator, a person with respiratory failure will probably die within minutes to hours. With the respirator, the chance that a person will live depends on the cause of the respiratory failure and the seriousness of the person's other illnesses.

Life-Saving Surgery may involve a wide range of procedures, for example, removal of an inflamed gall bladder or appendix. Without surgery, a person with a serious illness may die within hours to days. With surgery, the chance that a person will live depends on why the person needed surgery and the seriousness of the person's other injuries or illnesses.

Blood Transfusion refers to blood given through a needle inserted in a person's vein. A person who is bleeding very heavily from a car accident, a stomach ulcer, or during major surgery, needs a blood transfusion. Without a blood transfusion, a person who is bleeding very heavily will probably die within hours. With a blood transfusion, the chance that a person will live depends on the seriousness of the person's other injuries or illnesses.

Life-Saving Antibiotics refers to the drugs needed to treat life-threatening infections; for example, pneumonia or meningitis. These drugs are usually given through a needle inserted in a person's vein. Without antibiotics, a person with a life-threatening infection will likely die in hours to days. With antibiotics, the chance that a person will live depends on the seriousness of the infection and the seriousness of the person's other illnesses.

Tube Feeding involves putting a tube into a person's stomach (through the nose, or through a small hole in the abdomen). A person who cannot eat (e.g., some in a coma) needs a feeding tube. Tube feeding is needed as long as the person cannot eat. Without tube feeding, a person who cannot eat or drink will die within days to weeks. With tube feeding, the chance that a person will live depends on the seriousness of the person's other injuries or illnesses.

REFERENCES

1. **US Renal Data System:** USRDS 1993 Annual Data Report. National Institute of Diabetes and Digestive Diseases, National Institutes of Health, Bethesda MD, March 1993.
2. **Neu S, Kjellstrand CM:** Stopping long-term dialysis. N Engl J Med 1986;314:14–20.
3. **Teno JM, Nelson HL, Lynn J:** Advance care planning: Priorities for ethical and empirical research. Hastings Cent Rep 1994;24:S32-S36.
4. **Emanuel L, Danis M, Pearlman RA, Singer PA:** Advance care planning as a process: Structuring the discussions in practice. J Am Geriatr Soc 1995;43:440–446.
5. **Sehgal A, Galbraith A, Chesney M, Schoenfeld P, Charles G, Lo B:** How strictly dialysis patients want their advance directives followed? JAMA 1992;267:59–63.
6. **Singer PA and the ESRD Network of New England:** Nephrologists' experience with and attitudes towards decisions to forego dialysis. J Am Soc Nephrol 1992;4: 229–234.
7. **Moss AH, Stocking CB, Sachs GA, Siegler M:** Variation in the attitude of dialysis unit medical directors toward decisions to withhold and withdraw dialysis. J Am Soc Nephrol 1993;4:229–234.
8. **Holley JL, Nespor S, Rault R:** Chronic in-center heamodialysis patients' attitudes, knowledge and behavior towards advance directives. J Am Soc Nephrol 1993;3: 1405–1408.
9. **Holley JL, Nespor S, Rault R:** The effects of providing chronic hemodialysis patients written material on advance directives. Am J Kidney Dis 1993;22:413–418.
10. **Swartz RD, Perry E:** Advance directives are associated

with "Good Deaths" in chronic dialysis patients. J Am Soc Nephrol 1993;3:1623–1630.
11. **Kaye M, Lella JW:** Discontinuation of dialysis therapy in the demented patient. Am J Nephrol 1986;6:75–79.
12. **Holley JL, Finucane TE, Moss AH:** Dialysis patients' attitudes about cardiopulmonary resuscitation and stopping dialysis. Am J Nephrol 1989;9:245–251.
13. **Reilly GS:** A questionnaire for dialysis patients on treatment cessation issues. Dial Transplant 1990;19:533–535.
14. **Cohen LM, Woods A, McCue J:** The challenge of advance directives and ESRD. Dial Transplant 1991;20:593–594,615.
15. **Singer PA:** Disease specific advance directives. Lancet 1994;344:594–596.
16. **Mendelssohn DC, Singer PA:** Advance directives in dialysis. Adv Renal Replacement Ther 1994;1:240–250.
17. **Colvin ER, Hammes BJ:** "If I Only Knew": A patient education program on advance directives. ANNA J 1991; 18:557–560.
18. **Emanuel LL, Barry MJ, Stoeckle JD, Ettelson LM, Emanuel EG:** Advance directives for medical care—A case for greater use. N Engl J Med 1991;324:889–895.
19. **Reinders M, Singer PA:** Which advance directives do patients prefer? J Gen Intern Med 1994;49–51.

"I remember that one day Baird Hastings brought Richards to visit the laboratory and I was brash enough to tell him that I hoped to study the proximal tubule. He murmured something polite and walked on. He didn't tell me what I was not bright enough to work out for myself—that it was a formidable enterprise and that I would have to mobilize all my resources to suceed . . . . By this time, a number of young M.D.s who wanted postdoctoral research experience had begun to join my laboratory. I reasoned, wrongly, that their medical school education would have taught them enough about surgical techniques so that they would only have to read the papers of the Richards group in order to emulate their technique. This was a mistake that almost ruined the laboratory."

Arthur K. Solomon. Transport pathways: Water movement across cell membranes. In: Membrane Transport. People and Ideas. Tosteson DC. ed. American Physiological Society, Bethesda, 1989.