Robert A. Pearlman, Helene Starks, Kevin C. Cain, William G. Cole, Donald L. Patrick and Richard F. Uhlmann

Integrating Preferences for Life-Sustaining Treatments and Health States Ratings into Meaningful Advance Care Discussions[1]

Abstract

Advance care planning tries to ensure that decision-making for decisionally incapacitated patients is patient-centered. This has particular relevance for end-of-life decisions. Although many people in the United States favor advance care planning, only a minority prepares advance directives. One impediment to clinician encouragement and involvement is not knowing how to discuss these issues.

To help frame advance care planning discussions, we studied the interrelationships between treatment preferences and health state ratings of patients and well adults. The study population included a diverse sample of well adults and patients (n=342). Six treatment preferences were elicited in current health and two hypothetical states describing permanent coma and severe dementia. The six treatments were antibiotics, long-term hemodialysis, short-term mechanical ventilation, cardiopulmonary resuscitation (CPR), long-term jejunal feeding tube, and long-term mechanical ventilation.

When participants declined noninvasive treatments, they usually declined more invasive treatments, and when they wanted to receive invasive treatments, they usually accepted less invasive ones. The data suggest an empirically derived, organizing sequence of treatments that represent increasing degrees of 'aggressiveness' that is influenced by invasiveness and treatment duration. CPR was in the mid-range of aggressiveness, and preferences for CPR were poor predictors of other treatment preferences.

These results suggest that eliciting preferences for only CPR is not sufficient information to infer a patient's preferences for more invasive or long-term life-sustaining treatments. In addition, knowing that patients want treatment in their current health does not generalize well to wanting treatment in more impaired functional health states. Lastly, refusing treatment in severely impaired states of health, such as severe dementia or permanent coma, does not generalize well to refusing treatment in less impaired states of health.

[1] This research was supported by Grant No. HS-06343 from the Agency for Health Care Policy and Research, Department of Health and Human Services. Dr. Pearlman received additional support from the Faculty Scholars Program of the Project on Death in America (Open Society Institute).

In this chapter the rationale for the role of advance care planning in end-of-life decision-making is reviewed. We also review our research in this area, complementing previously published data with new analyses and discuss how these data help frame advance care planning discussions. Finally, an outline is given for a research agenda on advance care planning.

Advance care planning has received attention as an important means to enhance end-of-life care.[1,2] The major goal of advance care planning is to extend a patient's right to self-determination into the period when he or she becomes decisionally incapacitated. This is supposed to occur by ensuring that medical decisions made on behalf of patients without decisional capacity are based on either their previous wishes or their best interests. Advance care planning aims to accomplish this by having (1) the patient's wishes, expressed during a period of prior decisional capacity, serve as an action guide, and/or (2) the patient specify a surrogate decision-maker who will represent him or her in making decisions.

It is important to differentiate advance care planning from advance directives. Advance care planning is a process that involves four steps: (1) thinking about one's values and preferences for medical care if one is unable to communicate, (2) communicating these values and preferences to loved ones and health care providers, (3) documenting values and preferences, and (4) ensuring that these documents are accessible and up-to-date. Advance directives represent only one part of this process: they are the mechanisms used to document patients' wishes or appoint surrogate decision-makers.

It is hoped that advance care planning will serve several additional functions: (1) reduce the risk of over-treatment and under-treatment, (2) minimize the conflicts among family members and between clinicians and family members, and (3) reduce the burden of surrogate decision-making that is placed on family members. Unfortunately, there are limited data that support the effectiveness of advance directives.[3-5] Before indicting the use of advance directives, it is prudent to recognize the barriers to effective advance care planning. These are outlined below.

- Reimbursement mechanisms for advance care planning discussions are uncertain.[6]
- Efforts to promote efficiency in the outpatient setting have reduced the length of provider-patient visits.
- In spite of patient interest, physicians often wait too long or never initiate advance care planning discussions.[7-9]
- When discussions occur, they are often superficial (for instance, cardiopulmonary resuscitation (CPR) is often discussed without reference to the need for mechanical ventilation or likelihood of failure).[10-12]
- Advance directives often are written using vague language or are restricted to terminal illness or permanent vegetative states. This inhibits clinical applicability.[5,12-14]
- Clinicians frequently are inadequately educated and trained to conduct advance care planning discussions.[11,15]
- Clinicians and surrogates lack good understanding of patients' wishes.[16-19]

These barriers led us to investigate preferences for life-sustaining treatment and attitudes about health states with a diverse sample of volunteers. Participants were

provided with detailed descriptions of health states and treatments to facilitate more informed decision-making. Once informed choices were elicited, the relationships between assessments of health states and treatment preferences were characterized, as well as the relationships between different treatment preferences within a health state and across health states. These data provide a valid profile of attitudes and preferences that could form the basis for meaningful advance care planning discussions. This in turn could result in better discussions, more meaningful advance directives, and increased utility in clinical settings. The specific study questions addressed in this research are as follows:

1. When people consider life in a particular circumstance as 'worse than death,' what is the likelihood that they will refuse life-sustaining treatments in that circumstance?
2. How well does a person's preference for one treatment in a specific health state predict that person's preferences for other treatments in the same health state?
3. How well does a person's preference for one treatment in a specific health state predict that person's preferences for the same treatment in other health states?
4. If an advance care planning discussion is organized based on the results from this data set, how would it be structured, and why?

Methods

Overview

The research findings reviewed in this chapter are derived from a longitudinal study conducted between 1991 and 1995 in which preferences for life-sustaining treatments were elicited under a variety of conditions. Participants also rated their current health state and two hypothetical states depicting severe dementia and permanent coma. Some of the results from this study have been published elsewhere.[20-21] In this chapter, these results are reviewed and additional analyses are presented.

Patient population

The study participants were volunteers from seven groups in the Seattle area: younger well adults age 21 to 65 (n = 50), older well adults over age 65 (n = 49), older adults (over 65 years of age) with at least one chronic illness (n = 49), persons with cancer and a physician-estimated life expectancy of 6-24 months (n = 49), persons with AIDS or class IV HIV infection (n = 50), survivors of a stroke that occurred within the last ten years and resulted in residual impairment (n = 45), and nursing home residents who were expected to remain in the nursing home for at least six months (n = 50). Participants had to be at least 21 years of age, have no major vision or hearing impairments, show cognitive ability according to the Telephone Interview for Cognitive Status, and speak English.[22] Well adults could not have any health condition that had lasted longer than one year, be receiving regular treatment by a health care provider or be taking medications more than twice monthly.

Table 1. Participant characteristics at baseline

	Younger well adults (n=50)	Older well adults (n=49)	Persons with chronic illness (n=49)	Persons with terminal cancer (n=48)	Persons with AIDS (n=50)	Stroke survivors (n=45)	Nursing home residents (n=51)	Total sample (n=342)
Characteristic								
Mean age, years (s.d.)	41 (12)	72 (6)	76 (7)	60 (11)	37 (7)	63 (13)	80 (12)	61 (19)
Female sex, %	58	67	59	44	6	38	80	50
Education, % some college	96	76	47	56	70	58	28	62
Married/living with partner, %	54	49	31	60	16	71	12	41
Self rating of health, % fair or poor	0	6	31	42	54	31	32	28
Functional status, %*								
No to little dysfunction	98	88	35	27	0	0	0	36
Mild to moderate dysfunction	2	10	47	50	54	58	14	33
Severe dysfunction	0	2	18	23	46	42	86	31
Have depressive symptoms, %†	8	6	12	17	46	27	28	21
Low satisfaction with health and quality of life, %‡	10	8	35	48	72	67	60	43

* Functional status measured by the Sickness Impact Profile.[23] Total Sickness Impact Profile scores < 3 represent no to little dysfunction, scores ranging from 3 to 19.99 represent mild to moderate dysfunction, and scores ≥ 20 represent severe dysfunction or the need for assistance with three or more activities of daily living.

† Depressive symptoms measured by the Center for Epidemiologic Studies-Depression scale.[24] A score of ≥ 16 on the Center for Epidemiologic Studies-Depression scale indicates probable depression.

‡ Satisfaction measured by the Perceived Quality of Life scale.[25] Low satisfaction is defined as a score less than the sample mean of 7.3.

All variables differ across participant groups, $p < 0.0001$.

Reprinted with permission from the Annals of Internal Medicine

Well adults were recruited by sending letters to addresses that were randomly selected from the telephone directory. Eligible patients were identified with the help of community and university-affiliated physicians and social service intermediaries. Potential participants were sent or given information statements about the project. If an individual was interested in learning more about the study, he or she could contact the study office. All persons who contacted the study office were screened. Informed consent occurred at the time of the interview. A total of 342 persons participated in the study. The characteristics of the participants are presented in Table 1.

Questionnaire description

Treatment preferences, health state ratings, and health status data were collected during in-person interviews. Preferences for antibiotics, long-term mechanical ventilation (with tracheostomy), long-term hemodialysis, long-term jejunal tube feeding, short-term mechanical ventilation, and CPR were elicited in each participant's current health and two hypothetical states representing severe dementia and permanent coma. Two versions of a visual aid to facilitate decision-making were used. Figure 1 shows the visual aid used to elicit preferences for CPR. A similar visual aid used for the other five treatments has been previously published.[20] That visual aid showed that the outcome of choosing treatment would result in a 100% chance of returning to the baseline state. Treatment preferences were elicited after reviewing the visual aid with the simple question, 'Do you want to receive treatment?'

The health states were characterized in four domains: (1) thinking, remembering and talking; (2) walking and mobility; (3) self care; and (4) pain and discomfort. For each domain, three to four levels were described with examples. For the current health situation, the participant selected the appropriate level of function for each domain.[20] The dementia state was characterized as 'think, remember, and talk with great difficulty; get around with great difficulty; perform self care with some difficulty; and are in no physical pain or discomfort.' The permanent coma situation was described as 'do not think, remember, or communicate in any way; are confined to a bed; do not perform self care activities; and are in no physical pain or discomfort.' These descriptions were complemented by examples written in everyday language. For example, 'get around with great difficulty' was further characterized with 'walk or use a cane, walker, or wheelchair but are limited to the house.' The descriptions of the levels and common language examples are presented elsewhere.[20] Health state ratings were elicited after reviewing the four domain descriptions with their corresponding examples. The ratings were elicited with the simple question, 'How would you rate this health state?'

Measurement

Treatment preferences were indicated on a five-point scale: 'definitely no', 'probably no', 'not sure', 'probably yes', and 'definitely yes'. Health states were rated on a seven-point scale: 'much worse than death', 'somewhat worse than death', 'a little worse than death', 'neither better nor worse than death', 'a little better than death', 'somewhat better than death', and 'much better than death'.

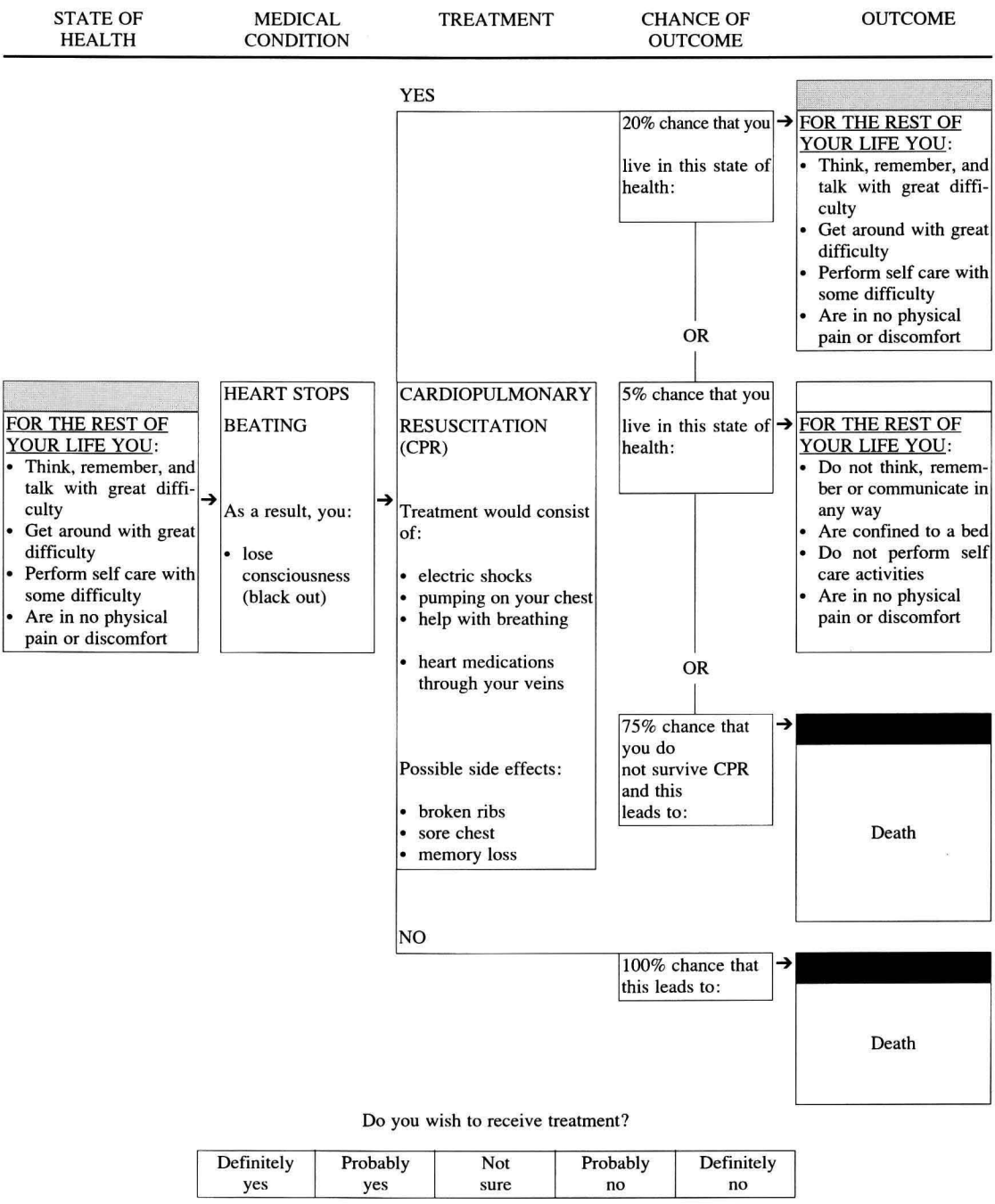

Figure 1. Sample of the visual aid to elicit preferences for CPR in the dementia health state. *Reprinted with permission from the Journal of Palliative Medicine.*

Analytic strategies

To facilitate analyses, the five-point treatment preference scale was collapsed into three clinically-based categories: forego treatment (representing 'definitely no' and 'probably no'), accept treatment (including 'definitely yes' and 'probably yes'), and not sure. The health state rating scale also was collapsed into three categories: worse than death, neither better nor worse, and better than death. To address the first study question, the percentage of treatment decisions that were refused when the health states were rated as 'worse than death' was calculated. To address the second and third study questions, positive and negative predictive values were used to assess the relationship between treatment preferences. Positive predictive value is the conditional probability that a person will want one treatment given a preference in favor of a different treatment. Negative predictive value is the conditional probability that a person will forego one treatment given a preference to forego a different treatment.

Results (previously reported)

Distribution of health state ratings and treatment preferences

Nearly all participants rated their current health as better than death. In contrast, 52% rated permanent coma as worse than death and 27% rated severe dementia as worse than death. Table 2 shows the distribution of treatment refusals in the three health states.

Table 2. Percentage of treatment refusals* in each of the three health states.

Treatment	Current health	Dementia	Coma
Antibiotics	5	20	62
Short-term mechanical ventilation	12	44	71
Cardiopulmonary resuscitation	23	60	85
Long-term dialysis	25	56	86
Long-term feeding tube	41	64	86
Long-term mechanical ventilation	58	77	86

* Includes 'probably no' and 'definitely no' treatment preference ratings.
Preferences for treatments differed across health states for every treatment ($p < 0.0001$) and across treatments for every health state ($p < 0.0001$).

Reprinted with permission from the Annals of Internal Medicine

Relationship between 'worse than death' health state ratings and treatment preferences

When health states were rated as worse than death, participants chose to forego life-sustaining treatments 85% of the time. The 15% of decisions in which participants accepted treatment in health states rated as 'worse than death' had several explanations.

First, many people wanted antibiotic treatment, viewing it as relatively simple and short-term. Second, some people used the 'worse than death' language to connote an undesirable state, rather than a literal interpretation in which death would be preferred to continued existence in that situation. Another reason given was that people wanted to respect the wishes of family members that they continue living.[20]

Predictive values between treatment preferences in current health

In general, the preference to receive more invasive treatments had high positive predictive value for less invasive treatments in current health (range, 0.86-1.0). For example, if a participant was willing to accept long-term treatment with a feeding tube, there was a greater than an 88% probability that s/he also would accept CPR, short-term mechanical ventilation, or intravenous antibiotics. In addition, preferences to forego less invasive treatments had moderately high negative predictive value for more invasive treatments (range, 0.61-0.94). For example, saying 'no' to intravenous antibiotics generalized to saying 'no' to all other life-sustaining treatments with greater than a 77% probability.[21]

Predictive values of treatment preferences between health states

The positive predictive values of treatments in permanent coma for the same treatment in severe dementia were high (range, 0.8-1.0). In contrast, wanting a treatment in current health did not generalize well to wanting the same treatment in the dementia situation (range, 0.44-0.77). Weak positive predictive values also were seen when trying to generalize treatment preferences from the dementia situation to the permanent coma situation (range 0.27-0.51).[21]

The negative predictive values of treatment preferences from current health to severe dementia were high (range, 0.88-0.97), excluding antibiotics which had a negative predictive value of 0.72. There were high negative predictive values when generalizing treatment preferences from the severe dementia situation to the permanent coma situation (range, 0.92-0.99). In contrast, weak negative predictive values were found generalizing from the permanent coma situation to the severe dementia situation (range, 0.20-0.77).[21]

Results (not previously reported)

Predictive values between treatments within hypothetical health states

As shown in Table 3a, the preference to receive more invasive treatments in the severe dementia situation had moderate to high positive predictive values for less invasive treatments, especially for intravenous antibiotics. For example, if a participant wanted long-term mechanical ventilation, there was a greater than a 78% probability that s/he also would want all other treatments. However, the converse was not true: no preference for any other life-sustaining treatment generalized well to long-term mechanical ventilation. Preferences for CPR did generalize well to antibiotics,

but only moderately well to short-term mechanical ventilation, long-term dialysis and long-term feeding tubes, and rather poorly to long-term mechanical ventilation.

Table 3a. Positive predictive value of treatments in dementia for each other.

	Then, the probability of saying 'yes' to this treatment is:						
If a person said 'yes' to:	n*	ABX	SMV	CPR	DYL	LFT	LMV
Antibiotics (ABX)	249	- -	.51	.41	.37	.33	.18
Short-term mechanical ventilation (SMV)	134	.96	- -	.60	.58	.49	.33
Cardiopulmonary resuscitation (CPR)	106	.97	.75	- -	.64	.59	.37
Long-term dialysis (DYL)	100	.92	.78	.68	- -	.63	.41
Long-term feeding tube (LFT)	82	.99	.79	.77	.77	- -	.45
Long-term mechanical ventilation (LMV)	47	.96	.94	.83	.87	.79	- -
Overall rate = yes†	342	.73	.39	.31	.29	.24	.14

Table 3b. Negative predictive value of treatments in dementia for each other.

	Then, the probability of saying 'no' to this treatment is:						
If a person said 'no' to:	n*	ABX	SMV	CPR	DYL	LFT	LMV
Antibiotics (ABX)	67	- -	.91	.99	.90	.96	1.00
Short-term mechanical ventilation (SMV)	150	.41	- -	.85	.83	.91	.95
Cardiopulmonary resuscitation (CPR)	206	.32	.62	- -	.76	.85	.93
Long-term dialysis (DYL)	192	.31	.65	.82	- -	.89	.96
Long-term feeding tube (LFT)	219	.29	.63	.80	.78	- -	.93
Long-term mechanical ventilation (LMV)	262	.26	.54	.73	.70	.77	- -
Overall rate = no†	342	.20	.44	.60	.56	.64	.77

* The n refers to the number of respondents who said 'yes' (Table 3a) or 'no' (Table 3b) to the treatments in the rows.

† The overall rates indicate how often participants wanted (Table 3a) or did not want (Table 3b) each of the treatments shown in the columns. All predictive values are significantly different from the overall rates ($p < 0.001$).

Table 3b shows that preferences to forego less invasive treatments in the severe dementia situation had moderate to high negative predictive values for more invasive treatments. For example, if a participant wanted to forego antibiotics, there was greater than an 89% probability that s/he would want to forego all other treatments. Preferences to forego most treatments generalized well to foregoing long-term feeding tubes and long-term mechanical ventilation. However, saying 'no' to long-term mechanical ventilation had moderate to poor negative predictive value for other treatments.

Tables 4a and 4b show results for predictive values between treatments in the permanent coma situation. There are similar patterns as with the dementia situation, but with lower positive predictive values and higher negative predictive values.

Table 4a. Positive predictive value of treatments in coma for each other.

	Then, the probability of saying 'yes' to this treatment is:						
If a person said 'yes' to:	n*	ABX	SMV	CPR	DYL	LFT	LMV
Antibiotics (ABX)	89	- -	.52	.36	.26	.20	.28
Short-term mechanical ventilation (SMV)	68	.68	- -	.44	.37	.34	.35
Cardiopulmonary resuscitation (CPR)	36	.89	.83	- -	.61	.50	.58
Long-term dialysis (DYL)	33	.70	.76	.67	- -	.61	.58
Long-term feeding tube (LFT)	26	.69	.88	.69	.77	- -	.62
Long-term mechanical ventilation (LMV)	30	.83	.80	.70	.63	.53	- -
Overall rate = yes†	342	.26	.20	.11	.10	.08	.09

Table 4b. Negative predictive value of treatments in coma for each other.

	Then, the probability of saying 'no' to this treatment is:						
If a person said 'no' to:	n*	ABX	SMV	CPR	DYL	LFT	LMV
Antibiotics (ABX)	210	- -	.91	.97	.95	.96	.98
Short-term mechanical ventilation (SMV)	243	.79	- -	.98	.98	.99	.98
Cardiopulmonary resuscitation (CPR)	288	.70	.82	- -	.95	.95	.95
Long-term dialysis (DYL)	293	.68	.81	.93	- -	.97	.95
Long-term feeding tube (LFT)	294	.68	.82	.93	.97	- -	.94
Long-term mechanical ventilation (LMV)	295	.70	.80	.93	.94	.94	- -
Overall rate = no†	342	.61	.71	.84	.86	.86	.86

* The n refers to the number of respondents who said 'yes' (Table 4a) or 'no' (Table 4b) to the treatments in the rows.

† The overall rates indicate how often participants wanted (Table 4a) or did not want (Table 4b) each of the treatments shown in the columns. All predictive values are significantly different from the overall rates ($p < 0.001$).

Predictive values of treatment preferences between health states

The predictive values of treatments in one state of health (index state) for the same treatment in another state of health (outcome state) varied widely, but several patterns can be seen (Tables 5a and 5b). First, high positive predictive values were seen for treatment preferences from either coma or dementia to current health. Second, the negative predictive values of treatment preferences from current health to permanent coma are moderately high.

Additionally, the data in the tables show that both positive and negative predictive values, within and across scenarios, are consistently more accurate (predictive) than the overall preference rates derived from all the participants. This indicates that for a given person, knowing some of his or her treatment preferences in one health state will more accurately predict preferences for another treatment in that health state or the same treatment in another health state than simply knowing, in general terms, what other people would want in similar circumstances.

Table 5a. Positive predictive values (PPV) for treatment preferences in one health state to another.

	Current health → Coma			Coma → Current health			Dementia → Current health		
Treatments:	n*	PPV	Rate†	n*	PPV	Rate†	n*	PPV	Rate†
Antibiotics	319	.27	.26††	89	.97	.93††	249	.99	.93
Short-term mechanical ventilation	287	.23	.20	68	.99	.84	134	.99	.84
Cardiopulmonary resuscitation	244	.14	.11	36	.97	.71	106	.99	.71
Long-term dialysis	217	.15	.10	33	.97	.63	100	.98	.63
Long-term feeding tube	166	.15	.08	26	.96	.49	82	.87	.49
Long-term mechanical ventilation	102	.24	.09	30	.80	.30	47	.96	.30

Table 5b. Negative predictive values (NPV) for treatment preferences in one health state to another.

	Current health → Coma			Coma → Current health			Dementia → Current health		
Treatments:	n*	NPV	Rate†	n*	NPV	Rate†	n*	NPV	Rate†
Antibiotics	18	.78	.61††	210	.07	.05††	67	.19	.05
Short-term mechanical ventilation	40	.87	.71††	243	.14	.12††	150	.23	.12
Cardiopulmonary resuscitation	77	1.00	.84	288	.27	.23	206	.36	.23
Long-term dialysis	87	1.00	.86	293	.30	.25	192	.43	.25
Long-term feeding tube	140	.97	.86	294	.46	.41	219	.58	.41
Long-term mechanical ventilation	200	.95	.86	295	.64	.58	262	.74	.58

* The n refers to the number of respondents who said 'yes' (Table 5a) or 'no' (Table 5b) to the treatments in the rows, considering the predicting health state to the left of the arrows.

† The rates reflect the fraction of participants who wanted (Table 5a) or did not want (Table 5b) the treatments in the rows, considering the second health state to the right of the arrows.

†† These predictive values do not differ significantly at the $p = 0.01$ level. All other values of PPV and NPV are significantly different from the rates ($p < 0.001$).

Discussion

In this research, the relationship between treatment preferences and ratings of health states as well as the predictive values of life-sustaining treatment preferences were examined. The data further support earlier research indicating that quality of life and perceptions of states worse than death motivate the desire to forego life-sustaining treatment.[26-27] The relationships between treatment preferences affirm earlier findings showing that (1) when patients decline noninvasive treatments, they usually decline more invasive treatments, and (2) when they want to receive invasive treatments they usually accept less invasive ones.[28]

The data also suggest an empirically-derived, organizing sequence in which to order treatments. The treatments as listed in Tables 3 and 4 (antibiotics, short-term mechanical ventilation, CPR, long-term dialysis, long-term feeding tube, and long-term mechanical ventilation) represent degrees of 'aggressiveness' that incorporate invasiveness and duration of treatment. This ordering of treatments is validated by the consistent patterns of predictive values along each row and down each column. Positive predictive values are always higher for less aggressive treatments and negative predictive values are always higher for more aggressive treatments.

Advance care planning discussions that pertain to treatment preferences and health state ratings can be organized by systematically reviewing the results from these analyses. Practice would suggest that a good place to begin a discussion of advance care planning is to inquire about who would be the best person to speak on the patient's behalf. Following this, the clinician can ask about life-sustaining treatment preferences in current health. If the patient says she 'wants nothing' in current health, the clinician should probe for an explanation that provides the context for these preferences. Patients who 'want nothing' in their current health are very likely not to want treatment under any circumstances. This interpretation can and should be verified directly with the patient.

If, however, a patient is interested in receiving life-sustaining treatment in current health, the next set of questions should determine whether the patient is interested in receiving life-sustaining treatment in all circumstances (including long-term coma and/or terminal illness). Since only a small minority of individuals desire life-sustaining treatment in all circumstances, identifying them quickly may streamline the discussion. The most common situation, however, is that patients have a mix of preferences. Thus, the next set of questions should have two goals: (1) to characterize two thresholds of unacceptability: one for health states and the other for treatments, and (2) to understand why the person would not want treatments under certain circumstances.

To achieve the first goal, a clinician should inquire about whether living under specified situations, such as severe dementia or permanent coma, would be considered a 'fate worse than death.'[27-29] A question that introduces this topic is, 'What kinds of situations do you fear the most?' If the patient identifies one or more of these situations, the clinician should explore the patient's reasons. Afterwards, the clinician should confirm that the patient would not want life-sustaining treatment if faced with a life-threatening illness in the situation(s). Asking about a few specific treatments should verify the inference that life-sustaining treatments should be withheld or withdrawn under these unacceptable circumstances. Occasionally a patient will indicate that a health state would be unacceptable and yet she would want one or more life-sustaining treatments. In these circumstances, asking the 'why' question should illuminate other important and clinically-relevant values or concerns that have bearing on advance care planning.

When a patient indicates that a situation is acceptable, follow-up questions about preferences for a few treatments should illuminate the patient's threshold for treatment acceptability. For example, if the patient is asked about long-term use of a mechanical ventilator and would desire such treatment, then the chances are good that she will want all other treatments in a particular state of health. Conversely, if a patient is asked and says no to treatment with antibiotics, she would likely not want other treatments.

There are three important clinical caveats that derive from these results. First, eliciting preferences only for CPR, as is often done, is not enough to understand a patient's overall preferences for life-sustaining treatment. CPR generalizes poorly to other life-sustaining treatments that are perceived to be more invasive or long-term. Second, wanting treatment in one's current health does not generalize well to wanting

treatment in more impaired functional health states. Third, refusing treatment in a severely impaired state of health (severe dementia or long-term coma) does not generalize well to refusing treatment in less impaired states of health (for instance, current health).

It is known that at present, physicians spend a very limited amount of time discussing advance care planning with their patients and often do not develop a shared understanding of their patients' values or preferences.[12,16-18] The extrapolation of these data into an approach to advance care planning discussions may help clinicians, as it is organized, balanced, and straight-forward. Moreover, by asking the 'why' questions after eliciting preferences and listening to the responses, the discussion will stay patient-focused. In addition, many patients have diagnoses with predictable prognoses. In these situations, the advance care planning discussions can be streamlined further by focusing on the anticipated circumstances for the particular patient.

The proposed advance care planning questions do not address the important challenge that patients need to understand the health states and treatments that are raised in any discussion. Without rich descriptions, patients may be unable to visualize the treatments and health states, and therefore may be poorly prepared to formulate preferences that reflect their values and interests. This barrier to effective advance care planning suggests the need for a patient-centered workbook. A workbook that is sensitive to the data presented herein is called *Your Life Your Choices*.[30] It is aimed to motivate patients and facilitate deliberation in advance care planning. It also describes in detail the health states and treatments that are often addressed in advance care planning discussions.

Some patients may prefer to discuss general values or goals of care rather than specific treatment preferences.[13,31] Unfortunately, reliance on general values has shown limited generalizability to treatment preferences. Similarly, treatment goals that rely on general statements, such as 'attempt cure' or 'consider quality of life,' appear to have limited ability to translate consistently into treatment preferences. Other patients may prefer to have family members decide what is best when the situation arises.[32-33] Reliance on the family may prevent over-interpretation of directives and is supported by social custom. However, relying on the family to make decisions for decisionally-incapacitated patients does not lessen the value of explicit discussions between patients and their family members before the need arises.

A major study limitation is that the people who agreed to participate differ from the general population in the United States because (1) they were predominantly white and well educated, and (2) they were willing to think about these issues. Another limitation is that participants were asked to assume three things that make the decisions less realistic than they would be in actual practice when formulating their treatment preferences. These included considering the hypothetical health states to be permanent, accepting the stated probabilities of treatment success, and that the decisions would not have economic implications.

Despite these reservations, we believe these data and the resultant approach to advance care planning discussions may help clinicians, patients, and their family members. Prior to asking the recommended questions however, clinicians should decide how they plan to (1) introduce the topic, (2) address the emotional content of

the discussions, (3) facilitate communication between the patient and family or surrogate decision-maker, (4) ensure that patients understand what they are talking about, and (5) follow-up either with regard to further deliberation or developing an advance directive.

Important research questions

Future research should take several paths. With comparable populations, research should evaluate the effect of these guidelines on discussions, proxy preparedness, and decision-making under conditions of decisional incapacity. Before generalizing these data and guidelines to different populations, other research should validate the correlates and predictive value of preferences in other populations within and across national boundaries and include a more diverse ethnic mix. The barriers to thinking about and discussing end-of-life care, as well as the role of the family and community in decision-making, may vary widely across societies. Moreover, many of the issues that frame the approach to decision-making at the end of life and/or under circumstances of decisional incapacity may vary across nationalities and cultures. These include, but are not limited to the following: physician culture as it relates to involving patients (and families) in medical decisions, the use of advanced medical technologies to prolong life, lay fears about over-treatment and loss of dignity, societal pressure to control health care costs, and the legal climate that surrounds advance care planning and medical behaviors that shorten life. These potentially influential factors suggest the need for collaborative international research.

References

1. Field MJ, Cassel CK (eds). Approaching Death: Improving Care at the End of Life. Washington, DC: Institute of Medicine, National Academy Press, 1997 (66-72).
2. Council on Ethical and Judicial Affairs. Optimal use of orders-not-to-intervene and advance directives. In: Reports on End-of-Life Care. Chicago, IL: American Medical Association, 1998(52-58).
3. Danis M, Sutherland LI, Garrett JM, et al. A prospective study of advance directives for life sustaining care. N Engl J Med 1991;324:882-887.
4. Schneiderman LJ, Kronick R, Kaplan RM, Anderson JP, Langer RD. Effect of offering advance directives on medical treatments and costs. Ann Intern Med 1992;117:5599-5906.
5. Teno JM, Licks S, Lynn J, et al. Do advance directives provide instructions that direct care? J Am Geriatr Soc 1997;45:508-512.
6. American Medical Association. Physicians' Current Procedural Terminology (4th edition). Chicago, IL: American Medical Association, 2000.
7. Goold S, Arnold R, Siminoff LA. Discussions about limiting treatment in a geriatric clinic. J Am Geriatr Soc 1993;41:277-281.
8. Reilly BM, Magnussen CR, Ross J, Ash J, Papa L, Wagner M. Can we talk? Inpatient discussions about advance directives in a community hospital. Arch Intern Med 1994;154:2299-2308.
9. Hakim RB, Teno JM, Harrell FE, et al. Factors associated with Do-Not-Resuscitate orders: Patients' preferences, prognoses, and physicians' judgments. Ann Intern Med 1996;125:284-293.
10. Shmerling RH, Bedell SE, Lilienfeld A, Delbanco TL. Discussing cardiopulmonary resuscitation: A study of elderly outpatients. J Gen Intern Med 1988;3:317-321.
11. Markson LJ, Fanale J, Steel K, Kern K, Annas G. Implementing advance directives in the primary care setting. Arch Intern Med 1994;154:2321-2327.

12. Tulsky JA, Fischer GS, Rose MR, Arnold RM. Opening the black box: How do physicians communicate about advance directives? Ann Intern Med 1998;129:441-449.
13. Doukas DJ, Gorenflo DW. Analyzing the Values History: An evaluation of patient medical values and advance directives. J Clin Ethics 1993;4:41-45.
14. Tonelli MR. Pulling the plug on living wills. A critical analysis of advance directives. Chest 1996; 110:816-822.
15. Pearlman RA. Advance directives: Are we asking the right questions? Hastings Cent Rep 1994;24: S24-S27.
16. Uhlmann RF, Pearlman RA, Cain KC. Physician's and spouse's predictions of elderly patients' resuscitation preferences. J Gerontol 1988;43:M115-21.
17. Seckler AB, Meier DE, Mulvhill M, Paris BEC. Substituted judgement: How accurate are proxy decisions? Ann Intern Med 1991;115:92-98.
18. Sulmasy DP, Terry PB, Weisman CS, et al. The accuracy of substituted judgments in patients with terminal diagnoses. Ann Intern Med 1998;128:621-629.
19. Teno JM, Hakim RB, Knaus WA, et al. Preferences for cardiopulmonary resuscitation: Physician-patient agreement and hospital resource use. J Gen Intern Med 1995;10:179-186.
20. Patrick DL, Pearlman RA, Starks HE, Cain KC, Cole WG, Uhlmann RF. Validation of life-sustaining treatment preferences: Implications for advance care planning. Ann Intern Med 1997;127:509-517.
21. Pearlman RA, Cain KC, Starks H, Cole WG, Uhlmann RF, Patrick DL. Preferences for life-sustaining treatments in advance care planning and surrogate decision-making. J Pall Med 2000;3:43-54.
22. Brandt J, Spencer M, Folstein M. The telephone interview for cognitive status. Neuropsychiatry Neuropsychology Behav Neurology 1988;1:111-117.
23. Bergner M, Bobbitt RA, Carter WB, Gilson BS. The Sickness Impact Profile: Development and final revision of a health status measure. Med Care 1981;18:787-805.
24. Radloff LS. CES-D scale: A self-report depression scale for research in the general population. Appl Psychol Measure 1977;1:385-401.
25. Patrick DL, Kinne S, Engelberg R, Pearlman RA. Functional status and perceived quality of life in adults with and without chronic conditions. J Clin Epidemiol 2000;53:1-7.
26. Starr TJ, Pearlman RA, Uhlmann RF. Quality of life factors in resuscitation decisions. J Gen Intern Med 1986;1:373-379.
27. Pearlman RA, Cain KC, Patrick DL, et al. Insights pertaining to patient assessments of states worse than death. J Clin Ethics 1993;4:33-41.
28. Emanuel LL., Barry MJ, Emanuel EJ, Stoeckle JD. Advance directives: Can patients' stated treatment choices be used to infer unstated choices? Med Care 1994;32:95-105.
29. Ditto PH, Druley JA, Moore KA, Danks JH, Smucker WD. Fates worse than death: The role of valued life activities in health-state evaluations. Health Psychol 1996;15:332-343.
30. Pearlman R, Starks H, Cain K, Cole W, Rosengren D, Patrick D. Your Life, Your Choices. Planning for future medical decisions: How to prepare a personalized living will. Springfield, VA: National Technical Information Service (98-159437), 1998.
31. Fischer GS, Alpert HR, Stoeckle JD, Emanuel LL. Can goals of care be used to predict intervention preferences in an advance directive? Arch Intern Med 1997;157:801-807.
32. High DM. All in the family: extended autonomy and expectations in surrogate health care decision-making. Gerontologist 1988;28:46-51.
33. Lynn J. Why I don't have a living will. Law Med Health Care 1991;19:101-104.