

# Patient Knowledge and Physician Predictions of Treatment Preferences After Discussion of Advance Directives

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**OBJECTIVE:** To determine patient knowledge about life-sustaining treatments and physician understanding of patient preferences for proxies and treatments after outpatient discussions about advance directives.

**DESIGN:** Cross-sectional interview-based and questionnaire-based survey.

**SETTING:** Two university general internal medicine practices, two Department of Veterans Affairs general internal medicine practices, and one university-based geriatrics practice, in two different cities.

**PATIENTS:** Fifty-six patients of primary care internists.

**INTERVENTION:** Physicians discussed "advance directives" (ADs) with one randomly selected patient during an outpatient visit.

**MEASUREMENTS AND MAIN RESULTS:** After the discussions, physicians identified the patient's proxy and predicted the patient's preferences for treatment in 20 scenarios. Patients provided treatment preferences in the 20 scenarios, the name of their preferred surrogate decision maker, and their understanding of cardiopulmonary resuscitation and mechanical ventilation. Of the 39 patients who discussed resuscitation, 43% were able to identify two important characteristics; 26% identified none; 66% did not know that most patients need mechanical ventilation after undergoing resuscitation. None of the 43 patients who had a discussion about mechanical ventilation had a good understanding of it; 67% did not know that patients generally cannot talk while on

ventilators; 46% expressed serious misconceptions about ventilators. There was poor agreement between physicians and their patients regarding treatment preferences in 18 of 20 scenarios ( $\kappa$  -0.04 to 0.31). Physicians correctly identified the proxy 89% of the time ( $\kappa$  0.78).

**CONCLUSIONS:** Patients leave routine AD discussions with serious misconceptions about life-sustaining treatments. Physicians are unable to predict treatment preferences but do learn about patients' preferences for surrogate decision makers.

**KEY WORDS:** advance directives; patient-doctor communication; medical ethics.

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Advance care planning offers patients an opportunity to gain control over their medical care should they ever lose decision-making capacity.<sup>1</sup> Ideally, this involves discussions with a primary physician that result in the physician's understanding and documentation of the patient's informed decisions regarding life-sustaining treatment in the event of a future medical crisis.

Many physicians and medical ethicists publicly advocate outpatient discussions between primary care physicians and their patients for advance care planning.<sup>2-6</sup> The Joint Commission for the Accreditation of Healthcare Organizations guidelines include a requirement to make advance directives (ADs) available to all patients in hospital-affiliated outpatient clinics.<sup>7</sup> Furthermore, many patients desire the opportunity to discuss advance care plans with their physicians while they are still relatively healthy.<sup>8-15</sup>

Nevertheless, enthusiasm for ADs has waned recently. Studies have called into question the impact that completion of AD forms has on care.<sup>16-19</sup> Although the quality of the physician-patient discussions about ADs presumably affects the utility of these documents, the discussions themselves have received little attention.

The prevailing view in the literature is that the process of advance care planning ought to parallel the process of informed consent.<sup>20</sup> In this model, just as patients choosing between therapeutic options need to understand their diagnosis, prognosis, and the proposed treatments' risks and benefits, patients making prospective decisions about future care need to understand the medical situations, treatment possibilities, and their risks and benefits. Furthermore, physicians must understand what treatments the patient would or would not accept in potential illness scenarios. A model for advance care planning in the nursing home setting, based on the principles of pro-

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spective informed consent and described by Miles et al., is well suited for adaptation to the outpatient setting.<sup>21</sup> In this model, the physician explains the purpose of the discussion, provides medical information to the patient to inform patient decision making, and gains knowledge about the patient's treatment goals, preferences for life-sustaining treatment in various possible future conditions, and preferred proxy decision maker.

A few small studies suggest that advance care planning conversations, as they are currently carried out, do not meet the criteria described above. However, these studies were conducted under simulated conditions,<sup>21,22</sup> or by observing residents discussing do-no-resuscitate orders with acutely ill hospitalized patients.<sup>23</sup> They also did not assess physician knowledge of patient preferences or patient understanding of relevant medical information after the discussions. Furthermore, a cross-sectional study showed that doctors who had had discussions about cardiopulmonary resuscitation (CPR) or mechanical ventilation with their patients were no better and sometimes worse at predicting their patients' treatment preferences in five scenarios than doctors who had not had such discussions.<sup>24</sup> No information was available about the actual content of the discussions.

The purpose of this study is to determine the level of patients' understanding of important concepts involved in end-of-life decision making and physicians' understanding of patients' preferences for care after routine outpatient discussions about ADs. By audiotaping these discussions, we were able to look for correlations between these outcomes and the conversations' content.

## METHODS

### Subjects

All primary care internists at five practice sites in two cities were eligible for the study. The sites included two university-based general internal medicine practices, two Department of Veterans Affairs (VA) general internal medicine practices, and one university-based geriatrics practice.

Patients were eligible if they were at least 65 years old or suffered from a serious medical illness, such as HIV infection, cancer, renal insufficiency (creatinine level >3 or chronic dialysis), history of cardiac arrest, or had chronic obstructive pulmonary disease, cirrhosis, or congestive heart failure requiring at least two hospitalizations in the last year. In addition, patients were excluded if they did not speak English, were judged incompetent to make medical decisions by their physician, or had previously discussed ADs with their physician.

We asked each physician to discuss "advance directives" with one of their regular patients chosen randomly from a list of eligible patients scheduled to see the physician on a selected clinic day. We included one patient per physician. Physicians had the opportunity to refuse to enroll a patient if they thought an AD discussion would be

inappropriate with that patient for any reason. Six physicians (11%) who exercised this option cited reasons such as concerns about the emotional state of the patient. After the physician consented, patients were reached by telephone. The study was explained to them, and consent was obtained. Patients signed a consent form on the day of their visit.

### Measurements

Each patient participated in a face-to-face interview after the audiotaped physician encounter. The interview was conducted immediately after the office visit in 93% of cases and always occurred within 48 hours of the encounter. The survey measured knowledge about life-sustaining treatments in a series of open-ended and multiple-choice questions. The survey also elicited the presence and identity of the preferred health care proxy decision maker. Finally, patients responded to questions about whether they would want treatment in 20 different illness scenarios. The scenarios were described in detail, and any medical terms used were defined. The context of the questions made it clear that the alternative to treatment was death. Patients were given an opportunity to ask questions about the scenarios if they did not understand them. In the six scenarios involving permanent unconsciousness and three involving severe mental disability, patients were asked about different interventions, such as tube feeding and mechanical ventilation. In the remaining 11 questions involving mechanical ventilation or CPR, the chance of complete recovery to the patient's current state of health was varied. When numeric probabilities were used, patients were shown a pie chart depicting the probability. For the scenarios involving permanent unconsciousness, the interviewer coded patients' spontaneous answers to whether they would want treatment as "yes," "no," "unsure," or "whatever my doctor thinks is best." For the other scenarios, patients chose from the following options: "definitely," "probably," "probably not," and "definitely not." Interviewers also noted when patients responded that they were unsure or that they wanted their doctor to make the decision. Table 1 contains examples of survey questions and scenarios. (Copies of the survey instrument can be obtained from the corresponding author.)

Physicians completed a self-administered questionnaire after the patient encounter. The questionnaire asked the physician to identify the surrogate preferred by the patient and to predict the patient's preferences for treatment in the scenarios contained in the patient survey. Physicians also responded to questions about the patient's medical conditions and the probability that the patient would survive a CPR attempt.

### Data Analysis

**Patient Knowledge of Life-Sustaining Treatments.** Two evaluators read the answers to the open-ended questions and

Table 1. Sample Questions from Patient Survey

Item Measured	Sample Questions
Knowledge of life-sustaining treatments	What do they do when they do CPR? If CPR succeeds in getting a patient's heart started, does that person usually need a breathing machine right after getting CPR?
Identity of a proxy decision-maker	If you get sick and can't tell your doctors what kind of medical treatment you want, is there a particular person that your doctors should go to to help make decisions about your treatment? What relation is this person to you?
Preference for treatment in different scenarios	A breathing machine or ventilator is a machine which forces air into a patient's lungs through a tube which goes in through the mouth and down into the lungs. Patients on a breathing machine are unable to talk while they are on it. Imagine that you suddenly became sick and your lungs failed, and your doctors thought that you needed to be placed on a breathing machine. Would you be willing to go on a breathing machine, if the doctors were not sure how long you would need to be on the breathing machine or how your health will be if you get off the breathing machine? If your heart suddenly stopped, would you want doctors to use CPR to try to revive you, if you had a 20% chance of surviving and an 80% chance of dying? Imagine that you have brain damage, just like in the last two questions. You are unable to move the right side of your body, to speak, or to understand people when they talk. You will always need help taking care of yourself. This time, you do not need a breathing machine at all to stay alive. But, you will never be able to eat or drink, and you need to receive food and water through a tube placed into the stomach in order to stay alive. You will need this for the rest of your life. Would you want to be treated with a feeding tube?

rated them according to predetermined criteria. Understanding of mechanical ventilators was rated as "good," "fair," or "poor," and the presence of specific misconceptions was noted. Patients had a "good understanding" if they knew that a ventilator forces air into the lungs, patients generally cannot speak while on a ventilator, and other abilities (to see, to communicate) depend on other aspects of the patient's medical condition. They had a "fair understanding" if they understood that a ventilator is used to help a patient breathe, but did not meet the criteria for a good understanding. Patients who thought that people on ventilators were necessarily comatose could qualify for this category, but patients harboring other major misconceptions, such as the belief that a ventilator is a "heart monitor" or the belief that it directly makes the heart continue to beat, were coded as having a "poor understanding." For CPR, the evaluators noted whether specific features of the process, such as chest compressions and artificial respiration, were mentioned by the patient. We checked interrater reliability using the  $\kappa$  statistic.<sup>25</sup> Kappa was greater than 0.6 (range 0.66–1.00) for all items except understanding of mechanical ventilators, where it was 0.53. Disagreements were resolved by consensus between the evaluators. Physician and patient estimates of chance of survival after receiving CPR were compared using the Wilcoxon Rank-Sum Test.

**Physician Ability to Predict Treatment Preferences and Proxies.** For each of the 20 scenarios in the survey, we compared physician and patient responses. For this analysis, responses were placed into two categories: "wants treatment" and "does not want treatment." Percentage of agree-

ment was defined as the percentage of physicians who correctly predicted their patients' preferences for the given scenario. Because percentage of agreement can be misleading in a situation in which a large proportion of the responses falls into one category, we also calculated the proportion of specific agreement, which evaluates agreement for the less commonly chosen option.<sup>25</sup> To account for the influence of chance, the  $\kappa$  statistic was computed for each scenario:  $\kappa > 0.6$  indicates good agreement, and  $\kappa > 0.4$  indicates moderate agreement.<sup>26</sup> When physicians or patients stated they were "unsure" about their treatment preference, we placed the response in the "treat" category for the analyses presented here, as that reflects actual practice. Results when the "unsure" responses are excluded from the analysis are similar to those when these responses are included in the "treat" category. In seven of the scenarios, there was one patient who wanted the doctor to make the decision. These responses were eliminated from the analysis reported here. If these responses are automatically counted in favor of the physician, it does not affect the results.

The physicians' beliefs about the existence of a proxy and the proxy's identity were compared with the patients' answers to these questions, using percentage of agreement and  $\kappa$ .

**Relation of Content of Discussions to Outcomes.** We explored how the actual content of the discussions about ADs influenced the outcomes of patient knowledge and physician ability to predict patient preferences. All audiotapes of the discussions were transcribed and coded. Transcripts were read by two raters. Raters identified each segment of uninterrupted speech that referred to CPR, mechanical ven-

tilation, presentation of quantitative probabilities (i.e., percentages), and presentation of qualitative probabilities (i.e., statements like “a good chance”). Using these codes, we identified which discussions contained some mention of each of these topics. Interrater reliability for these codes, measuring the extent to which raters agreed that a particular code was applicable in a given discussion, was good, with  $\kappa > 0.6$  (range 0.70–0.90). Using a UNIX-based computer program that identifies all text labeled with any given code, we also used the codes to search for characteristics of the conversations that might explain differences in the ability of physicians to predict preferences.

## RESULTS

Fifty-six (93%) of 60 eligible physicians participated. The physicians had a mean age of 37 years and a mean of 11 years' experience; 56% were male and 93% were white. They reported spending an average of 20 hours a week in direct patient care (range 2–50), and they knew the patients in this study an average of 2.5 years (range 0.08–12).

Fifty-six (70%) of 80 patients who were approached agreed to participate. They had a mean age of 72 years; 68% were male, and 84% were white. Their marital status, insurance, religion, and major medical diagnoses are listed

in Table 2. Patients who refused to participate were more likely to be Protestant than those who agreed ( $p = .03$ , Table 2). Twenty-three percent already had an AD, unknown to the physicians prior to the study.

## Patient Understanding of Topics Discussed

Thirty-nine (70%) of the discussions mentioned CPR. The patients who had these discussions greatly overestimated their chances of survival after an in-hospital cardiopulmonary arrest. The patients' median estimate of the probability of survival to hospital discharge was 70%, compared with a 20% median probability of survival stated by their physicians ( $p < .0001$ , Wilcoxon Rank Sum).

Most of these patients were able to describe some specific features of CPR. In response to the open-ended question, “What do they do when they do CPR?,” 71% identified chest compressions, 60% identified some sort of assisted breathing (mouth-to-mouth or intubation), and 23% alluded to defibrillation. One patient identified the use of medications, and one mentioned the possibility of brain damage after resuscitation. Forty-three percent identified two or more of these characteristics, but 26% did not identify any. One response was: “Well, they breathe into your lungs and they try to get your lungs started up again, and

Table 2. Characteristics of Participating and Nonparticipating Patients

Characteristic	Participants (n = 56)	Nonparticipants (n = 24)	p Value*
Age, mean (range), yrs	72 (58–88)	74 (67–87)	.78
Male, %	68	60	.49
White, %	84	80	.75
Education, % at least some college	24	32	.91
Religion, %			.03
Protestant	52	63	
Catholic	36	17	
Jewish	7	0	
Other/none	5	21	
Married, %	61	64	.72
Insurance, % <sup>†</sup>			
VA <sup>‡</sup>	45		
Medicare/supplemental	42		
Medicare only	2		
Medicaid	2		
Medical conditions, % <sup>†</sup>			
Ischemic heart disease	44		
Prior stroke	21		
COPD <sup>§</sup>	21		
CHF <sup>  </sup>	12		
Renal insufficiency	12		
Cancer	9		
Cirrhosis	5		

\*Pearson's  $\chi^2$  test was applied to all categorical data. Student's unpaired t test was applied to age.

<sup>†</sup>No information was available on medical conditions or insurance status for the patients who refused to participate.

<sup>‡</sup>These patients were treated at the VA facilities.

<sup>§</sup>Chronic obstructive pulmonary disease.

<sup>||</sup>Congestive heart failure.

that I think is done in the field. Perhaps if it's a heart problem, they pound on your chest, and if they have the facility, I guess they can do shock treatments."

However, to the question "If CPR succeeds in getting a patient's heart started, does that patient usually need a breathing machine right after CPR?," 34% answered "yes," 32% answered "no," and 34% were unsure. There were no significant differences in responses between patients who had a discussion about CPR and those whose discussions did not include CPR.

Discussion concerning mechanical ventilation occurred with 43 (77%) of the patients. Patients whose discussions included mechanical ventilation had a poor understanding of what this procedure entails, and a significant number harbored important misconceptions. Table 3 shows these patients' responses to an open-ended question about mechanical ventilation. No subject who discussed ventilators had a good understanding of what they involved, and 50% had a poor understanding. The only subject with a good understanding had an AD discussion that did not explicitly involve mechanical ventilation. Here is an example of a response exhibiting "poor understanding":

A breathing machine is one that is the same as, something that looks like a heart machine. It tells you how your heart is beating, and it tells you—a living machine.

Below is an example of a response exhibiting "fair understanding":

*Interviewer:* Do you have any idea what it does or how it might work?

*Patient:* Makes you breathe, and tries to keep you alive, I guess.

*Interviewer:* Do you know how it works to make you breathe?

*Patient:* No.

**Table 3. Evaluation of Patient Responses\* to the Question, "What Do You Know About Being on a Respirator or Ventilator?"**

	<i>n</i> (%)
Understanding of ventilator	
Little understanding	17 (50)
Vague understanding	17 (50)
Good understanding	0 (0)
"Can you talk on a ventilator?"	
Yes	11 (37)
No	10 (33)
Unsure	9 (30)
Fallacies	
Ventilators are oxygen tanks	7 (20)
Ventilators monitor the heart	2 (6)
Ventilators make the heart beat	2 (6)
Ventilated people are always comatose	7 (20)
Other fallacy	2 (6)
At least one fallacy	16 (46)

\*Results shown are from patients whose advance directive discussions explicitly involved mechanical respiration.

*Interviewer:* Do you know how it connects to your body?

*Patient:* No.

*Interviewer:* What do you think it would be like to be on one?

*Patient:* Oh, I don't want to be on one.

*Interviewer:* OK. Do you have any idea what it might be like to be one?

*Patient:* I don't know.

In response to the question "Can you talk while you are on a ventilator?" 67% either said "yes" or were unsure. Sixteen (46%) of the patients expressed serious misconceptions about ventilators: seven thought they were oxygen tanks, seven assumed that all ventilated patients were comatose, two believed that they were heart monitors, two stated that they helped the heart to beat, and two had other misconceptions (Table 3). There were no significant differences in patients' understanding regardless of whether their discussion included mechanical ventilation.

Participants who had previously written ADs did not have better knowledge of CPR or mechanical ventilation on any of these measures. In fact, those who had ADs were more likely to express the view that ventilators directly kept the heart beating ( $p = .001$ ).

### Physician Understanding of Treatment Preferences

In 13 of the 20 scenarios, there was little variation in treatment preferences among patients: in 4 scenarios, 75% or more patients wanted treatment, and in 9 scenarios, 75% or more patients did not want treatment. The percentage of agreement between doctors and patients ranged from 59% to 83%, and was greater than 75% in 10 of the scenarios. All but two of the scenarios with more than 75% agreement were scenarios in which there was little variation in treatment responses among patients.

The  $\kappa$  statistic indicated moderate agreement between physicians and their patients regarding treatment preferences in only 2 of the 20 scenarios. In the scenario involving severe permanent brain damage with an acute, intercurrent illness requiring a ventilator for only a short amount of time, the agreement was 78% with a  $\kappa$  of 0.47. In the scenario involving the need for a ventilator for an unknown period of time, the agreement was 76% with a  $\kappa$  of 0.44. Interestingly, these were the two scenarios in which there was high percentage of agreement even though there was considerable variation in patient preference. In the remaining 18 scenarios,  $\kappa$  ranged from  $-0.04$  to 0.31 (median 0.15), despite the fact that the median percentage of agreement was 70% (range 59–86%).

The disparity between the  $\kappa$  values and the percentages of agreement generally resulted from an inability of physicians to predict patients' idiosyncratic preferences. For example, to the question "Would you want to go on a breathing machine if there was a 5% chance of getting off that machine?" 23% of patients answered "yes," and 77% answered "no." Physicians accurately identified those pa-

tients who did not want a respirator 83% of the time. However, only 17% of physicians whose patients answered “yes” predicted this response (Table 4). A similar pattern was evident in the other scenarios.

We analyzed the discussions to determine whether differences in content might explain why some physicians were able to predict correctly patients’ idiosyncratic responses in this scenario. Examination of passages that had been coded as relating to respirators or to the probabilities of outcomes revealed important differences.

In the four cases in which the doctor correctly predicted that the patient wanted treatment, either the doctor or the patient explicitly discussed the desire for treatment in the context of low probability of success. For example, one physician asked, “We need to know if you are a five-percenter . . . If I have to put you on a ventilator and there’s a five percent chance of getting you off that ventilator, would you want it . . .”

In another case, it was the patient who stated his views on reversible illness: “. . . if there’s any chance at all of reviving a sentient, sensible person, for heaven’s sake, use it.”

The 10 doctors who incorrectly believed that their patients would not want treatment failed to elicit from the patient a treatment preference in the event of a low probability of success. In most of the conversations, the concept did not arise at all. In two discussions, probability was described in vague terms. For example, one doctor said, “If there’s reasonable doubt, we err on the side of going, rather than not going.” The patient agreed, but what constituted “reasonable doubt” was never spelled out.

There was one case in which the likely source of the doctor’s mistaken impression of the patient’s preferences is evident:

*Physician:* Because sometimes what happens is that those attempts—tries in getting people well are futile and just prolongs suffering. . . . If people make a decision ahead of time . . . that if they are ever in a position where they are on a respirator and things look pretty hopeless, that someone would make a decision of basically stopping all treatment. OK, some people even make the decision that they don’t even want to be on a respirator.

*Patient:* I don’t want to be on one.

Although the patient may only be responding to the extremely grim scenario that the physician is depicting, his comment can be interpreted to mean that he never wants

to be on a respirator. In fact, this physician predicted that the patient would answer “no” to all of the ventilator scenarios that were in the survey, whereas the patient answered “yes” to all of them except two cases: the case in which the doctors are unsure of the prognosis and the case in which the doctors believed that the patient would never come off of the ventilator.

### Physicians’ Ability to Predict Patient Surrogates

Of those patients who told us that they had a preferred proxy decision maker, 76% of physicians were aware of this fact. Furthermore, physicians who were aware that their patients had a preferred proxy correctly identified the proxy 89% of the time ( $\kappa = 0.78$ ).

## DISCUSSION

Our results indicate that these discussions fell short of the goals represented by Miles’ model of advance care planning discussions.<sup>21</sup> It is true that after a discussion about ADs, physicians were able to identify their patients’ preferred proxy. However, physicians were unable to predict their patients’ specific treatment preferences better than chance in 18 of 20 scenarios, and patients left the conversations with serious misunderstandings about CPR and mechanical ventilation.

One of the most disconcerting findings of this study was that patients expressed strong preferences about treatments that they did not understand. A patient who states that he would never accept artificial ventilation, not recognizing that it sometimes is briefly needed to provide a full recovery, is in danger of being denied a treatment that he would want if he understood it better. Conversely, a patient who wants CPR, believing that she would have a 70% chance of full recovery, is in danger of being subjected to an intervention she might not want if she understood the true likelihood of success.<sup>27</sup>

Our patients generally believed that they would have a 70% chance of recovery to hospital discharge after CPR, which is remarkably close to the survival rate of CPR in television programs,<sup>28</sup> but far above that predicted by their physicians and far above the actual survival rate (9–16%).<sup>29,30</sup> Other studies have also reported that patients do not understand terms commonly used in living wills<sup>11</sup> and do not have a good understanding of CPR.<sup>13</sup> Clearly, if these discussions are to meet the requirements of prospective informed consent, physicians will need to be aware of prior misconceptions that patients may have about life-sustaining treatments, and will have to ensure that they come away with an understanding of the treatments that are being discussed.

We also found that physicians were unable to predict treatment preferences better than chance, despite high percentages of agreement for most scenarios. One may ask if physicians have a 70% or 80% chance of correctly predicting a patient’s treatment preference, does the low  $\kappa$

**Table 4. Relation Between Patient Preferences and Physician Predictions of Preferences for the Scenario of Mechanical Ventilation with a 5% Chance of Recovery**

	Physician Prediction		Total
	Treat	Do Not Treat	
Patient wants treatment	4 (29%)	10 (71%)	14
Patient does not want treatment	7 (17%)	35 (83%)	42

value matter? We believe it does. Physicians generally have a high degree of accuracy only in cases in which large majorities of patients have the same treatment choice. However, physicians have low accuracy for patients with idiosyncratic preferences. This implies that physicians are expressing preexisting conceptions of what patients want in general, rather than using information gathered from a particular patient to predict that person's true wishes.

The discussions provide some clues on how physicians might identify idiosyncratic preferences. In the case we examined in depth, the physicians who incorrectly believed that their patient would not want treatment failed to elicit their patient's preference when success is very unlikely. This suggests physicians should ask a series of questions about the patient's views on treatment in the face of uncertainty and different probabilities of success. This might be accomplished either by using very specific numeric descriptions of probabilities or by exploring patients' underlying values and goals in more detail. Further research is needed to determine other factors that may cause patient preferences to vary and to develop methods to discuss these topics efficiently.

There are a number of suggestions in the literature about how to conduct advance care planning discussions effectively. The model proposed by Miles involves having practitioners concentrate on eight specific content points, and represents an effort to meet the criteria of prospective informed consent.<sup>21</sup> Interestingly, after hearing a 90-minute lecture on the content areas, physicians still exhibited serious deficiencies in their conversations<sup>21</sup> indicating the need to teach physicians not just what to discuss, but how to discuss it. Emanuel et al. recommend a five-step process, which includes allocating portions of three different visits to introducing the topic, facilitating a structured discussion, and actually completing and recording an AD.<sup>31</sup> This model gives the patient time to read informational materials, talk to family members, assimilate difficult information, and ask questions, and may overcome some of the shortcomings observed in our discussions. Finally, Patrick et al. endorse asking patients to rate health states and to state treatment preferences, allowing physicians to explore any discrepancies between the two approaches.<sup>32</sup> This may help physicians to discover patient misunderstandings and also to better understand patients' values and preferences. We need empiric studies to determine whether these approaches would enhance patient understanding of important concepts and physician understanding of patient preferences.

This study has several limitations. The sample size was small, limiting our ability to quantitatively determine differences between groups. However, the study included five separate sites in two cities, and nearly all of the eligible physicians participated, which decreases the chances that our physicians differ from other practitioners. The small sample size allowed us to scrutinize qualitatively the content of the discussions and answers to open-ended interview questions.

Because we have no information about patient knowledge or physician understanding of patient preferences prior to the discussion, this study cannot tell us how the discussions affected these variables. It is possible, for example, that the discussions increased or even decreased patient knowledge. We were concerned that surveying the patients and doctors prior to the discussions would alter the content of the discussions and bias our results. Nevertheless, the principal findings of this study, that patient knowledge and physician understanding are inadequate following a discussion about ADs, remain true, even in the absence of knowledge of their quality beforehand.

There are methodologic concerns with using scenarios to assess patient preferences. If patients do not understand the scenario, for example, their answers mean little. To ensure validity, our questions were framed to help patients understand what the experience would be like. We avoided technical terms and explained interventions, and we presented probabilities in visual form.<sup>33</sup>

Finally, people who believe that these discussions should focus more on values and goals than on specific scenarios might object that we are measuring the wrong outcomes. Nevertheless, in-depth, qualitative analysis of these discussions shows that patient values and goals were rarely discussed in depth (unpublished observations).

Many influential individuals and organizations advocate outpatient discussions about ADs. Nevertheless, these conversations, as currently conducted, do not further the goals of ADs. Better communication regarding these issues is critical if ADs are to promote patients' values during critical illness.

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