

# Opening the Black Box: How Do Physicians Communicate about Advance Directives?

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**Background:** The quality of communication that leads to the completion of written advance directives may influence the usefulness of these documents, but the nature of that communication remains relatively unexplored.

**Objective:** To describe how physicians discuss advance directives with patients.

**Design:** Prospective study.

**Setting:** Five outpatient primary care medicine practices in Durham, North Carolina, and Pittsburgh, Pennsylvania.

**Participants:** 56 attending internists and 56 of their established patients. Eligible patients were at least 65 years of age or had a serious medical illness.

**Measurements:** Two raters coded transcripts of audiotaped discussions about advance directives to document how physicians introduced the topic of advance directives, discussed scenarios and treatments, provided information, elicited patient values, and identified surrogate decision makers.

**Results:** Conversations about advance directives averaged 5.6 minutes; physicians spoke for two thirds of this time. In 91% of cases, physicians discussed dire scenarios in which most patients would not want to be treated, and 48% asked patients about their preferences in reversible scenarios. Fifty-five percent of physicians discussed scenarios involving uncertainty, typically using vague language. Patients' values were rarely explored in detail. In 88% of cases, physicians discussed surrogate decision making and documents to aid in advance care planning.

**Conclusions:** Although they accomplished the goal of introducing patients to advance directives, discussions infrequently dealt with patients' values and attitudes toward uncertainty. Physicians may not have addressed the topic in a way that would be of substantial use in future decision making, and these discussions did not meet the standards proposed in the literature.

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Professional societies, citizens' groups, legislators and the courts all advocate the use of advance directives to ensure that physicians respect wishes of patients with regard to treatment at end of life (1-5). Physicians are encouraged to discuss these issues in the outpatient setting while patients are healthy and competent. Despite enthusiasm for the use of advance directives, research raises doubts about the ability of advance directives to influence care (6-12).

To understand why these documents do not work as intended, investigators have examined many aspects of the advance directive process, such as the form of the document used, the durability of directives, and the ways in which directives are interpreted (6, 8, 13, 14). However, the quality of communication between physicians and patients leads to the creation of a written directive remains largely an unexplored black box.

Studies of advance directive discussions suggest that physicians do not provide patients with adequate information (15, 16). However, these studies used role playing or standardized patients rather than actual patient-physician encounters or lack generalizability, typically studying housestaff consultations with inpatients about do-not-resuscitate orders (16-20).

We sought to learn how attending physicians in outpatient practices discuss advance directives with their patients and to observe how closely these discussions adhere to the informed consent model described in the literature.

## Methods

### Participants

All primary care internists at five practice sites in Durham, North Carolina, and Pittsburgh, Pennsylvania, were eligible for the study; only the investigators were excluded. The sites were two university-based general medicine practices, two Veterans Affairs general medicine practices, and one university-based geriatrics practice. Patients were eligible for the study if they were at least 65 years of a

See related article on pp 495-500.

**Table 1. Major Coding Categories for Discussions about Advance Directives and Samples of Specific Codes**

Discussion Task	Specific Codes
Describe advance directives	Describes advance directives accurately Describes advance directives inaccurately Mentions that patient can change mind
Give rationale for discussing advance directive	Discussion is for a research project Physicians are supposed to talk about this with their patients Right to make decisions about one's own care To determine what the patient wants and to prevent care that the patient does not desire
Discuss advance directive forms	Learns whether advance directive exists States that physician will provide forms Refers patient to social worker or attorney
Discuss scenarios and treatments	Dire scenario Disabling illness Reversible illness, cure assumed Quantitative probability Qualitative probability Uncertain event, no probability described Cardiopulmonary resuscitation Mechanical ventilation Artificial nutrition or hydration Admission to intensive care unit
Provide medical information	Describes medical procedure Determines what the patient knows
Elicit patient values	Elicits values, goals, and reasons Statements of values, goals, and reasons Specific reasons
Identify surrogate decision makers	Identifies specific surrogate (such as spouse, child, or sibling) Advises discussion with surrogate

had a serious medical illness (including cancer; previous cardiac arrest; HIV infection; renal insufficiency [creatinine concentration >3 mg/dL (250 μmol/L) or long-term dialysis]; and chronic obstructive pulmonary disease, congestive heart failure, or cirrhosis severe enough to cause two hospitalizations in the past year) that made discussion of advance directives relevant. They had to speak English, had to be judged competent by their physician to make medical decisions, and had to have not previously discussed advance directives with their physician. We studied one patient per physician.

After physicians indicated a convenient clinic session, we randomly selected an eligible patient with whom the physician would "discuss advance directives in whatever way you think is appropriate for this patient." If physicians felt that such a discussion was inappropriate for that patient, they were asked, in order, about the next eligible patient until a patient was chosen. If no eligible patients were available, we selected another clinic session and repeated the process. We called eligible patients before their visit and requested their consent to participate in a study

"to learn how doctors communicate with their patients when making decisions about future medical treatments."

### Data Collection

We audiotaped the selected encounters from 1 April 1994 and 30 October 1994. Physicians completed a self-administered survey that asked about their background and attitudes toward advance directives. We obtained demographic and attitudinal data from patients in face-to-face interviews. The protocol was approved by institutional review boards at the Duke University, Durham Veterans Affairs, and University of Pittsburgh medical centers.

### Data Analysis

#### Code Book Development

All audiotapes were transcribed and coded. We developed the code book through an iterative process (21). First, we created general coding categories for all pertinent topics identified in the literature (4, 18, 22–25). Although no clear consensus exists about the ideal content of these discussions, experts generally recommend a model that reflects the established standards of informed consent (26, 27). After explaining the rationale for advance directives, physicians should describe the nature of potential procedures and the risks, benefits, and likely outcomes of and alternatives to these treatments. They should learn whether patients desire treatments under specific scenarios (23, 28). Others also advise physicians to attend to patients' values and to identify surrogate decision makers (16, 22, 29). All agree that these discussions should be conducted in an empathic manner, with sensitivity to patients' emotional needs (16–18, 25). Because this model is not empirically derived, it is only a best approximation for judging discussion quality; it is not a gold standard.

On the basis of the model, we coded the ways in which physicians accomplished the following tasks: introducing the topic, describing advance directives, giving rationales for advance directives, describing pertinent forms, discussing scenarios and treatments, providing medical information, eliciting patient values, and identifying surrogate decision makers. We also developed codes to evaluate the quality of the overall communication process. For each general content area, we formulated a list of specific codes (Table 1).

Next, the research team read the study transcripts to ensure that the coding system captured all relevant issues. Coding categories were adjusted as necessary. After developing a draft of the code book, the research team coded a subset of transcripts to identify problems and formulate coding

rules. The final code book contained 70 items spanning 11 topic areas (Appendix). A copy of the complete coding instrument is available from the authors on request.

### Reliability of the Code Book

Two raters independently coded all transcripts. The raters applied as many codes as necessary to the content of each speaker's "turn," which was defined as a segment of uninterrupted speech.  $\kappa$  scores, used to measure interrater reliability, were greater than 0.40 for 58 of the 70 codes, indicating moderate or better agreement. No codes with  $\kappa$  scores less than 0.40 were used, with one exception. The code for "dire scenario" had a  $\kappa$  score of 0.39, was present in 91% of cases, and represented a central concept that emerged repeatedly in qualitative analysis. Disagreements in coding were resolved by consensus between the two coders. Disagreements remained in 11% of cases and were resolved by the entire research team. The following statement illustrates a case in which the team initially disagreed about whether the scenario was truly dire but, after discussion, decided to apply the code.

OK, what if you became ill, for example with something like a stroke. You were in the hospital and you were in a coma, all right. There was very little chance of you ever coming out of that coma. In other words, you could breathe and your heart was still beating, but you couldn't really think about things.

### Statistical Analysis

We entered the coded transcripts into the Unix Text Analyzer database (University of Pittsburgh Center for Medical Ethics), which facilitates indexing and retrieval and is capable of quantitative assessments of qualitative text (such as frequency counts on codes) (30). We calculated frequencies for each of the codes and used the chi-square and *t*-tests to identify variables associated with presence or absence of specific codes. We used standard qualitative methods to analyze communication approaches and relevant sections of coded text (21).

## Results

### Participants

Sixty physicians in five practice sites were eligible, and 56 agreed to participate (93%) (Table 2). The median age of the physicians was 37 years (range, 28 to 63 years); 56% were men, and 93% were white. They spent a median of 18 hours per week in direct patient care (range, 2 to 50 hours per week) and had practiced medicine for a median of 10 years (range, 3 to 38 years). Ninety-five percent of physicians stated that they felt comfortable talking

**Table 2. Characteristics of Physicians and Patients**

Characteristic	V
<b>Physicians*</b>	
Median age (range), y	37 (2)
Men, %	56
White, %	93
Median length of practice (range), y	10 (3)
Median time per week spent in patient care (range), h	18 (2)
Median duration of the patient-physician relationship (range), y	1.2 (0)
<b>Patients†</b>	
Median age (range), y	72 (5)
Men, %	68
White, %	84
Less than a 12th-grade education, %	66
Median predicted 5-year survival (range), %	72 (9)

\* Fifty-six of 60 eligible physicians (93%).  
 † Fifty-six of 81 eligible patients (69%).

to patients about advance directives, but 61% discussed advance directives in the outpatient setting.

Eighty-nine patients were eligible for the study. In 8 cases, physicians refused the discussion because they felt that the patient was emotionally unstable or had had too few previous visits. Fifty-six (63%) of 81 recruited patients (69%) agreed to participate. Their median age was 72 years (range, 58 to 84 years); 68% were men, 84% were white, and had less than a 12th-grade education. Twenty-seven percent of patients rated their overall health as good or excellent, 27% rated it as good, and 46% rated it as fair or poor. The patients had known their physicians for a median of 1.2 years (range, 0.1 month to 12 years). The median chance that patients would survive for 5 years, according to their physicians, was 72% (range, 9% to 97%). Patients and persons who refused did not differ significantly in any measured variables, except that participants were Catholic.

### Communication Process

The median advance directive discussion lasted 5.6 minutes (range, 0.9 to 15.0 minutes). Physicians spoke for a median of 3.9 minutes (range, 1.1 to 10.9 minutes), and patients spoke for the remainder of 1.7 minutes (range, 0.3 to 9.6 minutes). When introducing the topic, 93% of physicians stated they were discussing advance directives, although 20% attributed the discussion only to a research project. Usually, the conversation ended without any specific follow-up plan. Forty-three percent of physicians mentioned the possibility of future discussions, 55% discussed advance directives in detail, and 25% asked patients whether they had questions. Only 16% of physicians told patients that they would change their mind.

In general, physicians were unlikely to attend to the emotional content of discussions. Only 25% of physicians acknowledged that talking about ac-

**Table 3. Presentation of Scenarios**

Scenario	Physicians Who Discussed Scenario, n (%) <sup>a</sup>
Direct	51 (91)
Direct only	14 (25)
Uncertain <sup>b</sup>	31 (55)
Uncertain only	0
Reversible <sup>c</sup>	27 (48)
Reversible only	0
Direct and reversible only	7 (13)
Direct and uncertain only	11 (20)
Uncertain and reversible only	1 (2)
Direct, uncertain, and reversible	19 (34)

<sup>a</sup> Chronic disability scenarios, which were discussed in 29% of cases, are not included in this table

<sup>b</sup> In discussions of direct scenarios, patients were characterized as permanently unconscious, confined to an intensive care unit indefinitely, about to die, or in an otherwise futile situation

<sup>c</sup> In discussions of uncertain scenarios, physicians acknowledged that recovery is uncertain, they sometimes used qualitative or quantitative language to express the probability of recovery

<sup>d</sup> In discussions of reversible scenarios, cure was assumed and patients were expected to resume their premorbid functioning

directives could be emotionally difficult; one physician said, "It is a tough topic, and a lot of people don't think about it. Or they don't like to think about it." Thirty-nine percent of physicians reassured the patient that their current health was not the reason why they were raising the topic.

### Framing Options through Scenarios

Ninety-three percent of physicians discussed advance directives by posing hypothetical scenarios and determining patient preferences in these scenarios. The three most common categories were direct scenarios, reversible scenarios, and uncertain scenarios (Table 3). In direct scenarios, patients were described as permanently unconscious, confined to an intensive care unit indefinitely, about to die, or in an otherwise futile situation (31, 32). Direct scenarios were discussed in 91% of cases. In reversible scenarios, which were discussed by 48% of physicians, cure was assumed and patients were expected to resume their premorbid functioning. In 55% of cases, physicians discussed uncertain scenarios in which they acknowledged that recovery is unpredictable. A fourth category, chronic disability, described hypothetical situations in which a patient is disabled after treatment. Only 29% of physicians discussed this scenario.

Physicians typically elicited patient preferences for one or two scenarios. In 27% of discussions mentioning a scenario, the direct scenario was the only scenario discussed; and in 14% of these discussions, only direct and reversible scenarios were discussed. Therefore, uncertainty was not mentioned in 41% of cases.

When physicians described direct scenarios, they portrayed situations in which few people, terminally ill or otherwise, would want treatment. For example,

If you were very sick with a terminal illness . . . if you had something that could never be cured and there was no cure available for it and you started to get really, really sick . . .

OR

If you or anyone were to get into a car accident, let's say, and had brain damage and were in a coma, and the doctors thought that the brain was damaged too much, the patient would never wake up, never be able to talk, never be able to see someone again, but the patient was otherwise alive . . . if your heart stopped . . . would you want them to start it again?

Reversible scenarios were often presented as situations in which most people would want treatment. The most common example was pneumonia requiring a brief period of mechanical ventilation:

Sometimes what ends up happening is that you have problems with your breathing and you need to be on a respirator breathing for you for a short period of time.

Implicit in discussions of reversible states was the physician's concern that patients not reject all forms of intensive care because of fears of extended life support:

Remember that going on life support may just be a temporary thing to get you over a small hump, or a small setback, with the expectation that you would recover fully. And you don't want to just rule out life support for fear, you know . . .

Most patients told their physicians that they would reject treatment in the face of certain death and would desire aggressive care for reversible illness. For example, no patient stated a desire for treatment in the direct scenario, whereas almost all were willing to undergo even "heroic" interventions in reversible situations. This dichotomous choice was reflected clearly in the following statements by patients:

If a person is to be [electrically] shocked . . . and come back normal, that would be fine. But if . . . you are going to come back as a vegetable, why hey, forget it.

Oh, well, if my heart stopped and I wasn't out of it, then I guess I would want it . . . But if I didn't know what I was doing, like a vegetable, then I would not want to live.

Physicians used vague language to describe scenarios, asking what patients would want if they became "very, very sick" or "had something that was very serious." They rarely attempted to define vague situations or to ascertain the meaning of such terms for the patient. Physicians were particularly vague when discussing outcomes. For example, a physician asked, "What if there was a chance that you would not ever come out of the coma?" In 34% of cases, physicians expressed probability in qualitative terms, such as "reasonable hope," "nearly hopeless," "unlikely," "probably," and "virtually uncertain." Numbers were used to describe probabilities in 11% of

cases. Only 13% of physicians mentioned potential outcomes of life-sustaining treatment other than death and complete recovery, such as cognitive disability or ventilator dependence.

### Providing Treatment Alternatives

In 96% of cases, physicians discussed treatment options, including cardiopulmonary resuscitation or mechanical ventilation (88%), artificial nutrition or hydration (25%), and admission to the intensive care unit (16%) (Table 4). Specific treatments were described in 27% of cases, and physicians attempted to learn what the patient knew about interventions in only 16% of conversations. In half of the cases in which an expression such as "life-sustaining treatment" or "life support" was used, no further explanation was given to ensure a shared understanding.

### Eliciting Values, Goals, and Reasons

Patients' personal values, goals for care, and reasons for treatment preferences were discussed in 71% of cases and were explicitly elicited by 34% of physicians. For example:

Physician: Right now, even though you do not have a terminal condition, you feel that you would not want to be resuscitated?  
 Patient: Yes.  
 Physician: Why do you feel that way?  
 Patient: I've been feeling that I don't have that much to live for.

In another case, the patient was speaking about his sick aunt:

Patient: If I get to that point, why prolong misery? You know.  
 Physician: Well, what, um...  
 Patient: I mean there's no chance of her ever getting back to decent health.  
 Physician: What is it about her quality of life now that you find intolerable?  
 Patient: Lying in bed 24 hours a day, waiting on somebody... somebody waiting on you.

More commonly, however, physicians did not explore the reasons for patients' preferences and merely determined whether they wanted specific interventions. They rarely asked patients to define a good quality of life, and none inquired about what constitutes a burden, even though not wanting to suffer or be a burden was frequently stated as a reason for refusing life-sustaining treatment. As one patient stated:

(If) I'm going to be unconscious and just lay there and be an expense to society, no, I don't want that. Or make the family suffer—just to sit there and watch me. I don't want that. But if it is something that I can still be a useful person to myself, yeah, I want everything done—that I would continue life.

**Table 4. Presentation of Life-Sustaining Treatments**

Treatment	Physicians Who Discussed Treatment, n (%)
Cardiopulmonary resuscitation	39 (70)
Mechanical ventilation	43 (77)
Cardiopulmonary resuscitation or mechanical ventilation	49 (88)
Artificial nutrition or hydration	14 (25)
Admission to the intensive care unit	9 (16)
Other	16 (29)

Although 25% of patients expressed a desire to be a "vegetable," no physician asked what meant to the patient.

### Discussion of Documents and Surrogate Decision Makers

Formal advance directive documents, such as living wills, were discussed in 88% of cases. The following is an example of a typical discussion:

(There) are options for you to write down in words what you would like to have done for you or not have done for you in the event that you became deathly sick or you weren't able to tell me what you wanted to have done or wouldn't have done. Another option would be for you to formally assign someone as a guardian of your health in situations... where you're not able to make those decisions, for whatever reason—say you got knocked on the head or you're knocked unconscious or you slip into a coma or something like that—that someone can speak with your voice, with your best interests at heart, and can answer those hard questions that doctors may need to ask at that point.

Of note, 21% of the patients had already completed an advance directive without their physician's knowledge. Twenty-three percent of physicians referred to provide patients with advance directive forms, 16% referred patients to attorneys, an additional 16% referred patients to a social worker or another provider in their practice. Forty-five percent of physicians did not instruct patients on how to obtain advance directive forms.

In 88% of cases, surrogate decision makers were discussed. During this discussion, 59% of patients identified a specific person and the remainder did not designate anyone. Sixty-three percent of physicians advised patients to discuss their preferences with their surrogates.

### Patient Reactions to Advance Directive Discussions

Overwhelmingly, patients viewed these discussions as positive experiences. In follow-up interviews, all of the patients stated that they were glad to have had the discussion, 96% felt that it had been worthwhile, and 95% agreed with the statement that it is a "good idea for doctors to talk to their patients about advance directives." All patients

believed that their physicians "did a good job talking about these issues." Only 7% felt uncomfortable during the discussion. This patient's comment was typical:

... It don't bother me to talk about it because, you know, I do know things happen. And I do know I can't stay here always. I know death is coming. But I don't know what's gonna happen before death.

## Discussion

We observed 56 discussions about advance directives between experienced physicians and their patients. On average, these conversations were short, with physicians talking two thirds of the time. Physicians typically discussed extreme scenarios that elicited little variation in preferences. Discussions of uncertainty were vague, and physicians often described treatments, but rarely in any detail. Although patients' values arose often in these discussions, physicians were unlikely to elicit or explore them. Finally, surrogate decision making and documents to aid in advance care planning were frequently mentioned.

Although these conversations accomplished the goal of introducing patients to the topic of advance directives, their usefulness in future decision making seems limited. Physicians and patients usually discussed the easiest scenarios. Few patients would wish to be kept alive by machines if they were permanently unconscious with no hope of recovery (33). Similarly, most patients desire aggressive care in a reversible scenario when the likelihood of returning to the premorbid state is high. A conversation about advance directives that probes no further than dire or reversible scenarios leaves most physicians and families no better off when they confront the more common, less clear-cut predicaments surrounding end-of-life care. Similarly, a patient's statement that he or she "wouldn't want to lay around just to be a burden on my family" is too vague without further explication (34, 35). Most of the discussions observed in this study would not have helped a physician struggling with treatment decisions for an aphasic 80-year-old patient with congestive heart failure and sepsis.

Various qualitative terms were used loosely to describe outcome probabilities. Such terms have numerical correlates in the minds of physicians and patients, but these correlates vary widely between subjects (36-39). Furthermore, many patients lack basic numeracy skills (40). Because patient preferences for life-sustaining treatments differ depending on their estimates of survival, this aspect of communication deserves considerable attention.

Our results are consistent with those in the liter-

ature. Braddock and colleagues (41) found that the elements of informed consent were rarely present during routine clinical decision making. In a small ethnographic study, Ventres and associates (42) observed that physicians focused primarily on learning patient preferences for technical interventions and ignored patients' goals for care. Tulskey and coworkers (16) audiotaped 31 medical residents discussing resuscitation decisions with hospitalized patients and found that the physicians often did not provide sufficient information to allow patients to make informed decisions.

Our study had several limitations. First, despite a high physician participation rate, our sample was small, and the study took place in the context of university and Veterans Affairs medical centers. Clearly, any attempt to generalize these observations to physicians and patients in other settings must be made cautiously. Second, study participation could have affected physician behavior. However, physicians were unaware of our hypotheses and coding categories. We specifically asked them to communicate in whatever way they "normally would," and many told us that this was their "usual" discussion of advance directives. The conditions of this study reflect the real situation that physicians experience when they conduct discussions to meet performance standards set by managed care or accrediting organizations. Because the physicians knew that they were being audiotaped, these results probably represent the best that the physicians could do when discussing advance directives. In addition, these physicians were experienced clinicians who had previously established relationships with their patients. It is unlikely that we captured unusually poor conversations. Finally, we did not ask the physicians about their specific goals for these conversations. Many view discussions of advance directives as a process. Our coding assessed performance in various domains, and physicians may not have planned to discuss all of those domains in one visit. However, follow-up discussions were mentioned less than half of the time, and most of the physicians attempted to reach closure in a single conversation. Furthermore, when physicians discuss scenarios and preferences, it is appropriate to determine whether adequate information was given to inform those preferences.

Why don't physicians communicate about advance directives in the manner advocated by experts? Most have never been taught these communication skills and have learned them only through personal experience (43). In addition, delving deeply into patients' values may be more emotionally challenging than discussing patients' preferences in "easy cases" or identifying surrogate decision makers. Some fear that discussions of "negative"

information will have an adverse effect on the patient (44, 45). Finally, practitioners face severe time pressures. During a 15- to 20-minute office visit, physicians must review a patient's medical problems, perform an examination, and perform preventive interventions. Little time is left for discussions of advance directives.

Alternately, the reason that physicians do not communicate according to the model may stem from problems with the model itself. Advance planning for situations with high levels of uncertainty is extraordinarily difficult, and our expectation for clinicians may be unrealistic (38, 46-48). Can patients truly be informed about all of the potential scenarios and treatments that they may someday confront? If patients have not experienced any of these treatments, how closely can stated preferences approximate true feelings? Are patients more interested in allowing a surrogate to choose for them or in developing trusting relationships with physicians on whom they can rely to make the appropriate decision (49-52)? We may be better served by learning more about patients' lives and values than by engaging in hypothetical conversations about future events. A more meaningful gold standard for advance care planning would derive from studies of patient preferences for information compared with trust and of the effects of various communication approaches on patient care, satisfaction, and use of life-sustaining treatments.

Most recent studies demonstrate that stated preferences for life-sustaining treatments, completed advance directives, and increased discussion between physicians and patients have little effect on care at the end of life (7, 53). Institutional barriers, the culture of medicine, or patient attitudes may all inhibit change. However, another possibility is that the discussions are not of the quality necessary to improve the abilities of physicians, patients, and families to make decisions in difficult cases. Our findings support this last hypothesis. Exhortations to increase the number of outpatient discussions about advance directives are not likely to improve patient care unless we learn how to improve communication and teach practitioners these skills.

## Appendix

### Discussion Codes

- A. Framing of purpose
  - A1. The discussion is for a research project
  - A2. Physicians are supposed to talk about this with their patients
  - A3. Right to make decisions about one's own care

- A4. To determine what the patient would want or to prevent care patient would want
- A5. Physician generally talks to patients at this
- A6. Previous experience with patient's illness
- A7. Previous experience with illness in family or friend
- B. Living wills, advance directives, and durable powers of attorney for health care
  - B1. Advance directives—not otherwise specified
  - B2. Existence of an advance directive
  - B3. Providing physician with patient's advance directive
  - B4. Assistance in obtaining advance directive documents
    - B4a. The physician can or will provide forms
    - B4b. Someone else can or will provide forms
    - B4c. Unclear who will provide forms
  - B5. Referral to social workers or attorney
    - B5a. Referral to an attorney
    - B5b. Referral to a social worker
  - B6. True description of advance directive
  - B7. Myths about advance directives
- C. Discussion of preferences: scenarios and treatments
  - C1. Dire scenario
  - C2. Disabling illness
  - C3. Reversible illness, cure assumed
  - C4. Probability
    - C4a. Quantitative probability
    - C4b. Qualitative probability
    - C4c. Uncertain event, no probability described
  - C5. Cardiopulmonary resuscitation
  - C6. Mechanical ventilation
  - C7. Artificial nutrition or hydration
  - C8. Admission to intensive care unit
  - C9. Desire for other specific therapeutic intervention
- D. Preferences
  - D1. Preference for treatment
  - D2. Preference against treatment
  - D3. Declines to state preference
  - D4. Has not thought about it
- E. Provision of medical information
  - E1. Description of medical procedure
  - E2. Request for information about medical procedure
  - E3. Determines what patient knows
- F. Vague terms
  - F1. Vague situations or interventions of particular interest
    - F1a. Heroics

- F1b. Machines
- F1c. Reasonable hope
- F1d. Vegetable
- F1e. Terminally ill
- F1f. Quality of life
- F1g. Natural death
- F2. Other vague terms
  - F2a. Vague scenarios or outcomes
  - F2b. Vague treatments
- F3. Specification of vague terms
- G. Reasons, values, and goals
  - G1. Eliciting values, goals, and reasons
  - G2. Statements of values, goals, and reasons
  - G3. Specific reasons
    - G3a. Not wanting to be a burden on others
    - G3b. Not wanting others to feel guilty
- H. Surrogates
  - H1. Surrogate—not otherwise specified
  - H2. Identity of a surrogate
    - H2a. Spouse
    - H2b. Child or children
    - H2c. Sibling
    - H2d. Other relative
    - H2e. Friend
    - H2f. Other
  - H3. Discussion with surrogates
- I. Communication
  - I1. Future conversations
  - I2. Current health is not the reason for this discussion
  - I3. Can change mind
  - I4. Positive feedback to patient
  - I5. Reflection
  - I6. Emotional response
  - I7. Physician opinion about preferences
  - I8. Physician leading statements
  - I9. Missed opportunities
  - I10. Documenting in medical record
- J. Friends and family
  - J1. About patient's family or friends
  - J2. About physician's family or friends
- K. Famous people
  - K1. Famous people with living wills

## Use of Codes

In the complete code book, each code listed above is followed by detailed instructions for its use. Below is an example of general rules from the "A" code section.

### A. Framing of purpose

These codes refer to attempts made by a doctor to describe the purpose of these conversations in general or the purpose of this particular conversation. They describe why the doctor is bringing this up now or the general purpose of this enterprise.

These codes may be used regarding a reason for completing a living will.

These codes should not be used if the statement refers

to a reason for bringing in a living will (for which there may be no code).

These codes may be used at any time in the conversation.

If advance directives are explicitly mentioned in the turn (or referred to by pronoun), the proper B code should be used as well.

These codes should only be used for the physician.

Below is an example of specific coding rules for the "A2" code. These rules often include text examples that meet the criteria for that code.

### A2. Physicians are supposed to talk about this with their patients

This code pertains to any statement that physicians "should" talk about this to their patients or that others believe that physicians should talk about this to their patients. The implication is that there is external pressure on physicians to talk about this.

"I'm bringing this up because it's something we should talk about."

"They want us to talk about this."

"The PSDA [Patient Self-Determination Act] says we should talk about this."

"Doctors are talking about this more and more."

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