Outpatients' Attitudes Regarding Advance Directives

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Background. Although many bedside ethical dilemmas can be avoided if patients discuss their wishes regarding the use of life-prolonging treatment and aggressiveness of care, many physicians are reluctant to raise this issue with their patients. Physicians may wait for such disscussions until a patient is ill or elderly or until the patient raises the issue first.

Methods. Three hundred adult patients visiting their family physician's office were asked to complete a 19-item questionnaire. In addition to providing demographic information, they were asked whether they had discussed their wishes regarding life-prolonging treatments with their physician; what their attitude was toward having these discussions in various situations; whom they wanted to initiate the discussion, and with whom else they had discussed their wishes.

Results. Of the respondents who had not previously discussed their wishes with their physician, 68% wanted the physician to initiate the discussion. Only 11% did not want their physician to bring up the subject. A majority of respondents in all age groups thought it was somewhat or very important to discuss this matter both when healthy and when very ill.

Conclusions. Very few patients would be upset if their physican raised the issue of life-prolonging treatment even if he or she did so during an initial patient visit. To avoid problems later, physicians should take an active role by raising these questions early in the patient-physician relationship rather than waiting for the patient to do so.

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Decisions regarding the use of "life-sustaining treatment" or a patient's "code status" often present difficult dilemmas. Bioethicists and others suggest that many bedside dilemmas could be avoided if patients discussed their wishes regarding life-prolonging treatment and aggressiveness of care well in advance of a crisis situation.[1–3] Recently publicized cases such as that of Nancy Cruzan illustrate the heightened uncertainty that occurs when these decisions are not made in advance.[4] It is suggested that people should have these discussions with their family and their personal physician and that a patient's wishes should be documented.[5,6] Furthermore, the physician should initiate these discussions.[3,7–11]

Yet physicians are often reluctant to raise this issue with patients. A physician's lack of understanding of advance directive laws may lead to avoiding the discussion of so-called living wills or durable powers of attorney. The results of a recent national survey by Doukas et al[12] indicate that family physicians who are more knowledgeable about living wills are more likely to discuss them with their patients. Physicians may also hesitate until a patient brings up the subject of advance directives, thereby indicating the patient's readiness to think about these emotionally difficult questions.[5]

Physicians may be concerned about the best timing for such discussions. Waiting until the patient is too ill to talk about aggressiveness of care might send the wrong message to the patient.[13,14] In a state of illness, patients could interpret such a discussion as being indicative of imminent death or the physician's unwillingness to provide necessary care. Unless faced with a patient who has a potentially life-threatening illness, some physicians never discuss the patient's wishes in the outpatient setting, and wait until a patient is too ill or incapacitated to make an informed decision for himself or herself.[15]

Studies conducted in hospital or nursing home settings have looked primarily at the wishes of the sick and the elderly or have examined physicians' attitudes toward discussing life-prolonging treatment with their patients.[16–20] Studies that have taken place in the outpatient setting have also primarily involved chronically or severely ill elderly patients.[7,21–24]

Very little is known regarding patients' attitudes toward discussing advance directives with their personal

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physician, before an acute illness, in an outpatient setting. A study by Emanuel et al[25] showed that outpatients "were favorably inclined toward planning for medical care." The Emanuel study involved providing patients with an extensive advance directive form outlining various treatment options for each of four hypothetical clinical situations. The form was discussed during a personal interview. Emanuel and colleagues attribute their patients' favorable attitudes in part to the patient education component of the extensive interview.

The current study was designed to further examine the attitudes of adult patients of all ages toward discussing their wishes regarding life-prolonging treatments with their family physician in an outpatient office setting.

Methods

The Medical College of Ohio Family Practice Center is located in Toledo.Over 2000 patients each month from diverse socioeconomic backgrounds receive care from eight faculty family physicians and 11 residents at the family practice center. Three hundred adult patients at the center were asked to complete a 19-item questionnaire that examined attitudes about discussing advance directives for health care. There was no educational component in the survey instrument other than a brief definition of terms such as "life-prolonging treatment." The questionnaire asked (1) whether the patient had previously discussed the use of life-prolonging treatment with his or her physician, (2) what the patient's attitudes were toward discussing this issue in a variety of situations, (3) whom the patient wanted to initiate the discussion, and (4) whom else the patient had talked to about his or her wishes. General demographic information was also requested, such as age, sex, race, marital status, education, and number of children.

In August 1991, the questionnaires were distributed to 300 consecutive adult patients (18 years of age and older) who had made at least one previous visit to the center. Questionnaries were completed by patients in the waiting room and placed in a return box. The results were kept anonymous. Descriptive statistics were used to analyze data. Chi-square analysis was used to compare groups of nominal data. Answers were compared between three age groups (18 to 40 years, 41 to 60 years, and 61 years and older).

Results

Of the 300 questionnaires distributed to patients, 251 were returned, for an overall 84% return rate. Eighteen were returned without having been completed. The return rate of completed questionnaires was 78% (n = 233). Six respondents did not complete the survey item regarding age and were excluded from any statistical analyses that compared age groups.

Table 1. Patient Responses When Asked If They Wanted Their Physician to Bring Up the Issue of Life-Prolonging Treatment

Age Group (y)	Yes, %	No, %	Uncertain, %
18 to 40	62	13	25
41 to 60	73	9	18
≥ 61	73	10	17

A majority of respondents were women (71%) and had completed at least a high school education (91%). Most were white (white, 84%; African-American, 14%; other, 2%) and less than 61 years of age (18 to 40 years, 45%; 41 to 60 years, 37%; 61 years or older, 18%).

Only 19 respondents (8%) answered that they had discussed their wishes regrading the use of life-prolonging treatment with their physician at the family practice center. Of these, 12 thought that definite conclusions had been reached with their physician, and 9 thought that their wishes regarding life-prolonging treatment had been written down in their patient record.

Of those respondents who had not discussed the use of life-prolonging treatment with their physician, a majority (143 [68%]) would want their physician to raise this subject in discussion. Only 23 (11%) respondents did not want the physician to bring up the subject, and 44 (21%) were uncertain. A majority of respondents in each of the three age groups wanted their physician to initiate the discussion (Table 1).

When asked if they had ever wanted to bring up the topic of life-prolonging treatment themselves during a visit with their physician, only 28 (13%) answered yes. Most respondents (62%) had not ever wanted to raise the subject. Another 24% were undecided.

All patients were surveyed regarding any discussions they had had about life-prolonging treatment with their spouse, other family members, friends, other physicians, or a lawyer. Among all respondents, 87 (37%) had not discussed their wishes with any other person. Of the 129 married respondents, 83 (64%) had discussed the matter with their spouse. Of the respondents who had not previously discussed the issue with their family physician, only two had discussed life-prolonging treatment with another physician, and six had spoken with a lawyer about their wishes.

When asked to judge how important they thought it was to make decisions about life-prolonging treatment options while they are still well, 48% stated that it was

Table 2. Patients' Perceptions of the Importance of Discussing the Use of Life-Prolonging Treatment When Well and When Very Ill (N = 233)

Patient's Health Status	Very Important, %	Somewhat Important, %	Uncertain, %	Somewhat Unimportant, %	Very Unimportant, %
Well	48	35	12	5	0
Very ill	83	9	5	2	1

very important (Table 2). A larger proportion (83%) said it would be "very important" to discuss life-prolonging treatment if they became very ill ("developed a life-threatening illness"). Across all three age groups the same proportion (83%) agreed that it would be "very important" to discuss their wishes with their physicians if they were very ill. In determining the importance of dealing with such questions while they are well, however, fewer in the younger age group (37% of those 18 to 40 years of age) answered "very important" compared with the older age groups (52% of those 41 to 60 years; 63% of those more than 60 years).

If they moved to another city and began seeing a new family physician, most respondents (62%) felt it would be appropriate for the new physician to discuss their wishes concerning life-prolonging treatments during the first visit. This majority of respondents was distributed relatively evenly among each of the three designated age groups (57%, 65%, and 64%, respectively).

Discussion

This survey was completed 2 months before implementation of Ohio's living will and durable power of attorney for health care legislation[26] and 4 months before implementation of the Patient Self-Determination Act (PSDA).[27] We believe that by completing the survey before these events, our respondents were not biased by media coverage of the issues.

Most of the patients in this study wanted to discuss their wishes regarding the use of life-prolonging treatments with their physician and preferred that this discussion be initiated by the physician. We found this desire to be present regardless of age or health status. Most patients were not inclined to raise the subject themselves.

We believe that further studies in the outpatient setting will show that patients are much more willing to discuss these questions when they are young and healthy than physicians currently believe. Decisions about advance directives should be made in the outpatient setting while patients are well. As Doukas and Brody suggested, encourage patients to "voice your advance directives early and voice often."[28] This allows patients and their physicians the opportunity to periodically assess whether advance directive choices have changed with the patient's age or health status.

Many studies suggest that advance directives be discussed, but do not suggest when this discussion should take place. While such discussions usually occur in the context of an established patient-physician relationship, the responses in our study suggest that a physician could open this area for discussion during a new patient's initial visit. Further study would be needed to assess a patient's reactions to the physician initiating a discussion on these issues during the first visit. Other factors, including cultural differences, may significantly affect patient attitudes toward discussing advance directives. For example, among the Navajo it is difficult to discuss future negative events because of their beliefs about causation of illness and death.[29]

Doukas and Brody recommend that primary care physicians "encourage patients who are concerned about their future control over treatment to execute an advance directive. . . ."[28] We would stress that physicians should take a proactive role, initating the discussion themselves rather than waiting for the patient to express his or her concerns. Patients who would object can be identified by their responses to the physician's first few questions without necessarily offending them. The physician can say: "It is important for me as your physician to understand your attitudes and beliefs about life-prolonging treatment. May I ask you a few questions?"

Ventres and Spencer[6] have suggested that the question of whether patients have signed an advance directive should be added to the adult review of systems when obtaining a patient's comprehensive history. While this is a reasonable suggestion, we recommend more emphasis on questioning them regarding the use of life-prolonging treatments. Although it is a subtle difference, it may be more prudent to discuss the patient's wishes than to focus on whether the patient has completed a document. The statement of one's wishes may be broader and more comprehensive than most advanced directive forms allow.

It may not be necessary to resolve the patient's views on his or her first visit. In fact, because of time constraints

and many other important issues, it may be impossible to adequately discuss advance directives in any single visit. An early introduction of the topic, however, offers some advantages to both patient and physician. First, it allows the physician to share his or her own attitudes toward the withholding or withdrawal of life-sustaining treatment. Second, the physician can begin an educational process with the patient, which may involve a discussion or a review of printed material given to the patient. Third, this approach may identify those patients who want to discuss the matter but would have been hesitant to bring it up themselves. Patients who know that their physician is open to discussing life-prolonging treatment, even if they do not take advantage of the physician's initial offer, may feel freer to raise the subject themselves in the future.

As the one responsible for continuity of a patient's care, the family physician is the appropriate person to counsel patients about advanced directives. These decisions are neither simple nor static. The family physician is in a good position to address changes in a patient's past decisions as he or she ages, as his or her health status changes, and as his or her views are altered by life events.

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