Community Attitudes And Knowledge About Advance Care Directives

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Abstract: ***Background:*** **Patients and their physicians are increasingly being encouraged to discuss end-of-life decisions. The purpose of this study was to enhance understanding of the public's attitudes and knowledge about medical decision making and advance care directives.**

Methods: **Eight focus groups of community members discussed their understanding of and attitudes about advance care directives. Transcripts of these discussions were analyzed using coding categories created from the transcripts.**

Results: **Eighty-three people attended the focus groups. Most discussions of advance care directives involved family members in the setting of family or personal illness. Elderly persons commonly confused wills with living wills. Most who had given advance directives did so either to make others follow their wishes or to ease family burdens. Among the great variety of reasons for not using advance directives was a perceived lack of personal relevance, as well as conceptual, moral, and practical difficulties. Participants were divided about whether it was appropriate for physicians to initiate discussions about life-sustaining care with their patients. We discerned three themes affecting individuals' opinions about personal decision making about advance directives: (1) trust in family and the medical system, (2) need for control, and (3) knowledge about advance directives.**

Conclusions: **Although living wills are advocated by many authorities, and many of our participants endorsed their use, our participants also cited numerous cautions and impediments to their use. As the role of advance care directives changes, physicians will need to be aware of their patients' perceptions, as well as the legalities of these documents. (J Am Board Fam Pract 1992; 5:565-72.)**

The ability to keep persons alive beyond their capacity to make decisions will increasingly encourage patients and their physicians to discuss advance care directives (ACDs). The recent Patient Self-Determination Act (PSDA) requires that all hospitals, nursing homes, home health agencies, health maintenance organizations, and hospices inquire whether new patients have advance directives and give patients written information regarding their right to make an advance directive under state law.[1,2] Another aspect of this act, not so widely known, is its requirement for community education about advance directives to promote discussion and decision making prior to entering a health care facility.[2,3]

Physicians and other providers will need a better understanding of current public knowledge and attitudes before they can easily assist individual patients in the use of ACDs. Several studies have attempted to quantify patients' attitudes toward living wills,[4-6] life-sustaining treatment,[7-11] and surrogate decision makers.[12-14] Lo, et al.[4] found that, although only 6 percent of patients had discussed ACDs with a physician, 68 percent wanted such a discussion. They also found that more than 70 percent would refuse cardiopulmonary resuscitation, feeding tubes, and intensive care should they be unable to make decisions for themselves. In contrast, Danis, et al.[8] found that 70 percent of patients and families would accept intensive treatment even if they would live just 1 month longer. This lack of con-

Submitted 8 June 1992.

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This study was partially supported by HRSA Faculty Development Training Grant PE57008-08 and NRSA Research Training in Primary Care Grant PE17001-04.

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sensus in the literature adds to the difficulties practicing physicians face in helping their patients with these decisions.

Lacking in this field are data that reveal how individuals decide about ACDs and that suggest which kind of ACDs are most likely to serve individual patients. To obtain this information, a qualitative research strategy exploring the full range of responses held by the public is especially useful. Focus groups, historically used in marketing, utilize the interaction of participants in group discussions to solicit individual opinions.[15,16] This method has recently been used in studies reported in the medical literature as well.[17,18] Our current study used focus groups of community members invited to discuss their experiences with and opinions about ACDs to add breadth and depth to our understanding of persons' attitudes and knowledge about medical decision making.

Methods

Community members from a midwestern university town with a population of 69,000 were solicited to attend focus groups that were described as a discussion of right-to-die issues. Because our primary interest was to obtain a wide spectrum of responses, focus group participants were not randomly selected from the community, rather they were selected from diverse groups and settings to provide an enriched sample. Participants were solicited through churches, community, and civic groups and by flyers and posters. Eight focus groups were formed: three groups of senior citizens (one in a nursing home, one in an assisted care apartment complex, and one at a community senior citizen club), two groups open to the general public, one group from an adult study class of a local Protestant church, one group specifically targeted to university students, and one group composed of members and friends of a right-to-life organization. No participants received payment for their attendance, but food was provided at all meetings.

Each focus group began with the participants filling out a brief, anonymous questionnaire that elicited demographic information. All discussions were audiotaped, and assistants observed each discussion, making written observations on the interactions and nonverbal communication. Each discussion was facilitated by the first author of this paper. After a brief introduction, the participants were asked to discuss whether they had ever spoken to anyone about the medical care they would want to receive if they were to become hopelessly ill and could no longer make decisions for themselves. The discussions were generally allowed to progress as the participants wished. Areas probed by the facilitator included the role of the physician, knowledge about written advance care directives, and reasons for or against giving verbal and written advance care directives. Discussions lasted between 45 and 90 minutes.

Each audiotape was then transcribed. Initial coding categories were devised from a random sample of transcript pages by the primary investigator. Each transcript was then read and coded independently by 2 investigators, with additions made to the initial coding categories when necessary. During individual meetings between the pair of investigators, the codings were discussed, adjustments were made, and eventually 100 percent agreement was obtained from each dyad. These coded comments were then sorted by category. During a series of meetings, all 5 investigators discussed and determined general trends and striking differences.

Results

Sample Characteristics

Eighty-three persons attended eight separate focus groups. The groups dichotomized into two broad categories by age: the first three groups were composed of elderly participants, and the last five groups were of persons of all ages. Only 6 of the 53 participants in the five general groups were older than 65 years. In general, the participants were highly educated, professional, and white; however, the older groups were less well educated and in poorer health. The older groups also had a higher percentage of women participants, and they had fewer persons on whom they could depend (Table 1).

The focus group discussions can be categorized into four main areas: a description of the types of advance care discussions participants had held, knowledge about ACDs, rationales for and against having ACDs, and the role of the physician as perceived by the group participants.

Advance Care Discussions

Most focus group participants had discussed ACDs with family members only. Children,

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Table 1. Focus Group Characteristics.

Characteristics	Older Groups (n = 30)	Younger Groups (n = 53)	*P* Value*
Mean age (years)	78	43	
Percent women	90	62	0.002
Mean number of dependents	0.6	2.0	0.002
Mean number of adults participant can depend on	2.9	3.5	0.005

*Chi-square.

spouses, and parents were mentioned most often. Younger participants also mentioned having discussions with friends, but not so often as with family members. At least 1 person in each group had spoken to a lawyer about his or her wishes, generally in the context of making a written document. Although participants in several groups had talked to their physicians about their wishes, the discussions were never initiated by the physician.

Most of the discussions of ACDs were prompted by an illness or death in the family. The second most common reason for starting a discussion was media coverage of recent court cases, such as the *Cruzan* decision, or dramatic presentations on television. Those in the senior citizens' groups, however, never mentioned media coverage as a factor for initiating a discussion of ACDs. Discussions also occurred among the younger participants when the participant was in a medical profession or had a family member in the medical field. Participants reported that most of the discussions they had held were general, often describing broad issues and moral concerns, but not commonly addressing personal desires or wishes.

Knowledge about Advance Care Directives

Most of the participants were familiar with the term *living will*, and many were familiar with the concept of a durable power of attorney for health care. The depth of understanding varied widely, however. Among the older groups, there was general confusion between a will and a living will, as well as between directions for life-sustaining care and burial instructions. Many questions were answered with such comments as, "I want to be buried by my husband," or "I leave it all to my 2 children." Even when attempts were made to clarify the questions, this confusion persisted among many in the older groups. When asked their definition of a living will, some admitted they did not know, but others defined it as this participant did:

> That's what you decide you want to happen after you are gone. That would be a living will. You are to leave it there until you do pass away.

Although members of other groups were more likely to understand the concepts of ACDs, there were still common misunderstandings. Most participants who expressed an opinion believed a lawyer was necessary to draft any written document, especially a durable power of attorney for health care. Participants also commonly thought that living wills and durable powers of attorney apply in any situation in which "I'm not able to communicate anything." In fact, in most states, living will statutes apply only to terminal conditions. There were also occasional misunderstandings about the cost of written ACDs and their validity outside the state in which they are signed.

Rationales for Advance Care Directives

Participants offered opinions about the value of ACDs from two perspectives: their own personal experiences with ACDs, and broader reasons they could see for persons in general to give either verbal or written instructions. There were two main reasons given for having an ACD (Table 2). The first was to make others follow their wishes. This concept was mentioned in nearly all the groups. Only one resident in the nursing home group had a living will, and she stated her reason for having one: "I wanted to have what I wanted to have planned — that's exactly the reason." Another participant believed that having control over her own destiny was important:

> And I think sort of the whole point of living wills or thinking or talking about this beforehand is so that people do know what I might want. Because I want to be able to have . . . the last control.

The second common reason for giving advance instructions was to ease the burden, both financially and emotionally, for family members and to ease their decision making. Commonly expressed thoughts included, "I want it out so it's not on

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Table 2. Rationales for and against Giving Advance Care Directives.

Participant Response	Rationale
For advance care directives	
General considerations	To make others follow one's wishes
	To ease the emotional and financial burden on family members
Against advance care directives	
Lack of personal relevance	Have not thought about it
	God will take each person in God's time
	Don't like to talk about death
	Family or doctor will know what to do
	"Too young" to be concerned
Conceptual difficulties	Terms are too vague or broad
	Unsure of own wishes
Moral difficulties	Could allow care to be withheld too soon
	Could increase burden on family
Practical difficulties	No family or friends
	Too complicated or expensive

their conscience," or "It takes the heat off of that person in making the decision."

Others were especially concerned about the financial burden that extended medical care might leave. This concern was expressed well by a participant at the senior citizens club:

> Well, if you know it's terminal anyway, then why should you be left to run up your bill and everything if they know they don't have the money to pay for it. I think that's real important.

Rationales against Advance Care Directives

In contrast to only two reasons given by the participants for having ACDs, the reasons for not having an ACD were much more numerous. Again, individuals included specific comments about why they had not given written or verbal instructions, as well as perceived societal reasons. The reasons fell into four categories: (1) lack of relevance, (2) conceptual difficulties, (3) moral difficulties, and (4) practical difficulties (Table 2).

For many participants, giving advance care directives had not become a relevant issue in their lives. Among different groups the specific reasons varied. Common among the older groups were the feelings, "The Man upstairs got the last word anyway," and "If it is your time to go, you go." Some older persons had an aversion to talking about death in general. One participant at the assisted living center simply stated, "I haven't thought much about that. I hate thinking about dying." This sentiment was mentioned in the younger groups in more global terms but rarely as a personal reason. One participant said, "Death has replaced sex as the taboo topic of conversation."

Probably the most common reason mentioned for not giving any advance directives by members of the older groups, but also brought up by several younger participants, was the feeling that family members or the physician would "know what to do." Comments from the assisted living center group exemplify this thought well:

> I think she [my daughter] knows me well enough, but I haven't pointed out anything. She'll take care of me.

> I have my children to take care of me; I ain't worrying about that.

Some participants in the younger groups expressed the thought that they were "too young" to worry about this issue. A student at the campus group, soon to be married, said,

> . . . we're more interested in health insurance and buying a home and getting a car and things like that, and we don't really think about things like that [advance care directives] because of our age.

A second category of reasons that participants gave for not having ACDs was related to conceptual difficulties. These participants were concerned that terms commonly used in ACDs, such as "extraordinary care," are too vague or broad or that they might be unsure of their wishes or change their minds in the future. These issues were rarely mentioned by the older groups but were common among the younger groups. A student in the campus group expressed her concern about terminology:

> That [extraordinary] is just kind of a broad word, and I just wondered who decides? I mean, is it left up to the children or the physician, or who decides what extraordinary means?

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The inability to allow for all eventualities was discussed by a participant in the church group:

> There are so many variables, too. I mean, we are talking about somebody with cancer, someone who has been in an automobile accident and has trauma; there are just so many variables that it is hard to sit down and write something at one point in time that is going to cover forever.

Yet another participant noted her own indecision:

> I haven't talked about where I am on it because I don't know yet. I have more questions about this issue than I have answers.

A third set of reasons involved moral or ethical dilemmas. Whereas almost every group mentioned at least one such concern, the majority of comments came from the right-to-life group. This group expressed concerns that ACDs might allow care to be withheld too soon or could result in a shirking of societal responsibility. Comments included the following:

> But the rest of the people are exposed to this . . . new pressure from society that says, "Sorry, we don't have time or money to treat you. Your life isn't worth it."

> We have to guard ourselves against whether you're feeling sorry for the person afflicted or whether you're feeling sorry for yourself having to take care of that individual, and I think it's very easy for an individual to deny your responsibility to that person.

There was also concern that ACDs might actually increase the burden on family members to follow known wishes. This concern was in direct contrast to what others expressed about easing family members' burdens by having ACDs and is expressed well by this comment:

> But in the same light, if you're giving one person the right to make a decision, that's quite a load on one person. You're asking a lot of that one person. I don't know if I could do that.

A last category of concern expressed by a smaller number of people dealt with practical difficulties. Among some of the elderly in the nursing home, comments were expressed that "I don't have anybody to tell." While this problem was not voiced by other groups with more social support, they were concerned that ACDs, especially written ones, were too complicated or too expensive. One participant commented, "I haven't done all my homework. I don't have all my stack of documents worked out, and I may never know enough."

Role of Physicians in Advance Care Discussions

As noted earlier, no physician had initiated a discussion of advance directives with any of the focus group participants. The participants, however, were divided about whether this behavior was appropriate for a physician. Across all groups there were participants who believed strongly that it was a physician's duty to discuss ACDs with his or her patients, as reflected by this comment, "I think it would be . . . ideal, if a physician would be able to bring this up with you in a time of health rather than a time of illness." Others even envisioned ways to add ACDs to the routine of a physician's office:

> When you're a new patient and you fill out all the insurance forms, why not also [include] at least the opportunity, in an education sheet, to fill out at least a living will and preferably something stronger.

Yet nearly as many thought that physicians should not bring advance directives up with their patients, that talk of this subject might frighten some patients. This feeling was noted in all groups, as is exemplified by these comments:

> I believe it's our decision to bring it to the physicians. I really don't think it should be the other way around.

> Bringing this issue up with the patient, unless you have a very good relationship with that patient — I'm going to think the doctor is not telling me anything and I've got some incurable illness and I'm probably going to be out of this world in 6 months.

Several participants were concerned that they might not have a primary care physician on whom they could depend for their health care. As one participant summed it:

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How do we know we're going to have the same personal physician when the time comes. We got one now, but we may not have one then; he or she may have left town, moved on, and so we don't have anyone we know.

Discussion

Because focus groups do not limit options, as do many quantitative methods, they allow the reasons and emotions behind public opinions to be expressed. A 1988 survey sponsored by the American Medical Association found that only 15 percent of Americans had a living will and that only 56 percent had told family members of their wishes concerning use of life-sustaining treatments.[19] Among the elderly, there is little use of even verbal instructions.[9,12] Our study attempted to explore the reasons behind findings such as these. Participants in our focus groups talked not only about the reasons why they had or had not given advance directives, but also about the context in which they were given.

While the range of reasons for favoring or not favoring ACDs is interesting in itself, analysis and categorization of our participants' responses provide three particularly important themes: trust, control, and knowledge. Each of these concepts runs along a continuum, from full trust in others to no trust, from wanting complete control to wanting others to make decisions, and from full understanding and knowledge to complete ignorance. Where individuals fall on each continuum seems likely to influence how they think about ACDs and could also determine what kind of ACD, if any, would best meet their needs.

Trust in family and physicians is an important issue for most people when they think about being unable to make health care decisions for themselves. Many participants in our study, especially the elderly, mentioned that they had no need for ACDs because family members or the physician would know what to do. In recent years, however, several studies have raised concerns about the ability of families and health care providers to predict a patient's wishes. Family members predicted patients' wishes correctly 53 to 90 percent of the time,[12,13] whereas physicians agreed with patients only 59 to 84 percent of the time.[12,14] Others have reported that only 40 percent of nursing home patients[9] and 16 to 34 percent of geriatric outpatients[6,12] had discussed their wishes with family members. Expecting that "My family will know what to do" regarding unspoken wishes might be unrealistic. It could be, though, that for some, trust in family decision makers supersedes the desire for control and having one's own wishes followed.

The second factor is the individual's desire for control of future medical care. Study participants who had ACDs valued control highly. "I wanted to have what I wanted," and "I want to be able to have the last control" were typical comments. Many of these participants also had little trust in the medical system or in family members to follow these wishes and therefore tried to make these wishes public. One participant even stated, "Really, in the end there is no ultimate protection if the doctor wants to make it happen." Others tended to be more fatalistic about the issue of decision making. Some simply said, "When it's your time to go, you go." It is difficult to know whether many of those who had not thought about it or were too young or had other relevancy concerns were in fact at one end of the control scale and comfortable with not having such control or whether there was a desire for control, but a lack of knowledge about the need for such directives. Other studies have noted lack of relevancy as a reason for not having ACDs[5] but have not addressed this lack of relevancy further. The answer, however, has important implications for the kind of information that these individuals will need to make an informed decision about ACDs.

The third factor is knowledge about ACDs. Most of our participants had a good understanding of written ACDs, which is not surprising, because many of our groups were self-selected for interest in this topic. Significant confusion and misunderstanding of these documents existed, however, among the elderly, many of whom came for the social interaction rather than for the specific topic. This lack of knowledge among the elderly has been noted in other studies in which participants asked to define living wills could do so correctly only 39 to 64 percent of the time.[6,11] Among our other groups, knowledge deficits tended to relate specifically to legal issues, such as the need to have a lawyer and applicability in certain situations. This confusion might result from these issues being defined by the statutes and common law of each state,

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which vary nationwide.[20] These misunderstandings could persuade some persons not to have wishes documented because they fear the complexity and cost. This concern about perceived complexity was, in fact, noted by a few of our participants.

The Patient Self-Determination Act (PSDA), which mainly addresses the area of knowledge, requires institutions to provide information to all adult patients on admission or first receipt of care. Many experts contend, however, that ideally such discussions should take place in the outpatient setting.[21] Whether physicians should initiate such talks with their patients is a matter of some debate.[22,23] Physicians have expressed concern that their patients might have reservations about discussing ACDs.[24,25] Yet physicians are being encouraged to discuss life-sustaining treatments with their patients during routine, nonemergency care.[26-28] The participants in our study were divided in their opinions whether physicians should bring this subject up with their patients. This finding is supported by findings of previous surveys and interviews, in which some groups have had positive reactions to physician-initiated discussions,[4,6,29] and others have expressed doubts about such routine discussions.[4,6]

Routine compliance with the PSDA can ease the concerns of some of our participants who worried that being asked about life-sustaining care forewarns news of a terminal diagnosis. Nevertheless, the PSDA will not eliminate the concerns of the participants who believed that it was not the physician's place to bring up such a topic. It is important for physicians to realize that some patients will not wish to discuss such issues. Other patients would be ready for discussions only at certain times. Physicians themselves might feel awkward when addressing the subject of life-sustaining care with young healthy persons. Family physicians are uniquely positioned to bring up ACDs when caring for patients who are dealing with a family member's death or serious illness or when the topic is in the media.

This study has several limitations. The participants were mainly white, well educated, and middle class. Very few who were poor or members of minority groups attended the focus groups. Our efforts to hold discussions at community centers and public housing centers in poorer neighborhoods failed. Issues other than those mentioned could have been raised by groups not represented in our sample. Because the discussions were participant centered, not every group discussed all the same issues. This structure allowed more spontaneity among the participants and deeper discussions of issues the group thought important, but it did limit gathering data about other topics. Focus groups cannot detail the distribution of these opinions, as can properly conducted surveys, but these survey questionnaires often prematurely limit the range of responses.[16] The issues raised by our participants, however, open other areas for research and education as physicians deal more with their patients' wishes for life-sustaining care.

In helping patients make advance care decisions, physicians will find it useful to assess their patients' positions on trust of family and physician, need for control, and knowledge of advance care documents. Those who desire to control life-sustaining decisions would do well to draw up a written ACD. But their choice of whether to sign a living will or a durable power of attorney or both will depend on their trust of proxies and whether they want more control than the mere selection of a proxy can provide. Those for whom trust is most important might want to execute both instruments with the durable power of attorney to govern unless the proxy is unavailable. Those for whom control is most important will want the living will to govern to the extent that it applies and only when it does not to resort to the durable power of attorney. Those who do not want to control those specific decisions will be better suited to a durable power of attorney than to a living will. These people might feel a need to control the selection of the decision maker but not necessarily the decision. Those who desire no control at all and trust the family or physician to do the right thing might prefer no ACD. In any case, providers should ensure that lack of knowledge is not the reason for this decision.

The PSDA might open the door for better patient-physician communication about these difficult but important decisions. For some, however, needs will be harder to assess and will require more extensive discussions. What could appear to be simple lack of interest might, in

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fact, be extreme trust in family, lack of desire for control, or simple ignorance. The information mandated by the PSDA is only the first step. Our findings suggest that institutions and physicians must also be sensitive to individual preferences in the areas of trust and desire for control.

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