

Barriers to Communication About End-of-Life Care in AIDS Patients

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OBJECTIVE: Patients and physicians do not adequately discuss patients' preferences for medical care at the end of life. Our objective was to perform a qualitative study using focus groups to identify barriers and facilitators to communication about end-of-life medical care for patients with AIDS and their physicians.

PARTICIPANTS: Patients with AIDS and physicians with moderate or extensive HIV experience were recruited from clinics and community-based settings using network sampling. A total of 47 patients participated in six focus groups and 19 physicians participated in three groups.

MEASUREMENTS AND MAIN RESULTS: Patients or physicians identified 29 barriers and facilitators to communication about end-of-life care. Many patients and physicians expressed discomfort talking about death and dying, and some felt that discussing end-of-life care could cause harm or even hasten death. Several patients expressed the view that a living will obviated the need for discussion with their physician. Previous experience of discrimination from the health care system was a strong barrier to end-of-life communication for some patients with AIDS. Some patients hesitate to bring up end-of-life issues because they want to protect their physicians from uncomfortable discussions. Many patients identified the quality of communication as an important facilitator to these difficult discussions.

CONCLUSIONS: Improving the quality of patient-physician communication about end-of-life care will require that physicians identify and overcome the barriers to this communication. To improve the quality of medical care at the end of life, we must address the quality of communication about end-of-life care.

KEY WORDS: end of life; death; AIDS; HIV infection; communication.

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Many Americans fear loss of control over their lives if they become critically ill and worry that their dying will be prolonged, involve invasive therapy, and be impersonal.¹ This concern is particularly important for those with chronic disease. There is substantial evidence, however, that physicians and patients do not adequately discuss patients' preferences for end-of-life medical care.²⁻⁴ The Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT), a controlled trial undertaken to improve care for critically ill individuals with chronic disease, found that less than 50% of physicians knew when their patients preferred to forgo cardiopulmonary resuscitation (CPR).⁵

Because physicians and patients may have different approaches to end-of-life decision making for AIDS than for other diseases,^{6,7} it is important to look at this disease separately. AIDS is the leading cause of death among men aged 15 to 44 years and the fourth leading cause of death among women in this age group.⁸ In addition, AIDS disproportionately affects individuals marginalized in our society.⁹ Many individuals with AIDS may be at risk of having medical care withheld by a system with which they do not easily interact,¹⁰ or of having inappropriately aggressive care because of inadequate communication with physicians.^{11,12} As a result, many persons with AIDS may be at increased risk of a "bad death."

Several survey studies demonstrate that although a majority of patients with AIDS would like to talk with their physicians about end-of-life care, only a minority have had such a discussion.^{4,12,13} If patients believe that patient-physician communication about end-of-life care is important and yet these discussions are infrequent, then substantial barriers to discussing end-of-life care must exist. Identification of the barriers to communication about end-of-life care is a necessary step to overcome them.^{14,15} The goal of this study is to identify and understand the barriers and facilitators to discussing end-of-life care for patients with AIDS and their physicians.

METHODS

We conducted six focus groups with a total of 47 patients with AIDS and three focus groups with a total of 19 physicians with AIDS experience. The groups were conducted between January and April of 1996. Each focus group comprised 6 to 11 subjects, a focus group leader with previous experience in qualitative research concerning end-of-life care, and one of the investigators (as an observer). During each session, the leader asked several

scripted, open-ended questions. After initial introductions, the leader asked the participants each if they had advance directives and whether they had discussed with their physician the kind of care they would want if they became too ill to speak for themselves.

The initial question about barriers to end-of-life discussion was "What are the things that make it hard to talk with your doctor about the kind of care you would want if you were too sick to speak for yourself?" Similarly, the initial question about facilitators to end-of-life discussion was "What are the things that make it easier to talk with your doctor about the kind of care you would want if you were too sick to speak for yourself?" The leader would restate or rephrase the question when necessary to continue conversation on the topic. In addition, the leader probed participants to clarify the meaning of statements when necessary, facilitated discussion between group members, and asked members who remained quiet for their opinion. The leader did not offer possible barriers or facilitators to end-of-life discussions. A similar approach was used in the physician groups. Focus group sessions were audiotaped and transcribed verbatim.

Recruitment of Participants

Entry criteria for patients with AIDS were as follows: at least 18 years of age, English-speaking, an AIDS-defining illness,¹⁶ and CD4 count of less than 200. Patients were excluded if they had a diagnosis of dementia and their physician felt that their cognitive impairment would interfere with participation in the group. Patients were recruited with flyers advertising for a focus group concerning patient-physician communication, but not specifying the focus on end-of-life care. Flyers were posted in university-affiliated and community-based clinics and community-based programs for persons with AIDS. In addition, we contacted leaders of support groups for injection drug users with HIV, persons of color with HIV, and women with HIV and asked them to notify participants of this research opportunity.

The inclusion criteria for physicians was having provided primary care for at least 30 patients with AIDS during the physician's career. Physicians with HIV experience were identified by key informants at university-affiliated HIV clinics and through an HIV educational coordinator at major private hospitals providing care to patients with HIV (network sampling). Patients and physicians were told that the focus group would discuss patient-physician communication for patients with AIDS, but the end-of-life focus was not specified during recruitment. Patients received \$10 for participation; physicians were not reimbursed.

Conduct of Focus Groups

Focus groups were formed around key characteristics to enhance group participation. For persons with AIDS, the key characteristics of the groups were as follows: gay

or bisexual men (two groups with 9 and 7 participants), women (two groups with 9 and 5 participants), injection drug users (one group with 11 participants), and persons of color (one group with 6 participants). The median age for patients was 38 years with a range of 23 to 58 years; the individual groups did not differ substantially in their median ages. Overall, 16 of the 47 participants were women (including 14 in the women's groups and 2 in the injection drug users' group). Individuals classifying themselves as African American or Latino comprised 17 of 47 patients (including 6 African Americans in the persons of color group, 4 African Americans in the women's groups, 3 Latinas in the women's groups, 3 African Americans in the injection drug users' group, and 1 Latino in the injection drug users' group).

The key characteristic around which the physician groups were formed was university employees or private practitioners. There were 2 groups formed from university-affiliated clinics (7 and 5 participants) and one group from community hospitals (7 participants). Overall, women comprised 6 of 19 physicians, and none of the physicians was African American or Latino.

Analysis of Transcripts

After initial review of focus group transcripts, investigators developed a coding scheme for barriers and facilitators to discussing end-of-life care. The transcripts were then reviewed independently by both investigators to classify passages (portions of text from a single speaker) into one of 29 barriers and facilitators. To address the trustworthiness of the data, we compared coding across investigators: we assigned the same code to 63% of the passages. We then reviewed discrepancies and came to consensus for each passage. All barriers or facilitators identified from the transcript review were identified in at least two different focus groups, suggesting that additional groups would not have identified more barriers or facilitators.¹⁷

RESULTS

Tables 1 and 2 list the 29 barriers and facilitators to patient-physician communication about end-of-life care for patients with AIDS. Barriers and facilitators are divided into those identified in patient and physician focus groups, patient groups only, or physician groups only. We present representative quotations to provide context for those barriers and facilitators that we felt were unexpected or particularly important.

One of the barriers frequently mentioned by patients and physicians is discomfort discussing death. One patient said, "I really didn't think about it when I did [my living will]. I just answered the questions they asked me. If I was to sit down and think about it, it probably would have bugged me but I just answered real quick. If I don't take too much time to think about it, it doesn't bother me." A physician identified this barrier saying, "It's fun to see pa-

Table 1. Barriers to Discussion of End-of-Life Medical Care*

Barriers identified by patient and physician focus groups
Discomfort in discussing death
Patient is not sick enough to talk about end-of-life care
Discussing death can cause harm or death
Patients avoid end-of-life discussion to protect physicians
Each person waiting until the other brings up end-of-life care
Barriers unique to patient focus groups
Discrimination by the medical system against certain groups
Persons with AIDS
Women
Nonwhite persons
Gay men and lesbians
Drug users
Poor and poorly educated
Treatment preferences are in flux so patients don't want to have preferences "set in stone"
Living will is a barrier because it makes discussion unnecessary
Barriers unique to physician focus groups
Young age of persons with AIDS
Too little time and too many other issues to discuss during appointment
Fear of undermining patient's hope
Physician's role is to make patients feel better
End-of-life discussion requires considerable energy and preparation
Physician fears being perceived as not being aggressive enough
Many levels of aggressiveness of care make discussions very complicated (i.e. CPR, antibiotics, feeding tubes)
Patient and family's culture differs from physician's culture
Insurance companies requiring change of physician at the end of life
Physician not ready for patient to die

*Identified in focus groups of persons with AIDS and physicians with extensive AIDS experience.

tients, and bringing up such a serious topic as their mortality, particularly for people with HIV infection for whom it is a very stressful and very real part of their 24-hour existence—I think it's difficult. It's usually the big elephant in the corner of the room that you don't talk about."

Physicians also worried about undermining a patient's hope. One physician said, "I think it's real important not to take their hope away, and I find a barrier to having this conversation is that I might be undermining hope." Another physician comments that, "No matter how many times I've done this before, I tell them, 'Look I'm not saying you're gonna die,' and they say, 'Well, then why are we talking about this?'"

Some patients talked extensively about experiencing discrimination in receiving health care. One patient said, "If you're a white heterosexual male that's never been on drugs, you're gonna get a different type of care than if

Table 2. Facilitators for Discussion of End-of-Life Medical Care*

Facilitators identified by patient and physician focus groups
Quality of patient-physician communication about end-of-life care
Trust in physician
Previous experiences with family/friends who died
Not wanting to be a burden to family
Duration/continuity of patient-physician relationship
Facilitators unique to patient focus groups
Concern about future quality of life
Desire for autonomy at the end of life
Physician cares about patient "as a person"
AIDS expertise of physician
Facilitators unique to physician focus groups
Loved one present for end-of-life discussion
When end-of-life discussions are expected by health care system
Patient Self-Determination Act as a "conversation-opener"

*Identified in focus groups of persons with AIDS and physicians with extensive AIDS experience.

you're a black homosexual that's had a history of drug use." Several patients said they could not talk about end-of-life care until they felt comfortable the physician would not discriminate against them: "It's hard to bring up . . . what my life is about and stuff about the end until I feel like [my doctor] isn't gonna judge me. It's relevant . . . [for] my doctor to know my history around addiction, but it wasn't until I got to know him that I was able to disclose."

Several patients and physicians felt that discussing end-of-life care could cause harm or even death. One patient said, "[My doctor] told me, you gotta do the living will. And I keep saying, okay, I will, I will, I will. But I never told him that I feel that if I sign that thing, I'm gonna die. To me, that's a death warrant. You sign it, you die. That's the way I was raised." Similarly, a physician said, "I don't think we really know with a terminal disease like this how negative [end-of-life discussions] might be and what that does to one's lifestyle and compliance with medications . . ." Another barrier identified by patients is the idea that patients shouldn't have an end-of-life discussion until they know what they want at the end of life: "I'm kind of holding out until the miracle happens . . . I wouldn't want to be on life support, but . . . I don't want to carve that in stone just yet, so I don't talk to the doctor about it."

Some patients feel the need to protect physicians from discussion that they perceive as uncomfortable or even illegal. One patient said, "I'm a little reticent to bring up all these end-of-the-line kind of things, you know, because I'll bum them [clinic staff] out over it." Another patient said, "I found myself not telling my doctor what was going on because I didn't want her . . . to be upset. I feel like I have the perfect doctor, which makes me want to

protect her." Physicians also identified this barrier: "I had a patient who thought it would be illegal for him to talk to me about end-of-life issues. He thought if he asked me for help at the end of life, he was going to jeopardize my medical license . . . he kept answering, no, he wasn't ready to give up because he thought it would be wrong for him to talk to me about my helping him to be more comfortable."

Several patients perceive the living will as obviating the need to discuss end-of-life care with physicians. It was common for patients to express the sentiment of one patient: "I just filled [the living will] out and gave it to the doctor and that's all they required. They put it in your file and that's the way it's done." Another patient expressed this same view: "When you do the papers, it pretty well lays it out there. It makes it clear. You've written it down. End of discussion. You don't . . . worry about it any more."

Finally, some patients feel they should wait for their doctors to raise these issues, while some doctors feel they should wait until the patient raises the issue. One patient said, "I would be a hell of a lot more comfortable if my doctor would come to me and say 'We need to talk about this.'" One physician expressed the opposite view: "You have to wait for [patients] to bring it up because they live it all the time . . . and I think part of the reason you don't bring it up is because you want them to bring it up. You have to give them a certain amount of denial . . . They're the ones who have to cross that border."

Two facilitators warrant description by example. Patients spoke of the importance of quality of life in thinking about end-of-life care: "It's not like I have these conversations all the time, but . . . when I'm sick or finally feel better we'll talk about these things because my decisions change . . . As my quality of life continues to regress, my thoughts about how long I want to do the fight change." Also, physicians report these discussions can be easier when family members are present: "It's less threatening when there are people there who might be sharing that decision. It's more comfortable because there's another person there who can help interpret what you're saying to the patient and can help the patient deal with [the issues] after they leave."

DISCUSSION

Interventions designed to improve the quality of end-of-life care, such as advance directives, facilitating patient-physician communication, or providing state-of-the-art prognostic information, have been disappointing.^{5,18-20} One potential explanation for these negative trials is that not all barriers to discussing end-of-life care have been overcome by the designed interventions.¹⁵ Some barriers to patient-physician communication found in this study have been identified previously. For example, previous studies have demonstrated that physicians are reluctant to discuss death with their patients.^{21,22} Several barriers to communication about end-of-life care, however, have

not, to our knowledge, been previously identified. These barriers include patients' avoidance of end-of-life discussions in order to protect health care providers, the living will as a barrier because it obviates discussion between physician and patient, and physician fears that discussion about end-of-life care will lead patients to perceive the physicians as not being aggressive enough. The identification of the living will as a barrier to end-of-life discussion is particularly important because it is seen by many as a facilitator to these discussions.

Of the many other barriers we identified, one deserves further comment. Some patients and physicians were concerned that discussing end-of-life care may be harmful to the patient and may even hasten death. This concern was raised in a study showing that some Navajo subjects believed discussion of advance directives could precipitate illness or death.²³ There have also been reports of cases in which end-of-life discussion seemed to cause psychological pain.²⁴ Although several studies have shown that the majority of patients with AIDS want to discuss end-of-life care with their physicians,^{4,12,13} health care providers should be aware that some patients may feel these discussions can cause harm. Providers should give their patients the opportunity to express this concern.

The focus group participants in this study identified the quality of communication about end-of-life care as one of the most important facilitators of this discussion. Although there have been relatively few studies of the quality of patient-physician communication about end-of-life care, Tulsky and colleagues assessed the quality of communication between hospitalized patients and medical residents concerning Do Not Resuscitate orders.^{25,26} They found that medical residents spent most of the time talking and missed many opportunities to allow patients to discuss their personal values and goals of therapy. These studies suggest that the quality of communication about end-of-life care is poor and unlikely to improve with our current medical education.

Some barriers found in this study may be addressed by physician and patient education. For example, patients should be made aware that the living will does not obviate discussion and that discussion about end-of-life care can occur before making "a final decision" about the end-of-life care. In addition, physicians should be aware that patients may be reluctant to discuss end-of-life care out of concern for protecting the physician or because of past experiences with discrimination from the health care system. Similarly, some facilitators may be useful to physicians attempting to have these discussions with patients. For example, focusing on the quality of life remaining may help patients think about difficult issues involved in limiting aggressive medical care. Scheduling joint appointments with patients and their family or friends may also facilitate these discussions. Other barriers to end-of-life communication, such as discomfort discussing death and the potential for end-of-life discussion to cause harm,

will be more difficult to address. Nonetheless, awareness of these potential barriers can allow physicians to look for signs of patient discomfort and offer the option of not discussing end-of-life care if a patient feels the discussion may cause harm.

This study has several important limitations. Although we attempted to form diverse groups of persons with AIDS, the participants may not be representative. Individuals willing to participate in a focus group about patient-physician communication may differ from those not willing to participate. This study took place in the Pacific Northwest, and there may be some geographical, racial, and ethnic differences between this and other regions. There is substantial evidence that persons of different racial and ethnic backgrounds have different attitudes toward end-of-life care and advance care planning.^{12,27,28} Our study was designed to incorporate diverse views, but not to compare the views of different racial and ethnic groups. A limitation of the focus group methodology is that it does not allow us to assess the prevalence of the barriers and facilitators and makes it difficult to explore each one in depth. There also exists the possibility that the group setting might stifle socially unacceptable responses from participants. Although these are important limitations, this qualitative methodology provides content validity and contextual meaning to the barriers and facilitators important to the participants in these groups. In addition, this methodology identified previously unrecognized barriers and facilitators. Finally, new developments in antiretroviral therapy are dramatically changing the attitudes of physicians and patients about the goals of medical care (see Gallagher J. Back in the running: new drugs are helping many people who have AIDS feel they can win the race, but surprising hurdles remain. *The Advocate* 1996;723:22-30; and Leland J. The end of AIDS. *Newsweek* December 2, 1996:65-73). These new therapies will clearly affect end-of-life discussion and planning, but the nature of this effect is unclear.

It remains an unproven hypothesis that improving patient-physician communication about end-of-life care can improve the quality of the dying experience for individuals with a chronic disease such as AIDS. To explore this hypothesis, research on the quality of end-of-life care must address difficult issues such as the quality of patient-physician communication about end-of-life care and the effect of communication on the quality of dying. Whether or not this hypothesis is proven, physicians interested in improving the quality of their communication with patients about end-of-life care will need to address the barriers and make use of the facilitators to this communication.

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REFLECTIONS

A Blessed 1996 Greeting

The Kiss of Death
Has a bad reputation.
The kiss at death
Can be beautiful.
All I needed to say
With a kiss was
Good-bye my darling.
And all she needed in response
Was to bid this life
A gentle adieu.

There were no lingering regrets—
Only the closing of a chapter
In a life supremely lived
And peacefully surrendered.

Grace, Mercy, and Peace to all

SAM HEDRICK
Concord, Mass.