

Communicating With Dying Patients Within the Spectrum of Medical Care From Terminal Diagnosis to Death

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Background: Efforts to improve communication between physicians and dying patients have been unsuccessful, and guidelines for improving patient-physician communication about end-of-life care are based primarily on expert opinion. This study assessed which aspects of communication between patients and physicians are important in end-of-life care.

Methods: Twenty focus groups were held with 137 individuals, including patients with chronic and terminal illnesses, family members, health care professionals from hospice or acute care settings, and physicians with expertise in end-of-life care. Focus group analyses determined domains of physician skill at end-of-life care. Communication with patients was identified as one of the most important domains. Analyses of components important in communicating with dying patients and their families were performed.

Results: The following 6 areas were of central importance in communicating with dying patients: talking

with patients in an honest and straightforward way, being willing to talk about dying, giving bad news in a sensitive way, listening to patients, encouraging questions from patients, and being sensitive to when patients are ready to talk about death. Within these components, subthemes emerged that provide guidelines for physicians and educators. Dying patients also identified the need to achieve a balance between being honest and straightforward and not discouraging hope.

Conclusions: Several areas emerged for physicians to focus their attention on when communicating with dying patients. These findings provide guidance in how to improve this communication. They also highlight the need to approach communication about end-of-life care as a spectrum that requires attention from the time of a terminal diagnosis through death.

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COMMUNICATION between physicians and dying patients about end-of-life care occurs infrequently^{1,2}; when it occurs, studies suggest that there are important shortcomings in the quality of this communication.³⁻⁵ Efforts to improve communication concerning end-of-life issues have been unsuccessful. For example, the SUPPORT (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) study found that poor communication persisted even after an intervention designed to improve communication.¹ Although attention to communication at the end of life has increased in recent years, most efforts have focused on specific topics, such as communicating about advance directives and delivering bad news.⁶⁻¹² For many patients, however, making decisions about medical care in the context of a terminal or life-threatening ill-

ness is a prolonged process, and receiving bad news and discussing advance directives are only small parts.¹³ Few studies have examined the entire spectrum of communication between physicians and dying patients from diagnosis to death or the perspectives of dying patients and family members. Given the lack of empiric data, guidelines for improving patient-physician communication about end-of-life care have been based primarily on expert opinion.^{12,14}

The primary purpose of this study was to develop a conceptual understanding of physician skill at end-of-life care from the perspectives of dying patients, family members of dying patients, and health care professionals who work with dying patients.¹⁵ A conceptual framework of 12 domains was developed using focus groups and qualitative analyses. Communication with patients emerged as one of the most important domains. This report examines the aspects of communi-

SUBJECTS AND METHODS

STUDY DESIGN AND RECRUITMENT

Study methods and recruitment have been described previously,¹⁵ but are reviewed in detail herein. Focus groups, a common qualitative research method,^{16,17} were used to examine physician skill at end-of-life care. We identified individuals from the following 4 distinct categories for focus groups: patients with a terminal diagnosis, family members who had had a loved one die, nurses and social workers with experience in end-of-life care, and physicians identified as experts at end-of-life care. Participants were recruited through purposive sampling,¹⁶ in which we accepted all eligible and interested participants until target numbers were reached. The University of Washington Human Subjects Committee, University of Washington, Seattle, approved all procedures.

Inclusion criteria for patients included C3 acquired immunodeficiency syndrome (AIDS) as defined by the Centers for Disease Control and Prevention,¹⁸ oxygen-dependent chronic obstructive pulmonary disease (COPD), or metastatic cancer or nonoperable lung cancer. To recruit patients, flyers were posted and distributed in physicians' offices throughout Seattle. In addition, researchers contacted leaders of AIDS, cancer, and COPD support groups in the area and recruited patients through these groups. Inclusion criteria for family members included having participated in or observed the medical care of a loved one who died 2 to 12 months previously. Family members were recruited through grief support groups, flyers in clinics, and key informants in hospice programs. Inclusion criteria for health care workers (nurses and social workers)

included working closely with dying patients and physicians in a health care setting. Health care workers were recruited through key informants in hospitals and hospice programs. To recruit physicians, nurses who participated in focus groups were asked to identify physicians who were outstanding at end-of-life care. Inclusion criteria for physicians included practicing a specialty in which end-of-life care for chronic conditions is commonly provided and being nominated by at least 1 nurse from a focus group. Specialties of physicians identified included primary care, infectious diseases, gerontology, pulmonary and critical care medicine, oncology, and neurology.

FOCUS GROUPS

Investigators developed a series of moderator guides for the different focus group categories, with similar structures and open-ended questions. Patients, family members, and health care workers were asked to think about physicians who were especially skilled at end-of-life care and then describe what was good or helpful about their care and what aspects of care could have been improved. Focus group participants were then asked to think about physicians whose care was poor and describe what was poor about their care. Finally, participants were asked to describe what are the most important qualities that physicians should possess to deliver excellent end-of-life care. Moderator guides are available by request from the authors.

A trained focus group facilitator (D.M.A.) was recruited to conduct the focus groups. All sessions lasted 90 minutes, except physician groups, which were 60 minutes. The facilitator also used scripted probes to continue discussion, to refocus the participants on issues relevant

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cation between patients and physicians that are important in the medical care of dying patients. The goal is to illuminate what specific steps physicians can take to improve communication with their patients about end-of-life care.

RESULTS

From transcript analyses, 12 domains were identified related to physician competence at end-of-life care. These domains included communication with patients, patient education, inclusion and recognition of family, competence, pain and symptom management, emotional support, personalization, attention to patient values, respect and humility, support of patient decision making, accessibility and continuity, and team coordination. Communication with patients was the most frequently identified domain in focus groups overall. Within this domain, 6 components were identified as centrally important to communicating with dying patients (**Table**). Each of these components is discussed separately below.

TALKING WITH PATIENTS IN AN HONEST AND STRAIGHTFORWARD WAY

Among the 6 components, patients, family members, and health care workers most frequently discussed the im-

portance of physicians talking with patients in an honest and straightforward way. Physicians also discussed this component frequently. Subcomponents addressed the following key areas: candor/honesty, laying everything out in a clear manner, understandable language, and communication style.

Candor/Honesty

Candor/honesty was seen by patients, family members, and health care workers as very important. Among patients with terminal diagnoses, this candor most often referred to provision of information about their medical condition. For example, a patient with COPD said, "Dr _____ has never told me my illness was serious. I've asked him, but he doesn't answer." Family members described the value of physicians being honest with the family without destroying their hope. For example, "He was honest with us and we said that's what we wanted and insisted on, but he never did anything to our hope . . . he didn't belittle it and he didn't build it up." A health care worker described the need for physicians to be honest about prognosis:

The question might be, "Tell me, Doc, how long do I have?" I've seen it a number of times—"Well, nobody knows that, you know," and avoiding that, when the patient is really asking, "What are the statistics for my [condition]? How many months

to end-of-life care, and to encourage all participants to share their views while discouraging anyone from monopolizing the discussion. Participants were paid \$30, and all sessions were audiotaped and transcribed verbatim.

Twenty focus groups met, with a total of 137 participants, from October 29, 1997, through July 1, 1998. Three groups included patients with COPD (n=24); 4 groups, patients with AIDS (n=36); and 4 groups, patients with cancer (n=19). Three focus groups included family members (n=20), and 4, health care workers (n=27). Finally, 2 groups included physicians from academic and community settings (n=11).

TRANSCRIPT ANALYSES

Qualitative analyses for this study have been described in detail previously.¹⁵ A detailed summary is presented herein. A list of domains relevant to care of dying patients by physicians was developed through an iterative process. Before conducting the focus groups, investigators developed an initial list of domains of competence through a literature review and extensive meetings among investigators and expert consultants (from the University of Washington, Seattle, Albert R. Jonsen, PhD, Anthony L. Back, MD, Stuart J. Farber, MD; from Harvard University, Boston, Mass, Susan D. Block, MD; and from Brown University, Providence, RI, Joan M. Teno, MD, MSc).

After the first 4 focus groups, investigators independently reviewed the transcripts and coded all relevant passages of speech into 1 or more of the initial domains. New domains were developed if passages did not appear to fit into existing domains. Using the revised list of domains, investigator pairs each reviewed and coded 6 or 7

transcripts. Each pair independently coded all relevant passages of speech, and then discussed and resolved coding disagreements. When agreement on a passage could not be achieved within a pair, the passage was brought to the entire investigative group. The team reviewed results of each transcript and modified the list of domains. To assess interrater reliability, investigator pairs coded the same 3 transcripts, and coding was compared across the 3 pairs. Agreement was found for 63% of codes across all 3 pairs of coders and 89% of codes for 2 of 3 pairs.

After all transcripts were coded, teams of investigators reviewed all passages within each domain to identify the major themes or components of the domain. Investigators identified at least 3 representative passages per component and used the words of patients or families to label the components. All investigators then met to review and to agree on all the components and representative passages.

For the current study focusing specifically on the domain of communication with patients, subsequent analyses were performed to determine the frequency with which each specific component occurred in each focus group category. One investigator (M.D.W.) reviewed the transcripts and coded all passages previously identified as falling within the domain representing communication with patients into components. A research assistant independently reviewed and coded the same passages. All coding was reviewed, and discrepancies between the coders were resolved. The numbers of components across all communication passages were then tabulated overall and for each focus group category to provide general guidelines concerning attention to the components within focus group discussions. Finally, each component was further analyzed to identify main subthemes, if any, within that component.

Frequency of Discussion of Components Concerning Communication With Patients at the End of Life by Focus Group Category*

Component	No. of Passages (Rank Order)				Total
	Focus Group Category				
	Patients	Family Members	Health Care Professionals	Physicians	
Talks with patients in an honest and straightforward way	50 (1)	25 (1)	36 (1)	10 (3)	121 (1)
Willing to talk about dying	11 (4)	13 (3)	31 (2)	12 (1)	67 (2)
Gives bad news in a sensitive way	16 (3)	14 (2)	27 (3)	6 (4)	63 (3)
Listens to patients	32 (2)	2 (5)	13 (4)	11 (2)	58 (4)
Encourages questions from patients	9 (5)	8 (4)	4 (6)	3 (5)	24 (5)
Sensitive to when patients are ready to talk about death	6 (6)	1 (6)	9 (5)	0	16 (6)

*These components of communication with patients were obtained through review of transcripts from focus groups with dying patients, family members, and health care professionals and physicians who work in end-of-life care. For each of the components, the number of passages coded to that component and the component's rank order (by number of passages for each focus group category) are shown.

do I have to live?" And that's all they want to know. . . . I appreciate seeing the honest answer.

Honesty concerning a patient's medical condition and prognosis appeared to go hand-in-hand with alleviation of uncertainty for many patients: "If I'm really in trouble, I want to know. I want to know what's going on so it isn't scary."

Laying Everything Out in a Clear Manner

Laying everything out in a clear manner referred to the organization of materials in combination with being honest about the patient's medical condition. The term *straightforward* was used frequently to describe the ability to be clear and direct. A family member described this ability: "We appreciated that he was just very straight-

forward, very direct, gave the options, in a way that we could all understand and was forthright with everything” A patient with cancer said, “My doctors were very clear with me, right off the bat. My surgeon and my chemo specialist, and that’s what I liked, you know—they just laid it right on the line, what’s happening”

Understandable Language

Patients and family members expressed frustration about confusing use of jargon they could not understand. For example, a patient with cancer said, “The oncologist spoke in such technical terms, I was just overwhelmed. Every word had about 5 or 6 syllables.” Health care workers described hearing physicians mask the meaning, through technical language or inappropriate metaphors, so that the imminence of a patient’s death was obscured. A health care worker said:

The doctor was trying to tell the family that the person was dying, but used this whole baseball analogy and . . . said, this is the whatever inning and then left the room. I said, “They’re trying to say that your sister is . . . about to die.” And they’re like, “What!?”

Another health care worker said: “I had a doc one time tell a family that a patient had suffered a terminal event. They had no clue.”

Communication Style

Expert physicians talked more about the importance of specific communication styles than did patients, family members, or health care workers. Specifics mentioned included sitting down, being at the same eye level, finding private environments in which to talk, using body language, nodding, making eye contact, and responding in a manner that makes it clear that the physician is listening. Patients also discussed the need for physicians to make eye contact. A patient with AIDS said, “I had one doctor who was going to operate on me, and all he would do is look at his paper. . . . The only time he would look at me is if I asked him a question and then it was only briefly.”

WILLINGNESS TO TALK ABOUT DYING

Willingness to talk about dying was raised frequently by physicians, health care workers, and family members. Comments concerning talk about dying revolved around 3 main areas: willingness to discuss dying, communication skills in talking about dying, and avoiding the dying patient.

Willingness to Discuss Dying

According to family members and health care workers, the avoidance of discussing dying was often an impediment to care and to adequate resolution for the patient and family concerning the patient’s terminal status. For example, a family member said, “He’d spent a few weeks in the hospital with all these different diagnoses con-

tinuing to roll out. And no one talked about him dying. That was really upsetting because we didn’t know how to process the information we were getting.” On the other hand, when dying was freely and sensitively discussed, it provided needed information and comfort. A patient with AIDS said, “My wife’s real comfortable with asking him questions [like], ‘What do I do when he dies? . . . What signs should I look for?’ I appreciate the candidness on his part, you know, when we’re talking about death issues.”

Communication Skills in Talking About Death

Among physicians willing to talk about dying, it appears that there are varying levels of skill at communicating information. One patient with cancer described the discomfort her physician showed when the topic of dying was raised: “She just can’t come out and say it straight, you know. I’ll just be sitting there going, . . . ‘Well what do you mean? . . . Am I going to die tomorrow or what?’ And she kind of goes into a little shock. . . . She just has a hard time spitting it out.” On the other hand, when the discussion is handled skillfully and without fear, it provides considerable comfort, as described by a family member:

It was easier for this older physician . . . to deal with the end-of-life issue for Dad and to say, this is what’s going to happen and it’s hard to tell how long you have, but this’ll be the last phase. . . . So it seemed that this person was unafraid of dealing with that fact that his patient was going to die. And that meant a lot to us.

Avoidance of the Dying Patient

Some family members discussed the manner in which physicians avoided interacting with the dying patient. This could take the form of talking to the family instead of the patient: “. . . He [talked to] the family group together, but he didn’t talk to my dad . . . that was very frustrating that we couldn’t get him to view my dad as a human being.” A physician recalled his own avoidance of telling a patient she was dying:

I went into the room and I did a terrible thing. I couldn’t really talk to the patient. I couldn’t say, “You know, you’re going to die now. I’m really sorry.” I basically [said], “Well, we’ll see how it goes, we’ll do our best to keep you comfortable,” but I didn’t really involve myself with the patient. And I still, to this day, regret my level of involvement with that patient. She knew darned well. . . .

GIVING BAD NEWS SENSITIVELY

Giving bad news sensitively was raised in focus groups with approximately comparable frequency to discussion concerning willingness to talk about dying. Among the 6 components, family members raised issues about giving bad news sensitively second most frequently, and patients and health care workers raised them third most frequently. The following 2 issues emerged as especially important in giving bad news sensitively: delivery manner and balancing sensitivity and honesty when discussing prognosis.

Delivery Manner

The initial delivery of a terminal diagnosis was often performed poorly. Poor delivery stemmed from being too blunt, not picking an appropriate time and place to provide bad news, and giving the sense that there was no hope. For example, a patient with AIDS said:

The doctor called us back right away, and he said, "Oh by the way, your tests came back and both you and your wife have AIDS." Here I am, getting ready to go to work. You know, rush out the door to the bus, and it's like, Whoa! No offer of counseling or anything, that was it. . . . I mean, he basically said, "Hey, listen, there's nothing more I can do for you."

A family member described hearing her sister's terminal diagnosis: "I was alone in the waiting room in the middle of the night, thinking there was this routine surgery going on, and I was informed, rather bluntly, that . . . [she] had cancer of an unknown type and that her chances are zip. It was devastating. Just the way that it was delivered." Receiving bad news often went hand in hand for the patient with the sense that the physician providing the news had given up on his or her care, as described by a family member:

The 3 main doctors involved agreed that it was terminal, that it was immediately terminal, was going to happen very fast. . . . [The patient] called one of them Dr Doom, and she'd come out in gales of laughter and she'd go, "Oh my God, he touched me! It's like . . . he already thinks I'm dead." But she mocked that, because it was painful. I mean, they definitely didn't seem to know how to speak to her anymore. It was like, "Well this is it." And . . . they barely spat things out.

Balancing Sensitivity and Honesty When Discussing Prognosis

Some patients discussed the need for physicians to maintain a balance between being realistic and providing them with information in a way with which they can cope. Some patients, for example, described feeling defeated by statistics that permit them no hope. One patient with cancer described her physician's discussion of her prognosis as "a death threat." Another said, "I always felt like when I was afraid of something, I could turn to *this* man and say, 'Give it to me plainly.' But I . . . preface it by saying, 'But don't scare me.'" Another patient said, "He didn't say, 'You have 20 months to live.' He said the statistics show that the averages are 20 months. He didn't qualify that by saying, 'Well, some people live 2 weeks, some people live 9 years.' . . . I mean, it takes a certain sensitivity."

A health care worker described the variability among patients in the need to maintain hope:

Not everybody wants to know. Some people are so comfortable with that other doctor who holds out the hope. . . . When the honest doctor comes in, . . . they're blown away with "This is the truth and this is probably what's going to happen." . . . They have different styles. For some people, it's negative and for some people, it's very positive.

LISTENING TO PATIENTS

Patients and physicians frequently raised the importance of listening. Family members and health care workers discussed this area less often. Although patients often named listening as a needed skill, they rarely went into detail as to what makes a good listener. Physicians provided some guidelines to facilitate active listening. Examples of comments by physicians are:

You do develop a repertoire of behaviors that helps you to listen. For instance, if you keep your mouth shut, you'll probably accomplish more than if you talk too much. . . . Listening is the most important thing. . . .

How many open-ended questions does a physician ask a patient during a visit? Because that's a way of measuring if the physician is willing and ready to listen to what a patient says. If he is not, he's going to ask yes and no questions and get out of there.

ENCOURAGING QUESTIONS

Although this was one of the less frequently mentioned of the 6 communication components, being open to and encouraging questions was considered an important area. Patients and family members expressed the enhanced understanding and comfort that resulted when physicians were open to and encouraged questions. One family member said:

What I found helpful was [the doctor] really made herself available to the family as well as to my mother and . . . said, "Please call and please ask questions." . . . and that attitude persisted throughout the whole time. So it allowed us to talk more and probably get some help when we needed it.

Some of the most positive comments from family members stemmed from recalling physicians who gathered the family in a comfortable place, encouraged questions, and displayed no discomfort with any questions posed. As a result, a family member said, "We always knew where we stood." Inability or unwillingness to encourage questions from patients and family members appeared to result at times from a discomfort with silence. A health care worker described physicians' discomfort with patients' and family members' silence:

I've been in family conferences where physicians aren't comfortable with the silence, that lull. . . . But [some] physicians are really able to, [through] experience or just their own personality, sit comfortably with that silence, and then allow and encourage people to ask questions. . . .

A corollary to encouraging and being open to questions raised by several patients, families, and, especially, health care workers was the importance of making sure that the information provided is understood. A health care worker said, "I have seen some physicians get frustrated at having to repeat information. I think when you're dealt that information, that this is the end . . . they really can't assimilate that in a 2-minute period. You may have to kind of go over it the next day."

SENSITIVITY TO WHEN PATIENTS ARE READY TO TALK ABOUT DYING

Timing of talk about dying was the least discussed among communication components, yet was raised as important to communication with patients. This was similar to the theme of providing realistic but sensitive information about prognosis when giving bad news, and appeared to call for judgment on the part of the physician concerning how much information a patient can assimilate about his or /her impending death. A patient with COPD said, "The ideal doctor would be able to do what is best for and know his patient well enough to know what he would feel most comfortable hearing. But that's a tough thing to know." A patient with AIDS said:

One thing that helped me with my situation was my doctors didn't tell me it was real, real bad, but I had to kind of see it for myself, or let it sink in before I could deal with the fact that, hey, this could be the last time you're going to see everybody and do all the little things you like to do. . . .

COMMENT

The relationships between dying patients and the physicians caring for them in their final months and days are complex, and direct data that document those relationships are scarce. Focus groups provide an effective qualitative technique for illuminating the perspectives of dying patients concerning the care they receive from physicians. In addition, family members of patients with terminal disease and health care professionals with extensive experience in end-of-life care can provide insights into aspects of end-of-life care provided by physicians that are especially important.

Based on focus group transcripts, good communication appears to be at the top of the list of priorities for effective end-of-life care.¹⁵ Components of communication that were discussed as important by dying patients, family members, health care workers, and expert physicians are grouped into 2 areas: basic communication skills (listening and encouraging questions), and areas specific to end-of-life care (giving bad news sensitively, talking about dying, and knowing when patients are ready to talk about dying). The component raised most often, talking with patients in an honest and straightforward way, spans basic communication skills and end-of-life care, with its dual emphasis on truthfulness and presenting information in an understandable manner.

These data suggest that the skills most important to patients and their families are talking with patients in an honest and straightforward way and listening to patients. A terminal diagnosis introduces a period of great complexity in the lives of patients and their families. They must cope not only with choices and decisions about treatment and subsequent tests, procedures, and treatment regimens, but also the many psychological, spiritual, interpersonal, and practical issues associated with dying. The data from these focus groups highlight the extent to which patients and families value the help of physicians who offer clear and honest assistance and who are willing to listen to them.

Of the themes raised in this study concerning communication, the only one that has received considerable

attention in the medical literature in relation to end-of-life care, is giving bad news.⁸⁻¹² Suggested techniques tend to focus on bad news as a single event requiring communication with the dying patient about their terminal status. Few physicians feel adequately trained to deliver bad news. In one study, nearly 50% of a group of oncologists rated their own ability to break bad news as poor to fair.¹⁹ Although giving bad news came out in our analyses as a separate component of communication with dying patients, all 6 of the communication components dealt with communicating about bad news in one form or another. The comments of focus group participants suggest that, once a terminal diagnosis is made, communication with physicians consists of a wide spectrum of ongoing communication about bad news. What patients and family members ask of physicians in this ongoing communication are honesty, sensitivity, and a willingness to talk about dying and listen to the patient.

Why is communicating with dying patients so difficult for physicians? Some explanations have been discussed in the medical literature. These include issues around fear of dying among physicians,^{20,21} psychological traits in some physicians that may lead to a need to overcome death,²² and the historical tendency in western medicine to focus on cure.²³ The data from this study suggest 2 additional reasons. First, physicians must strive to achieve a delicate balance between providing honest information and doing so in a sensitive way that does not discourage hope. Physicians who are too blunt can shatter that hope for patients and leave them feeling abandoned. Increased sensitivity to timing and enhanced communication skills around these issues are needed. Furthermore, there is some variability between patients as to how much information they want and how quickly they want to receive it. Physicians must gauge when a patient is ready to hear bad news from their discussions with the patient.

Another reason that communicating with dying patients may be difficult is that physicians may be trained or used to thinking of giving bad news as a 1-time event. However, physicians often must give their patients a spectrum of bad news that begins with the initial terminal diagnosis and continues through the eventuality of failed treatments, physical decline, and ultimately, death. Thus, for physicians who have a difficult time giving bad news, the need for ongoing delivery of bad news may engender insensitivity or avoidance. Many of the negative behaviors described by patients, family members, and health care workers (for example, avoidance of discussing dying, poor delivery, and abandonment of the patient) may emanate from this discomfort.

Our data suggest specific areas that physicians can target to improve their communications with dying patients and family members that augment previous guidelines.⁸⁻¹⁴ The top priority that came across from patients, family members, and health care workers was the need for physicians to be honest and candid. Information should be laid out in an organized, straightforward manner using language that is understood. Listening with interest, especially through asking open-ended questions, is perceived as a strong basic skill that symbolizes the physician's concern for the patient. Giving patients and families sufficient opportunity to ask questions in

an unthreatening and unhurried environment can minimize misinterpretations or lack of understanding. At the same time, it is important to gauge the amount and type of information that patients can assimilate and are ready to hear. Maintaining an element of hope is important to many patients. If cure is not an option, then hope may be oriented toward maximizing quality of life and making the patient comfortable. Any hope offered must be realistic and relevant. Physicians should be ready and willing to discuss dying with patients who are nearing the end of life and with their families. This means addressing the topic with the patients and families directly, yet in a manner that ensures that the patient understands he or she will not be abandoned.

This study has several limitations. Focus group data are limited to individuals who volunteer to participate. It is possible that individuals with negative experiences may be more likely to volunteer for groups examining physicians' skills. However, participants were prompted to discuss positive and negative experiences, and comments appeared to be balanced. Other limitations introduced by the focus group methods have been cited in the literature, including less control in group interviews than in individual interviews, difficulty of data analysis compared with quantitative studies, and variability between groups introduced by unique social dynamics in each group.²⁴ Because group dynamics may influence discussion through the influence or domination of a few participants, the number of comments attributed to a component of communication does not necessarily represent the relative importance of that component. Study methods were developed and implemented to limit domination of the discussion by one or a few participants. However, the numbers presented are best used as general guidelines and are not appropriate for statistical analyses. Finally, all participants resided in the Seattle area, and the ethnic mix of participants was representative for this area. Findings may vary in other geographic locations.

This study highlights the need for the initiation of training programs for physicians oriented toward enhancing communication skills when working with dying patients and their families. Such training programs should focus on teaching physicians to talk about dying, to listen to patients and family members, and to be sensitive to when patients are ready to talk about dying. The ambiguity that exists between the need to be honest and the desire to maintain hope is a challenge for physicians and an important area for future research. The voices of the participants in this study highlight the importance of improving the quality of physician-patient communication throughout the spectrum of medical care at the end of life.

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REFERENCES

1. The SUPPORT Principal Investigators. A controlled trial to improve care for seriously ill hospitalized patients: the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT). *JAMA*. 1995;274:1591-1598.
2. Hofmann JC, Wenger NS, Davis RB, et al. Patient preferences for communication with physicians about end-of-life decisions. *Ann Intern Med*. 1997;127:1-12.
3. Tulsky JA, Fischer GS, Rose MR, Arnold RM. Opening the black box: how do physicians communicate about advance directives? *Ann Intern Med*. 1998;129:441-449.
4. Hanson LC, Danis M, Garrett J. What is wrong with end-of-life care? opinions of bereaved family members. *J Am Geriatr Soc*. 1997;45:1339-1344.
5. Tulsky JA, Chesney MA, Lob B. How do medical residents discuss resuscitation with patients? *J Gen Intern Med*. 1995;10:436-442.
6. Singer PA, Martin DK, Lavery JV, Thiel EC, Kelnor M, Mendelssohn DC. Reconceptualizing advance care planning from the patient's perspective. *Arch Intern Med*. 1998;158:879-884.
7. Fischer GS, Tulsky JA, Rose MA, Siminoff LA, Arnold RM. Patient knowledge and physician predictions of treatment preferences after discussion of advance directives. *J Gen Intern Med*. 1998;13:447-454.
8. Ellis PM, Tattersall MH. How should doctors communicate the diagnosis of cancer to patients? *Ann Med*. 1999;31:336-341.
9. Girgis A, Sanson-Fisher RW. Breaking bad news, I: current best advice for clinicians. *Behav Med*. 1998;24:53-59.
10. Walsh RA, Girgis A, Sanson-Fisher RW. Breaking bad news, II: what evidence is available to guide clinicians? *Behav Med*. 1998;24:61-72.
11. Campbell EM, Sanson-Fisher RW. Breaking bad news, III: encouraging the adoption of best practices. *Behav Med*. 1998;24:73-80.
12. Ptacek JT, Eberhardt TL. Breaking bad news: a review of the literature. *JAMA*. 1996;276:496-502.
13. Institute of Medicine. *Approaching Death: Improving Care at the End of Life*. Washington, DC: National Academy Press; 1998.
14. Girgis A, Sanson-Fisher RW. Breaking bad news: consensus guidelines for medical practitioners. *J Clin Oncol*. 1995;13:2449-2456.
15. Curtis JR, Wenrich MD, Carline JD, Shannon SE, Ambrozy DM, Ramsey PG. Understanding physicians' skills at end-of-life care: perspectives of patients, families, and health care workers. *J Gen Intern Med*. 2001;16:41-49.
16. Pope C, Mays N. Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ*. 1995;311:42-45.
17. Kitzinger J. Introducing focus groups. *BMJ*. 1995;311:299-302.
18. Centers for Disease Control and Prevention. 1993 revised classification system for HIV infection and expanded surveillance case definition for AIDS among adolescents and adults. *MMWR Morb Mortal Wkly Rep*. 1992;41(RR-17):1-20.
19. Baile WF, Globler GA, Lenzi R, Beale EA, Kudelka AP. Discussing disease progression and end-of-life decisions. *Oncology*. 1999;13:1021-1038.
20. Kvale J, Berg L, Groff JY, Lange G. Factors associated with residents' attitudes toward dying patients. *Fam Med*. 1999;31:691-696.
21. Lowry F. Does doctors' own fear of dying hinder palliative care? *CMAJ*. 1997;157:301-302.
22. Gabbard GO. The role of compulsiveness in the normal physician. *JAMA*. 1985;254:2926-2929.
23. Holstein M. Reflections on death and dying. *Acad Med*. 1997;72:848-855.
24. Krueger RA. *Focus Groups: A Practical Guide for Applied Research*. Thousand Oaks, Calif: Sage Publications; 1988.