Discussing Palliative Care with Patients

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Palliative care focuses on relief of suffering, psychosocial support, and closure near the end of life. Even experienced physicians often struggle when initiating complex, emotionally laden discussions about palliative care with seriously ill patients and their families. We use two hypothetical case scenarios to illustrate how physicians can initiate these discussions and to emphasize and illustrate several communication techniques.

Physicians can elicit a patient's concerns, goals, and values by using open-ended questions and following up on the patient's response before discussing specific clinical decisions. Physicians can acknowledge patients' emotions, explore the meaning of these emotions, and encourage patients to say more about difficult topics. Physicians should also screen for unaddressed spiritual and existential concerns. Some patients may make statements or ask questions that are difficult for physicians to respond to. We provide examples of responses that align the physician with patients' wishes without reinforcing unrealistic plans. Exploring such difficult issues may lessen feelings of aloneness even when the physician cannot "fix" the problem, and it raises new opportunities for patients to find comfort.

In addition to addressing physical suffering, physicians can extend their caring by acknowledging and exploring psychosocial, existential, or spiritual suffering. As patients struggle to find closure in their lives, active listening and empathy have therapeutic value in and of themselves.

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Palliative care focuses on relief of suffering, psychosocial support, and, as much as possible, closure near the end of life. As disease progresses, many patients choose palliation as the paramount goal of care. However, palliative care delivery is often inadequate. Pain and other suffering often are unrelieved (1, 2), and hospice care is begun only in the last week of life in 16% of cases (3). Many reasons explain why palliative care is often unsatisfactory, including reimbursement disincentives, patient and physician reluctance to acknowledge suffering or death, and limited training in or experience with caring for dying patients (1). Furthermore, even experienced physicians often struggle when discussing palliative care with patients and families.

We review communications skills to improve discussions with patients about palliative care. Because there are few rigorous outcome studies of communication about palliative care, the suggestions that we offer stem from clinical experience and analogy to research on physician–patient communication from other contexts (4). This paper is structured around several common questions: How can physicians begin to discuss palliative care? How might physicians respond to difficult patient statements and questions? How can physicians discuss palliative care while disease-remitting treatments are continued? We use two hypothetical case scenarios to illustrate potential answers to these questions.

How Can Physicians Begin To Discuss Palliative Care?

Case 1: Mr. A. was a 54-year-old businessman who had carcinoma of the colon with liver metastases that had progressed despite two regimens of chemotherapy. He was hospitalized because of bruises, oozing from venipuncture sites, and nosebleeds caused by disseminated intravascular coagulation. The previous evening, he tripped while going to the bathroom, causing a laceration and ecchymoses around his eyes. The chronic pain from his liver

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metastases was adequately controlled with around-the-clock opioids.

Physician: What is your understanding of where things stand now with your illness?

Mr. A.: I know that the cancer is growing in my liver and that things don't look good.

Physician: Yes, I wish that the liver lesions had gotten smaller. (Pause.) Tell me what is most important to you now.

Mr. A.: I want to spend as much time as possible at home with my family.

Physician: How is your family coping with all of this?

Mr. A.: (Starts crying.) My daughter is afraid to be with me because of all the bruises and the black eyes.

It is easy to imagine several ineffective ways that a physician might have responded in case 1. The physician might not have checked the patient's understanding of his prognosis or inquired about his concerns, but instead talked about the biotechnical aspects of care, such as the results of clotting studies. When the patient said that "things don't look good," the physician might have exhorted him not to lose hope and directed the discussion to experimental chemotherapy. When the patient began to cry, the physician might have tried to protect himself and the patient and squelched the discussion by turning the conversation to how adjusting the heparin dose might resolve the bleeding that frightened his daughter. More constructively, the physician could continue to explore Mr. A.'s experience.

Physician: What would you like to say to her when she is afraid?

Mr. A.: (Still crying.) I want her to know that it is still me and that I love her more than she can ever know.

Physician: You love her so much, it must feel terrible to think about leaving her. (Pause.) How can your time with your daughter be as meaningful as possible?

What communication techniques contribute to the success of this physician–patient interaction? The same simple techniques that physicians are trained to use in everyday clinical encounters can facilitate discussions in palliative care. These techniques include exploring the patient's perception of illness and prognosis by using open-ended questions and by asking follow-up questions that incorporate the patient's own words.

In this interview, the physician first elicits the patient's concerns, goals, and values rather than discussing specific clinical decisions. After Mr. A.'s concerns and general goals are clarified, specific decisions, such as a do-not-resuscitate order, may be easier to make. In contrast, many physicians begin by discussing specific management decisions and talk about palliative care only after a decision has been made to limit life-prolonging interventions (5).

Table 1. Potentially Useful Open-Ended Questions about End-of-Life Care

"What concerns you most about your illness?"
"How is treatment going for you (your family)?"
"As you think about your illness, what is the best and the worst that might happen?"
"What has been most difficult about this illness for you?"
"What are your hopes (your expectations, your fears) for the future?"
"As you think about the future, what is most important to you (what matters the most to you)?"

Open-ended questions generally are useful in eliciting patient concerns and emotions and in continuing such discussions (6, 7). **Table 1** lists potentially useful open-ended questions about end-of-life care. These questions ask for an expansive answer and cannot be answered with simply "yes" or "no." However, they focus attention on a particular domain of care and may direct attention to frequently avoided, emotionally significant issues.

The patient's own language can guide the physician's follow-up responses and questions. Using Mr. A.'s own words lets him know that he is being carefully listened to and that his perspective is important. Patients who sense that they are understood may feel more comfortable in disclosing additional concerns and emotions. Just as physicians use empathic comments in exploring the patient's clinical symptoms, such comments also help in acknowledging the patient's emotions, exploring their meaning, and encouraging the patient to say more about difficult topics (8, 9). Some physicians may fear that focusing attention on emotions may scare the patient and family or open up feelings of hopelessness and despair that they are powerless to alleviate. However, patients and families are having these emotional responses, whether or not the physician chooses to probe them. At a minimum, once these emotions are discussed openly, the patient and family are no longer alone with them. Furthermore, fear, anxiety, and depression may be amenable to simple interventions once they are understood. Rather than avoiding Mr. A.'s grief regarding his daughter, the physician might explore how Mr. A. might talk to her about his illness and death.

Physician (addressing Mrs. A.): I would like to know if you have any additional concerns.

Mrs. A.: I am scared that he will bleed uncontrollably at home, and I won't know what to do. I would call 911 if this happens. At least they can help me.

Table 2. Potentially Useful Questions with Which To Explore Spiritual and Existential Issues

"Is faith (religion, spirituality) important to you in this illness?"
"Has faith (religion, spirituality) been important to you at other times in your life?"
"Do you have someone to talk to about religious matters?"
"Would you like to explore religious matters with someone?"

With the patient's consent, physicians can involve close family members in discussions about palliative care. Family members frequently raise additional issues, and their cooperation may be essential for some health care options. For example, most patients on hospice need a committed primary caregiver at home. Mrs. A.'s major fear is not her husband's death but rather whether she will be able to handle the final stages of his dying. Physicians may hesitate to ask about the patient's or family's fears because they may be insoluble. Indeed, uncontrollable bleeding is difficult to palliate. However, understanding Mrs. A.'s fears and concerns is an essential first step before they are addressed and plans are made for Mr. A. to return home.

Physician (to Mrs. A.): Yes, bleeding can be frightening, particularly if you're at home with your daughter. Are there other things that are frightening or too much to handle?

Mrs. A.: I know Jim wants to be home, and I want that too. But sometimes it feels that I'm in too far over my head.

After Mrs. A.'s concerns are fully elucidated, the physician then can explain how hospice provides support for care at home, including 24-hour access by telephone, home visits on short notice for such events as major bleeding, and admission to an inpatient palliative care unit if needed (10).

Physicians sometimes shy away from terms like *hospice* or *palliative care* because they imply that death is imminent (11). However, euphemisms, such as *supportive care*, *comfort care*, or *comprehensive care*, may be ambiguous or misleading. Whatever language is used, physicians should ensure a common understanding of the term's meanings. It is often useful to discuss or provide specific examples of the elements of palliative care, such as pain management and family support, without labeling them palliative or terminal care.

During these emotionally intense encounters, physicians must remember to ask directly about the patient's symptoms and functioning. This information is necessary to provide relief. A "review of systems" of common problems for dying patients should include pain, fatigue, shortness of breath, and symptoms specific to the site of the patient's illness. If pain is present, the physician should ask the patient to quantify it on a numeric scale (12). Screening for depression is essential because depression is common and often overlooked (13). The simple question, "Are you depressed?" may be a useful screening tool (14, 15).

Stoic patients may deny physical or psychosocial distress. In such circumstances, the physician can gather information about the patient's needs indirectly by asking such questions as, "How is your wife (daughter, son, etc.) dealing with your illness?" The physician can build follow-up questions on the patient's responses, allowing the patient to explore the impact of his or her illness on family members. Another approach is to ask, "Have any family members or friends had a similar illness?" If so, the physician might ask what symptoms or concerns they experienced. Some patients find that they can express fears and concerns once removed, through the experiences of a family member or friend, that they could never admit to directly.

Most experts in palliative care believe that attention to spiritual, existential, and religious issues is a crucial component of palliative care (16, 17). The physician's role in initiating or following through with these discussions is controversial because physicians vary in their interest, comfort, and skills regarding these issues. Given the opportunity, many patients may choose to talk to a pastor, priest, rabbi, or other spiritual advisor with whom they have an existing relationship. On the other hand, patients who lack formal religious affiliation, have lost faith, are alienated from their religion, or are atheist or agnostic may prefer to discuss spiritual and existential issues with their physicians. Whatever their own views, physicians or other members of the health care team should screen for unaddressed spiritual and existential concerns. **Table 2** suggests open-ended questions that may help to initiate such discussions.

In response to such open-ended screening questions, some patients may want to discuss existential and spiritual issues with their physician. Patients may believe that physicians may gain spiritual insight through providing close care to dying patients. In one poll, 39% of respondents considered it very

Table 3. More Direct Questions That May Be Useful with Patients Who Want To Discuss Spiritual and Existential Issues

"What do you still want to accomplish during your life?"
"What thoughts have you had about why you got this illness at this time?"
"What might be left undone if you were to die today?"*
"What is your understanding about what happens after you die?"
"Given that your time is limited, what legacy do you want to leave your family?"
"What do you want your children and grandchildren to remember about you?"

* Reference 17.

important to have a physician who was spiritually attuned to them (18). More direct follow-up questions, as suggested in **Table 3**, may be useful for such patients and for physicians who are comfortable with more in-depth discussions.

For other patients, someone other than the physician will be best suited to help them come to terms with their mortality and to find meaning in the final stage of their life. Physicians can help arrange contact with an appropriate religious or spiritual advisor: "These are important issues. I'd be glad to arrange for a pastor (or priest or rabbi) to meet with you." Even if physicians do not personally discuss these issues in depth with their patients, they can validate the importance of such topics and encourage the patient to continue to explore them.

How Can Physicians Respond to Difficult Patient Statements and Questions?

Not surprisingly, patient answers to open-ended questions can be disturbing or difficult to respond to. Suppose that Mr. A., the patient with progressive metastatic colon cancer, said that the most important thing for him was to be alive for his daughter's birthday, almost a year away. The physician believes that Mr. A. has a 90% chance of dying within 6 months. How might the physician respond? The physician might say directly, "I wish I could tell you that you will be here for your daughter's next birthday. It is possible, but unfortunately the odds aren't with you. (Pause.) If it doesn't work out that you can be there, are there things that you should consider doing now?" An interpretative comment ("Is it frightening to think about not being with her?") is riskier because it goes beyond the patient's statement, but it may also validate the patient's underlying emotion and encourage further discussion. As an alternative, the physician might say, "I know that you're trying very hard to keep your hopes up. Are you sometimes afraid that you won't be there for your family?" This response aligns the physician with the patient's wish, without reinforcing unrealistic plans. Later, the physician might say, "What would you want to say to your daughter on her birthday?" By returning to Mr. A.'s original wish about his daughter's birthday, this question might lead to a discussion of making a videotaped message for his daughter.

Palliative care discussions may uncover problems without solutions. Some patients no longer find meaning in life or fear punishment in the afterlife, and some families are overwhelmed. When patients reveal such concerns, physicians may feel that their probing has made the situation worse. In these difficult situations, physicians can keep in mind several points. First, uncovering painful emotions does seem to increase short-term suffering. In the longer term, however, exploring such difficult issues may lessen feelings of aloneness and raise opportunities to find comfort and resolution. Second, the physician's feelings are often an important clue to how the patient is feeling. If the physician feels overwhelmed, frustrated, discouraged, or angry, the patient may well have similar feelings. Sharing such feelings may lessen isolation and lead to an experience of connectedness for both patient and physician (9). Third, physicians can clarify their own role and self-expectations. Physicians do not need to fix all identified problems. Being a "fellow traveler" who understands and listens carefully to insoluble problems often is therapeutic. Patients no longer feel alone with their problems if they believe that their concerns have been heard. Physicians should recall that the term *compassion* comes from the Latin words for "feel with" or "suffer with" the patient. Statements such as "I wish that medicine had better answers" may show alliance with the patient's hopes and be more soothing than we expect. Finally, physicians do not have sole responsibility for responding to the patient's suffering but can call on nurses, social workers, chaplains, psychologists, and psychiatrists for help (13, 16, 19).

How Can Physicians Discuss Palliative Care While Disease-Remitting Treatments Are Continued?

Case 2: Mrs. D. was an 82-year-old woman with diabetes, azotemia, angina, and congestive heart failure. Her two daughters lived in the same building and did her housework and shopping. Mrs. D. was hospitalized for the third time in 2 months because of angina and an exacerbation of congestive heart failure. The following conversation occurs at a family meeting.

Physician: Mrs. D., what concerns you most about your condition?

Mrs. D.: I hate feeling that I can't breathe. What's going to happen if my breathing gets worse? I would rather be dead than go to a nursing home, but I also feel that I'm a burden on my daughter. I used to be so independent!

Mrs. D.'s daughter: Mom, you are not a burden! We will do whatever it takes to keep you out of a nursing home.

Like Mrs. D.'s daughter, the physician might have tried to reassure her immediately. The physician could have attempted this in several ways. He could have focused on the biotechnical aspects of

care, discussing how angioplasty might improve her health, so that she would not need to depend on her daughter. As an alternative, the physician could have said that her daughters obviously loved her deeply and were glad to help her. Instead of limiting discussion through reassurance, the physician began to explore the patient's concerns by building on her statements:

Physician: In what ways do you feel like a burden?

Mrs. D.: I am terrified of being alone when my daughter is at work. What if something happens and I suddenly can't breathe? My daughters have to work, and they can't spend their whole lives caring for me. Yet I don't want to go to a nursing home.

Physician: You sound very distressed about the possibility of a nursing home. What is the worst part of that for you?

When this line of inquiry is complete, the physician might explore the patient's other main fear of being unable to breathe as her condition deteriorates:

Physician: What terrifies you the most about your breathing?

Mrs. D.: The feeling of suffocation is so frightening. I am not at all afraid of death, but I am terrified of drowning along the way.

Instead of immediately trying to reassure the patient, as the daughter did, the physician encourages the patient to say more about her concerns. The physician uses Mrs. D.'s own words about being a burden or going to a nursing home or suffocating to further probe her concerns. Physicians naturally want to reassure patients. However, reassurance may deter patients from disclosing their concerns and emotions in enough detail that they can be understood (7). In addition, offering reassurance prematurely before fully understanding patients' concerns may paradoxically increase their worry about the future. Eliciting and openly discussing Mrs. D.'s fears enables the physician to develop a comprehensive, individualized plan to address her problems. Although Mrs. D. did not want major surgery, she agreed to angioplasty to relieve ischemia-related dyspnea and allow her to be more active. In addition, the family and social worker would look into geriatric day care so that Mrs. D. would not be alone during the day.

Because Mrs. D. was terrified about feeling short of breath, the physician reassured her that severe shortness of breath could be relieved in the future. The physician suggested having the daughters learn to administer morphine to her at home if needed.

Mrs. D.'s daughter: Wait, you're not giving up on her, are you?

Physician: Absolutely not! Morphine is one of the most effective medicines we have to relieve shortness of breath. I will explain more in a minute. But first can you tell me what you mean by "giving up"?

The physician's initial response to the daughter is an unqualified expression of nonabandonment (20) and a clarification of the role of morphine to palliate shortness of breath. He follows this with an open-ended question to clarify the daughter's perception of "giving up." Later, the physician can explore the daughter's concern about the use of opioids by asking, "What have you heard about morphine to relieve shortness of breath or pain?" Common misconceptions are that opioids are dangerous, cause addiction, shorten life, or are used only as a last resort. In fact, they are relatively safe, rarely if ever cause addiction or respiratory depression in the terminally ill, and are a mainstay of therapy for dyspnea as well as for pain (21). The physician explains that morphine can relieve severe shortness of breath at home if nitroglycerin and oxygen are ineffective. He also explains that the paramedics often use morphine in patients with severe heart failure. Later the physician can discuss decisions about hospice, resuscitation, and intubation (5, 22, 23). It would also be useful to check with Mrs. D. and her daughters about whether the suggested plan addresses their concerns.

Objections to This Approach

Some physicians may object that this approach of open-ended questions and empathic comments leaves the physician too distant from the patient. Physicians should not be afraid to draw on their clinical experience to give patients recommendations for medical care (24), particularly when patients ask them directly what they would do for themselves or for a relative. Some physicians go further, suggesting that physicians share with patients their own thoughts on death and spirituality or anecdotes about good deaths from their own experience. However, other physicians choose not to share their personal views of a good death. These physicians believe that the focus should remain on the patient and his or her situation and avoid imposing their personal views on the patient. Moreover, active listening and empathic communication may be more likely than self-disclosure to result in patient disclosures that facilitate a personal connection (25). Regardless of their willingness to share their own views on dying with patients, physicians can try to comfort patients by listening closely to their concerns and accurately identifying their feelings.

Another objection is that, in a multicultural society, patients have very different attitudes toward discussing death. In particular, some cultures believe that discussion of death hastens its occurrence (26, 27). Thus, advance planning about end-of-life care may be inappropriate for patients from these backgrounds. Usually, it is still possible to talk sensitively about alleviation of suffering, concerns about the future, or how serious illness is managed and discussed in their culture. Because people vary within every culture, each patient and family needs to approached as individuals. The approaches recommended in this paper, which encourage the physician to listen carefully and allow the patient's concerns to drive the discussion, ensure respect for patients' values.

Conclusion

In conclusion, palliative care is important to consider throughout the course of serious chronic illness. Interviewing techniques, such as asking open-ended questions about end-of-life issues, building on and exploring patient responses, and addressing the associated emotions, can help initiate difficult discussions about palliative care. In addition to addressing physical suffering, physicians can extend their caring by acknowledging and exploring psychosocial, existential, or spiritual suffering. As patients struggle to find closure in their lives, active listening and empathy have therapeutic value in and of themselves.

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