

Discussing Hospice Care

By Charles F. von Gunten

HERE'S THE CASE: A 38-year-old married woman with two young children is admitted to the hospital because of pain and fatigue. She has a history of hormone receptor–negative breast cancer, metastatic to bone and liver, initially treated with combination chemotherapy, achieving a partial response. She now has evidence of progressive disease despite receiving four different chemotherapy regimens. There are neither written advance directives nor evidence of discussions about advance care planning in the medical record.

SCENARIO ONE

On hospital day 3, an oncologist, looking harried and uncomfortable, enters the room.

MD: (*with unusual somberness*) Mrs. M., I don't think there is anything more we can do for you. I think its time for hospice.

Mrs. M: (*looking frightened*) What? You mean there's nothing else?

MD: I'm sorry.

The oncologist leaves the room.

SCENARIO TWO

Her oncologist enters the room.

MD: (*earnestly and sweetly*) Mrs. M, umm, uhhh, how are you feeling?

Mrs. M: (*tentatively, after a pause*) I'm a bit better, thank you.

MD: (*speaking quickly and cheerfully*) Well, I'd like to have the team that helps with comfort come see you. Is that all right?

Mrs. M: (*mirroring the doctor's cheerfulness*) Sure, if you think they can help.

MD: Great, I'll tell them to come by.

The physician leaves the room.

These clinical approaches are ones that are repeated over and over in hospitals across the country. There would be no disagreement among knowledgeable health care providers that Mrs. M. is eligible for hospice care. The patient has advanced chemotherapy-resistant metastatic cancer with a life expectancy of less than 6 months if the disease follows its usual course. There is no therapy likely to change that prognosis.

In the United States, it is widely noted that hospice care should be the standard of care for patients in this situa-

tion.^{1,2} Yet, it is also noted that most patients are not referred for such care in a timely fashion. Overall, nearly 50% of patients with cancer in the United States are ultimately referred for hospice care. However, there is broad regional variation, with referrals for patients with cancer varying from less than 15% to more than 80%.

The median amount of time that patients are enrolled in hospice care is short—21 days as of 2001.³ Nearly one third are enrolled for less than 7 days.³ This means that many patients are not enrolled long enough to reap the benefits.

One reason for the short hospice stays is that many physicians are not well versed with talking about hospice care. The scenarios above represent composites of discussions that I've witnessed or that I've heard described by both physicians and patients. I said similar things in the course of my training. They illustrate a mismatch between knowledge and skill. The physician may know that hospice care is appropriate. But if the physician hasn't developed the skills to sensitively convey that knowledge, it doesn't do much good. In other words, if the physician is not able to convey the benefits of hospice in an appropriate situation, the patient is unlikely to accept care that will facilitate his or her optimal care.

Let's analyze the two hospice discussion scenarios detailed above. In both, the physicians fail to place the discussion in the context of a larger discussion of goals of care.⁴ In neither case do they engage in a discussion about the issues that are most pertinent to decision making or important to the patient. They do not find out what the patient knows about her situation, what she is expecting, or for what she is hoping. They don't educate the patient about hospice or the treatment goals it will help to achieve.

The physician in the first scenario is clearly uncomfortable with the subject and with the task at hand. The physician implies that hospice is something that happens "when there's nothing left to do." In other words, it's a mark of hopelessness. The shape of the conversation, its brevity,

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and the words themselves all imply that the patient should abandon hope. Further, the implication is that the physician should have no further role in her care.

The physician in the second scenario avoids the issue altogether. The affect and content all imply that nothing much is changing. We can imagine the next act in this scenario. The admission team from the hospice will come. When they introduce themselves and describe their role, the patient will be shocked, in large part because she was unprepared. The hospice team will also be a bit shocked, put into the uncomfortable position of being strangers giving unexpected information.

I suppose we could hold the view that these physicians are "bad," that they should know better. Another point of view, that I think is far more accurate, is that they are doing the best they know how. In the first scenario, the physician is likely structuring a conversation that the physician has never seen another physician do (or is repeating what the physician has seen). In the second scenario, the physician recognizes a lack of skill and not unreasonably hopes someone else will do it better. If asked, I would speculate that both would acknowledge their limitations. They would acknowledge that patients and families find these scenarios to be "bad." They would also say they would like to know how to do it better.

The central issue here is hope. How can a referral to a hospice program be reconciled with the need to sustain hope? The first physician thinks it cannot be done; referral to hospice is synonymous with giving up hope. An image of facing the guillotine or some similar horror is conjured. This physician believes it is the physician's responsibility to deliver the news and then turn attention to the other patients for whom the physician can still "do something."

The second physician wants to sustain hope, so much so that the physician prefers that someone else do the truth telling. In this way, the physician never has to challenge the meaning of hope or engage in its ongoing support.

How can things be better? I think it takes three things. First is a more robust view of hope and the physician's role. Second is a more accurate understanding of what palliative care and hospice can be. Third is a structured way to engage in the conversation, particularly for beginners.

HOPE

Hope is the expectation that something good will happen in the future. Human beings cannot live without hope. In fact, its absence is pathological. We call it clinical depression.

Hope is different from wishing. It is not an escape from reality; it is a way of engaging with reality in which there is an expectation that goals can be achieved.

The object of hope can, and at times should, change. Patients with cancer frequently move between hoping it isn't true to hoping it can be cured, to hoping it can be put into remission, to hoping it won't grow too fast, to hoping it won't hurt, to hoping to put things in order, to hoping to not be a burden, to hoping for a good death, to hoping their families will prosper without them. Thus, while hopefulness remains, the objects of hope change. The physician can, and should, play an important role in sustaining and directing hope.

Sustaining hope is not served by lying. Unrealistic hope leads to surprises and devastating disappointments. This is not to advocate "truth dumping," but deliberate withholding of information to sustain hope is generally condemned in Western cultures. Further, patients say they don't want it. More than 90% of those surveyed say that they want the truth if they have a life-threatening illness.⁵

PALLIATIVE CARE AND HOSPICE

Palliative care is interdisciplinary care that focuses on the relief of suffering and the improvement of quality of life. It can be combined with therapies designed to cure disease and/or to prolong life, or it can be the total focus of care.

Hospice agencies are organized to deliver palliative care when the goals of care are predominately palliative. They will provide care to the patient and family as the unit of care. Patients can expect a team of people to help their physicians optimize both the quality of their life as well as that of their family. That care extends into bereavement after the patients have died.

At best, palliative care is interwoven throughout the course of oncologic care. For those who will ultimately die of their cancer, hospice represents the completion of good care. Hospice is neither the opposite of health care or an alternative to good health care, nor the antithesis of aggressive care.

DISCUSSING HOSPICE

A stepwise approach to discussing hospice referral is helpful. This is particularly true for those who are inexperienced or who are early in their training, where this has generally not been demonstrated.

A multistep protocol has been suggested to guide the discussion of goals of care. Discussing hospice referral is but one element of such a discussion. In this sense, it is an example of the interview in which important medical information needs to be conveyed.⁶ Over the course of many years, I have adapted these approaches to teach this skill to house staff, physicians, and other trainees.⁷ The steps are summarized in Table 1.

Table 1. Recommended Steps for Discussing Hospice

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1. Establish an appropriate setting for the discussion.
 2. Ask the patient and family what they understand.
 3. Find out what they expect will happen.
 4. Discuss overall goals and how hospice will help achieve them.
 5. Respond to emotions.
 6. Establish and implement the plan.
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1. Establish the Setting

Arrange to have the conversation in a place that ensures comfort and privacy for everyone. Be sure to sit down in order to be at eye level with the patient. Ask the patient if family members or others should be present. Be prepared to postpone the discussion if this is true. Introduce the subject with phrases such as:

- I'd like to talk with you about our overall goals for your care.
- I'd like to review where we are and make plans for the future. Would you like your son to be here with you?
- I'd like to discuss something I discuss with my patients who are in a situation similar to yours.

2. What Does the Patient Understand?

Ask an open-ended question to elicit what the patient understands about his or her current health situation. This is an important step and one that many clinicians skip. Get the patient talking about how he or she sees the current health situation. If the doctor is doing all the talking, it is unlikely that the rest of the conversation will go well. Consider starting with phrases such as:

- What do you understand about your current health situation?
- Tell me about how you see your health.
- What do you understand from what the doctors have told you?

If it becomes clear that the patient does not have the same understanding that you have about their overall health, this is the time to determine whether they want to discuss the real picture or not. I remember being asked to see a patient who had extensive gastric cancer and refused any discussion of hospice care. When I asked him what he understood, he told me he had some cancer, but he expected additional chemotherapy to shrink it again. Although he knew it had come back, he was expecting more chemotherapy to be of benefit. Although he could describe that he had been told the cancer was resistant to chemotherapy, he didn't believe it. It's not surprising that a discussion about hospice care didn't go well. This conversation allowed me to frame the issues in terms of conflict resolution about the state of his cancer rather than whether or not he should "go to hospice."

3. What Does the Patient Expect?

For patients who understand the status of their disease, the next step is to ask the patient to consider the future. Use this step to determine or reconfirm general goals of care. Examples of ways to start this portion are:

- What do you see for yourself in the future?
- Have you ever thought about how you want things to be if you were much more ill?
- What are you hoping for?

This step allows you to listen while the patient describes a real or imagined future. In my experience, most patients with advanced cancer describe their thoughts about dying when guided this way. Most say they want to be comfortable and don't want to be a burden on their families. They also describe wanting to be at home, but not if it makes it too difficult for others to care for them.

This step creates an opportunity for the physician to clarify what is likely or unlikely to happen. Don't hesitate to ask follow-up questions in order to clarify the patient's vision of the future. If there is a sharp discontinuity between what you expect and what the patient expects, this is the time to discover it. Many patients imagine a horrible future of pain, disability, degradation, and hopelessness. For these patients, it is not surprising that they grasp for any promise that will deliver them. Describing what is likely, including that most patients can expect a comfortable death, can help.

In other words, be sure you share the same understanding of the overall goals of care. This step will also give you a sense of the person's values and priorities.

4. Discuss Hospice Care

Now that you have set the stage with a joint understanding of the patient's present and future, you can discuss hospice care. You can use your insight into the patient's values and priorities to structure the conversation. Use language that the patient will understand and give information in small pieces. Stop frequently to check for reactions, to ask for questions, and to clarify misunderstandings.

I find it very helpful to summarize the patient's goals as part of introducing a discussion of hospice care. For example:

- You've told me that you want to be as independent and comfortable as possible. You've also said you'd like to spend as much time with your family and avoid hospitalization. Hospice care is the best way I know of to help you achieve those goals .
- You've said the trips to see me in the office are more and more difficult. I believe it would be helpful to get the hospice program involved at this point.
- I understand that your goals are to live to see your son

get married. By getting the hospice program involved, I think we will have the best chance of achieving that goal.

- It sounds like you are particularly concerned about your husband and family. The hospice bereavement program will follow them for up to a year after your death to help them cope and adjust.

By establishing goals and introducing hospice as a way of achieving them, it puts hospice care solidly into the spectrum of other medical therapies and programs. Further, having goals is a way to express hope. No matter where we are in life, we have goals to hope for. Some are just more likely than others.

As an example, I plan my life expecting some goals are achievable (eg, a satisfying career and comfortable retirement). Others, I would be pleasantly surprised if they happen (eg, being asked to be chairman of medicine at a leading university), and some merge with fantasy (eg, being asked to be Secretary of Health and Human Services). Goal setting in medicine, including at the end of life, has similar ranges.

Listen carefully to the patient's responses. Many patients have distorted views of hospice care. Others have never heard the term. As in other areas of the clinical interview, it helps to ask an open-ended question and listen to the patient's response rather than launch into a speech describing your understanding of hospice care. For example, for the patient who responds by saying, "Hospice?!" I say, "What does that word mean to you?" Patients who respond this way frequently describe a place to go to die or what you do when you "give up." I ask them to tell me more, including describing what they've heard or experienced. Some people describe some awful stories—there are some hospice programs that have given substandard care—just like some patients describe care from other physicians or hospitals that is substandard. First eliciting their concerns and fears allows me to describe the hospice programs with which I work. We can then compare and contrast our mutual experiences and expectations. Further, we can problem solve about what additional information or reassurance is needed. That frequently includes what they can do if they don't like the hospice program. It is reassuring to know that patients can opt out any time or change hospice programs. Further, it helps to know that I am willing to stay their physician until the end.

If the patient and family have never heard the term, it permits me to explain that hospice is a program that helps the patient and family achieve the goals we've just described. It's a team of people who help meet the patient's and family's physical, psychological, social, and spiritual needs, including during the bereavement period. Further,

Medicare and most other insurance programs cover it. I tell them that I can ask someone from the hospice program to come by to just give information about the details.

Another way to approach this part of the discussion is to begin by offering your own recommendation. After all, hospice is a program of medical therapy with indications and contraindications. In that sense, it is not different from other possible programs like hospitalization, skilled care, or rehabilitation therapy offered to patients with cancer. You can offer your suggestion, just as you would for other therapies, and elicit the patient's response. Examples of this approach would be:

- From what you've told me, I think it would be best if we got the hospice involved now.
- I recommend that we call the hospice people.
- I always ask the hospice to get involved for my patients at this stage of their illness.

Reasonable physicians may argue that it is unnecessary and potentially confusing to patients and families to ask them to decide about hospice care. If it is the standard of care, it should be presented that way. Patients and families are ill served if physicians regard the principle of autonomy as meaning that physicians must offer all possible therapies from which patients and families choose, as though they were choosing items from a menu in a restaurant. To offer hospice as a choice implies that it is a choice about whether or not they will die.

As a consultant who has often been called in for patients who "won't go to hospice," I have frequently found that the root issue is confusion about the overall goals and the conviction that a decision to "go to hospice" is a decision to die, or to stop fighting, or to stop wanting to live. Patients may need help to see that a decision about hospice is not necessarily related to decisions about the intensity of the efforts to care for the patient. In fact, they may need reassurance about "continuing to care."

An analogy can be useful. When someone goes to Las Vegas to gamble, how many hope to win a million dollars? How many plan their lives *as if* they are going to win a million dollars? In other words, what people are willing to accept and what they hope for may be very different things. In fact, the two frequently exist simultaneously. Someone can go to Las Vegas and accept the fact that she will not become a millionaire, but that won't stop her from putting her dollars in the slot machines.

For most patients, referral to hospice means an increase in the intensity of services. It also means an increase in resources available to them. Under the Medicare Hospice Benefit, all costs of care related to the terminal illness are covered without a deductible. That includes medications, caregiver services, and supplies. It also includes counseling

and support for the family that can continue after the patient's death. It can be confidently stated that a referral to hospice does not mean that the medical team will not continue to care for the patient, nor stop striving for the patient to live "as well as possible, for as long as possible."

Some patients have found it reassuring to hear about those patients who get better or "graduate" from hospice care. It shouldn't be surprising that some patients live longer than expected with the increase in medical care that is delivered. Further, since patients can "get out" of hospice at any time, if a new therapy that is promising is discovered, of course it could be offered.

Many patients find the care available to family to be a welcome and unexpected benefit. More than symptoms, many patients fear being a burden. The hospice provides staff who clearly help reduce that burden. They can help arrange continuous care when necessary, they are on call 24 hours a day for emergencies or preventive advice, they can send in volunteers, and they have an array of counselors providing an experienced and sensitive ear. Years ago one of our patients asked, "Why do I need a social worker?" One of our wise social workers replied, "I'm not sure you do, but you may want someone who's been through this before."

5. Respond to Emotions

Patients, families, and surrogates may experience profound emotions in response to a discussion of hospice when conducted in this way. It shouldn't be surprising that patients, when considering the end of their life, might cry. Parents, if the patient is a child, are likely to be very emotional and need support from the physician and other members of the health care team. Usually, the emotional response is brief.

Respond sympathetically. The most profound initial response a physician can make may be silence and offering facial tissues. Consider using phrases such as:

- I can see this makes you sad.
- Tell me more about how you are feeling.
- You seem angry.

In teaching the skills described here to house staff, the most common barrier they describe is not wanting to precipitate emotion that they don't feel prepared to handle. Consequently, they either avoid these conversations entirely or structure them in such a way as to minimize the chance of the patient being "out of control."

The best way to overcome this barrier is to learn how to sympathetically respond to the patient who has an emotional response. As with most aspects of being a physician, a sense of competence leads to a willingness to engage in the challenge. The most important message is that emotional responses are usually short-lived. The vast majority of

patients have good coping skills and appreciate the presence of the doctor while they work through the experience and emotions of their illness.

It is appropriate, and frequently helpful, to acknowledge that it is difficult to discuss this issue. Your body language can reinforce this. Many respected clinicians will feel sad and may express that emotion. Some say that they cry. Patients and families report this as a sign that their physician cared. They don't see it as a sign of weakness.

6. Establish a Plan

Establish and implement a plan that is well articulated and understood. Your plan might include asking the hospice team to come by just for information. Then, you'll discuss it again with the patient. Your plans might include convening a family meeting to discuss the patient's preferences or assure that a key family member living out of town is notified about the patient's status and treatment plans.

If the plan includes referral for hospice care, then communicate your findings to the hospice agency. Just as in other aspects of medical care, continuity is enhanced when there is complete communication. The hospice team will be able to deliver better care if they don't just get a referral but instead receive very explicit information from the physician about the communications that led up to the referral, particularly if they were made complex by conflicting patient/family or intrafamilial differences.

CASE REVISITED

Let's revisit the case presented at the beginning of this article. What might the conversation look like if the steps above had been followed?

An oncologist enters the room, unhurried and comfortable.

MD: Mrs. M, I'd like to talk with you about where we're going with your care. Is this a good time?

Mrs. M: *(pause)* Yes.

Physician puts a chair beside her bed, adjusts the curtain around the bed, and sits down.

MD: Now then, will you summarize for me what you understand about where we are now?

Mrs. M: *(pause)* Well, the cancer is getting worse. You said the scans showed the tumors in the liver are bigger, and there are more spots on the bone scan. The last chemotherapy didn't shrink the cancer like we hoped.

MD: *(nodding)* Right.

Mrs. M: *(after a pause)* And you said you didn't know of another kind of chemo you thought would work.

MD: That's right. I've talked to some of my colleagues, and no one thinks there's anything that is likely to help. *(pause)* What are you expecting now?

Mrs. M: (*thoughtful, and a bit teary*) Well, I guess I'm going to die of this cancer (*starting to cry more*).

MD: (*sitting quietly, moves box of tissues closer to patient*)

Mrs. M: (*stopping crying, dabbing her eyes*) I've thought a lot about this, you know. I was hoping it wouldn't happen for a while (*smiling wryly*).

MD: What have you been thinking?

Mrs. M: Well, I'd like it to be peaceful . . . and without any pain. I don't want to be a burden to my kids. I'd like to just fall asleep. And I want my husband to be able to cope, and for my children to grow up and remember me.

MD: Anything else?

Mrs. M: (*brightening a bit*) Well, before I go, I'd like to stay the hell out of this hospital. No offense, Doc, but I'd rather be home. And I'd like to go to Las Vegas one more time!

MD: (*laughing*) It sounds like what you are saying is you want to make the most of the time that is left.

Mrs. M: That's right.

MD: Mrs. M, I think it's time we got the hospice program involved. Have you heard that term before?

Mrs. M: Isn't that a place where you go to die?

MD: No, although that's what many people think. It's a team of people who can help me take care of you at this stage of your illness. From what we've talked about, it seems like our goals now are for you to be as independent

and comfortable as possible until you die. And you want to be sure your family will be able to cope. Is that right?

Mrs. M: Yes.

MD: What I'd like to do is ask them to come by to give you some more information. Then we can talk about it. Would that be all right with you?

Mrs. M: Yes (*looking a little fearful*). Doc, you're not giving up on me, are you?

MD: Not a chance. I told you I'd be your doctor for as long as you wanted me. I always recommend hospice to my patients at this stage of their illness. It's the best way I know of to take care of you now.

Mrs. M: (*looking relieved*) OK. Tell 'em to come see me. *The physician leaves the room.*

Successful discussions about hospice care begin with a shared understanding of the current situation and shared goals for the future. Then hospice referral becomes a way to achieve those goals. Like most skills, it is easier when it is practiced and when there is a structure to guide the beginner. Working to help patients and families achieve their goals and understand the limits of modern medical care can be rewarding when this skill is mastered.

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