VOLUME 24 · NUMBER 25 · SEPTEMBER 1 2006

JOURNAL OF CLINICAL ONCOLOGY

THE ART OF ONCOLOGY:
When the Tumor Is Not the Target

Discussing Prognosis: "How Much Do You Want to Know?" Talking to Patients Who Do Not Want Information or Who Are Ambivalent

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Submitted January 17, 2006; accepted March 25, 2006.

Authors' disclosures of potential conflicts of interest are found at the end of this article.

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0732-183X/06/2425-4214/$20.00

DOI: 10.1200/JCO.2006.06.008

INTRODUCTION

Dr D had decided to try to ask patients how much they wanted to know about prognosis. Mr X, a 44-year-old man with large B-cell lymphoma, who had relapsed less than 1 year after receiving cyclophosphamide, doxorubicin, vincristine, and prednisone and rituximab, said he did not want to talk about prognosis at all. He said, "The numbers don't really matter—I have to do what you tell me gives me the best chance." Mrs Y, a 68-year-old woman with stage III breast cancer coming for her first visit after starting adjuvant chemotherapy, could not seem to decide whether she wanted prognostic information. "I'm worried about knowing, and I'm worried about not knowing," she said. "What do you think I should do?"

A description of a patient-centered approach for discussing prognosis rather than the commonly used strategies of realism, optimism, and avoidance has been published in this issue of the *Journal of Clinical Oncology*.[1] This approach recommended that oncologists start by asking patients a straightforward opening question, "How much do you want to know about prognosis?" and the approach was illustrated for a patient who was prepared to have an explicit discussion. However, approximately 20% of patients do not want to discuss prognostic information or only want to hear good news.[2,3] How should an oncologist, like Dr D, handle that situation? This article describes how to approach patients who either do not want to discuss prognostic information or who are ambivalent—who simultaneously want to know and do not want to know.

FOR PATIENTS WHO DO NOT WANT INFORMATION

Some patients will indicate, in response to an opening question, that they do not want to discuss prognostic information, leaving the physician in an awkward position. On one hand, the physician wants to respect the patient's wishes and on the other hand, he worries that hopes—rather than facts—may affect the patient's decision making. Two general principles are useful in these situations. First, understanding why a patient does not want to know may—paradoxically—enable a physician to find a way to discuss a difficult subject. Second, decision making does not always require that the patient understand detailed prognostic information. Confronting patients with information they did not want is often a waste of time as they often will not hear it. If patients are forced to hear information, they often respond quite negatively to the bearer of the news, believing the data are harming them and that their physicians are not on their side.

Try to Elicit and Understand Why the Patient Does Not Want to Know

Although many physicians simply retreat after hearing that a patient does not want to talk about prognosis, understanding the patient's view can provide insight into the patient's reasoning and coping. In fact, the discussion about why the patient does not want to talk can be a useful trust-building step. For example, a physician could elicit this discussion by saying, "If you could help me understand your thinking about why you would rather not talk about prognosis, it will help me know more about how to discuss other serious issues."

Acknowledge the Patient's Concerns, Both at the Informational and Emotional Levels

Physicians who are highly attuned to information needs may attend less explicitly to emotional reactions because they feel less confident in dealing with them or because they sense (accurately) that emotional reactions cannot be changed. Yet, explicitly acknowledging the patient's emotional concerns can be the single most useful tool in dealing with patients who do not want to talk about prognosis. While it could be argued that oncologists should not be therapists, a small amount of empathy[4,5] can go a long way in these situations. Acknowledging the patient's emotions can enable the patient to process his emotional reaction and slow down the conversation enough to proceed with a topic that, for many

patients, is important and scary. For example, Dr D might say, "I know this can be difficult to talk about," which might enable Mr X to reveal that he is sad and worried that discussion will deepen his sorrow, or that he is concerned about how the information will affect his wife—all issues with practical consequences for Dr D.

Make a Private Assessment About Whether Prognosis Might Change Patient's Current Decision Making

In some situations, physicians may feel that a patient has a misunderstanding of his prognosis that is contributing to poor decision making. Here the physician might consider negotiating for limited disclosure or clarifying whether another person (ie, designated proxy) should receive the information. The key question is: does the patient need the information now? If the physician cannot identify a compelling reason to discuss prognostic information during this session, then she should follow the patient's wishes. For Mr X, with relapsed lymphoma, Dr D may well feel that the next medical step, which would be second-line chemotherapy and discussion about pursuing a stem-cell transplantation, could proceed without a detailed prognostic discussion that day. Dr D might then ask for permission to revisit the topic by asking, "My experience is that people's interest in prognosis may change over time, and so I'd like to be able to check in with you again about this in the future. And you should feel free to tell me if you decide you want more information. Is that OK?"

Some patients may want to name another person to receive the information, in effect naming a proxy for information. These proxies, in our experience, are very likely to use the information to help the patient make realistic decisions. Interestingly, the patient typically goes along with the decision and may not ask for more information about its implications.

In the exceptional circumstance when the physician believes that there is a compelling reason for discussing prognostic information and the patient does not identify someone else for you to discuss the information with, negotiating for limited disclosure is recommended. Start with a statement that explains why you think some information is needed, "I understand that you would rather not talk about prognosis today, and I want to respect that. And I also want to tell you that I see some reasons that prognosis is important for us to cover today—I think it might influence the decision you are thinking about. What do you think about that?"

Table 1 illustrates an example of a patient who declines to talk about one kind of information, but agrees to talk about another kind of information.

FOR PATIENTS WHO ARE AMBIVALENT

A substantial fraction of patients are like Mrs Y. These patients have mixed feelings about knowing their prognosis: they both want to know and do not want to know. These ambivalent patients can frustrate physicians because the patient may go back and forth in one visit, wanting the opposite of whatever the physician proposes. Ambivalence may also be subtle: a patient might say verbally that she wants to talk about prognosis, but simultaneously gives other signals—she changes the topic or looks away. The principle for dealing with ambivalence is to discuss it explicitly, allowing patients to talk about both pros and cons.[6,7]

Name the Ambivalence

Acknowledge that the patient has good reasons for wanting to talk and for not wanting to have the information. One might say, for example, "It sounds like you have some reasons that you want to know and reasons that you don't want to know. Do I have this right?" This step demonstrates to the patient that the physician understands their individual complexity and is not going to try to close the discussion prematurely.

Explore the Pros and Cons of Knowing and Not Knowing

Rather than trying to push the patient into either category, ask the patient to explain both sides of their dilemma. For example, a physician could say, "I hear that you have mixed feelings about this, so could you help me understand your feelings—on both sides—in more detail?" As the patient talks, a decision may become clear.

Acknowledge the Difficulty of the Patient's Situation

A great deal of ambivalence around discussing prognostic information is based on tension between wanting to know the information for pragmatic reasons and being fearful of the emotional effects of the information on the self and loved ones. This tension is not something that a simple communication technique can relieve. It is recommended first that physicians try to demonstrate that they perceive the difficulty of the patient's situation, and second that the physician is willing to simply be present with the patient in the situation. This requires both mindful attention,[8] and verbally, an empathic response to demonstrate that the physician is willing, in that moment, to share the patient's plight. Some physicians treat the empathy as a clause before an action statement ("I know this is bad, but we can do another test, medication, or chemotherapy"), which undercuts the power of empathy. In these situations, the physician is encouraged to just empathize with the patient's difficult situation, and wait for the patient to initiate the next step in determining how much information she needs. At this point, physician empathy can provide the support and safety needed for the patient to face a difficult reality.

Consider Outlining the Options for Discussion and Consequences

While empathy enables physicians to engage most ambivalent patients, one additional step can also be helpful. This involves outlining the options for discussion, usually different levels of disclosure, and the ways in which these options will meet the patient's concerns. Making the consequences—from the patient's perspective—more concrete may enable the patient to come to a decision. For example, an oncologist might say to a patient, being torn between wanting to plan ahead and worried that the discussion will be discouraging, "There are a couple of different options for information here. One option would be for me to talk about how the statistics might influence how we would handle different possibilities. Another option would be for me to talk just about how often the chemo works and for how long, and for us to talk about how we would handle those possibilities. I think either of those options would be very useful in helping you plan, and it may be that, by having proactive plans, you won't be as discouraged."

Table 2 illustrates a conversation with an ambivalent patient.

LIMITATIONS AND STRENGTHS OF THIS APPROACH

One limitation of this approach is that it may involve new roles and new skills. Physicians who try this approach need to be willing to step out of a role as a paternalistic medical expert and into a different role as experienced guide. They must be willing to discuss both biomedical knowledge and uncertainty, and handle strong emotions from patients, without becoming derailed themselves.[9,10] The negotiation techniques illustrated here are not meant for every part of the visit. For example, describing proven treatment protocols does not involve negotiation. Negotiation cannot be substituted for other aspects of

Table 1. Patient Who Does Not Want Prognostic Information

Speaker	Conversation	Commentary (physician's thoughts in italics)
MD	Are you interested in talking about the prognosis for this kind of cancer? Some people want lots of details, some just want the big picture and others would rather I talk about these issues with their family—what about you?	The opening question
PT	I know you can't tell me exactly how long I have.	*This might be a decline—I'll check this out*
MD	Well, that's true. The best I can do is give you information that is based on statistics and averages. And I know that not everyone wants that.	Trying to understand why patient doesn't want to know
PT	Only God knows what will happen to me.	*This sounds like a core belief*
MD	It sounds like faith is important to you.	
PT	Of course it is. My whole church is praying for me.	*Her coping is linked to her faith*
MD	It's great to have that kind of support.	Acknowledging the patient's concerns; private assessment: she doesn't have to know today
PT	I don't know what I'd do without it.	Private assessment: she doesn't have to know today
MD	It's very nice. Now can I check in about something else? I acknowledge that statistics are certainly no substitute for God, but sometimes they can be useful for planning. As you think about the future, what concerns you the most?	Exploring the patient's concerns
PT	I'm hoping that this chemo that you have been talking about is going to work.	
MD	Are you interested in talking about how often the chemo does work?	*Perhaps this is the information about the future that she really wants*
PT	Ummm, OK.	
MD	It sounds like you're not sure if you want to talk about that.	
PT	Well, actually I do but what can you say? Isn't this in God's hands?	*I wonder if she is worried that talking about prognosis will conflict with her faith.*
MD	Can I mention something? I think that talking about the chances that the chemo will work doesn't really affect someone's faith. I think you can have a lot of faith and still benefit from the information that we have from clinical trials and research. Some people find knowing about what has happened to other people helps them plan.	
PT	Well, that makes sense. So how often does the chemo work?	
MD	So the chemo makes the cancer shrink for about four out of every 10 people that take it. That means that for six out of 10 people, the cancer did not shrink. We will check your CT scan after about two months of chemo to see if it is shrinking your cancer. And if the chemo is working, we will continue. If the chemo is not working, and the cancer is growing, then we're in a new situation with different chances. Does that all make sense to you?	
PT	You said four out of 10 people have their cancer shrink, is that right?	*She's not sure she got it*
MD	Yes, you've got it exactly. Is this anything like what you expected?	
PT	I'm going to tell my friends at church. I'm worried about this.	
MD	I know this information can be hard to hear.	
PT	Yes, it is hard. But I'm glad you told me.	
MD	Do you have other questions now?	
PT	No, I don't need more just now.	
MD	Can I check in with you next time about any questions you might have about prognosis?	Asking permission to revisit the topic
PT	Certainly.	

Abbreviations: MD, physician; PT, patient; chemo, chemotherapy; CT, computer tomography.

physician work, such as physical assessments or interpretation of test results. This approach, like other forms of negotiation, requires an upfront time investment. However, the investment is small, and is usually repaid in reduced time and frustration required by follow-up phone calls or visits.

The strength of this approach is that it allows the physician to give each patient what he needs, rather than guess, or assume that what is appropriate for one patient will work for another patient. Instead of viewing prognosis questions like a test question that has no good answer, this approach gives physicians a way to align themselves with the patient, find out what really matters, use their medical expertise wisely, and build a rich therapeutic relationship over time. Using this approach reduces the need for physicians to distance themselves, as would be required if they were going to forge ahead with the bitter truth in an unprepared patient, or try to remember what kind of partial truth they told a patient last time, or pretend not to have a knowledge that they spent years acquiring. Physicians using this approach should feel more authentic, more attuned to individual patient needs, and more deeply involved with their medical decisions.

FINAL THOUGHTS

Approaching prognostic discussion by asking patients how much they want to know will result in a minority of patients stating that they do not want to talk about prognosis. This article and a related article[1] outline a set of discussions and negotiation tools that physicians can use to open up prognostic discussions. Understanding why patients want to limit information and their emotional reactions can enable oncologists to find ways to talk about difficult information and guide patients toward sound medical decisions.

Table 2. Patient Who Is Ambivalent About Prognostic Information

Speaker	Conversation	Commentary (physician's thoughts in italics)
MD	So, we've talked about the treatment options. Many people are also interested in talking about their prognosis. Is that something you want to cover today?	The opening question
PT	I'm not sure. I don't know if I want to hear any more bad news. But in a way I think I ought to know.	*He sounds ambivalent*
MD	I understand that you have mixed feelings about this. Like, you want to know and you don't want to know, is that how it is?	Naming the ambivalence
PT	Yes, that's it.	
MD	I can understand that you might not want to talk about prognosis today. Could you help me understand what might happen if we did discuss it?	Trying to understand why he doesn't want to discuss prognosis
PT	Well I know that I need to know this, but....	*He sounds hesitant*
MD	(waits silently for patient to finish)	*I'll give him some silence so he can think*
PT	Is it bad? I don't want to know if it is bad.	
MD	So how about if we deal with it one step at a time. When you asked, is it bad, what were you thinking?	Exploring the cons of knowing
PT	If it's bad I don't know if I can take it.	*He sounds scared*
MD	Do you mean that knowing a really serious prognosis might make you feel depressed?	
PT	Yes. I'm having a tough time already. Plus, I'll feel like I'm on a timeline.	
MD	Oh, you mean that it will make you feel like you're supposed to have just that much time and no more?	Acknowledging the difficulty of the patient's situation
PT	Yes.	
MD	Well, I can see that that's kind of scary.	Acknowledging the difficulty of the patient's situation
PT	It is scary—things are a little out of control.	
MD	Yes, things have happened so fast I can see how you'd feel a little out of control.	Acknowledging the difficulty of the patient's situation; making a private assessment about whether the patient needs to know now: *he is just starting his palliative chemotherapy, so we have a little time*
MD	How about this: and I'll check in with you again about this another time. Or you can ask me. Would that be OK?	Asking to revisit the topic
PT	That sounds good.	
MD	Would there also be a good side to knowing more about your prognosis?	Exploring the pros of knowing the information
PT	Well, it would probably help me plan and be realistic.	
MD	Well, this is also true.	Acknowledging the patient's concerns
PT	That would probably help my family.	
MD	So I can see some pros and cons for talking about this. How do you think we should handle this?	
PT	I think I should talk to my wife.	
MD	That sounds like a good plan. How about if you talk to her and I'll check in with you next time about how it went? In the meantime, let's focus on dealing with the treatment. I think there are a lot of things we can do to treat the cancer and improve the symptoms, including your mood....	*I want to reaffirm my commitment*

Abbreviations: MD, physician; PT, patient.

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Acknowledgment

We acknowledge National Cancer Institute Grant No. R25 92055, their Oncotalk colleagues Walter Baile, MD, Kelly Fryer-Edwards, PhD, and James Tulsky, MD, and all the oncologists who have participated in the Oncotalk retreats.

Authors' Disclosures of Potential Conflicts of Interest

The authors indicated no potential conflicts of interest.