

Virtual Mentor

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Vignette 2: Physician to Patient in Clinical Trial

Hoping for the Best, Preparing for the Worst

Commentary by Frederic W. Platt, MD

A patient of yours with prostate cancer has been given a prognosis of 4-6 months and has enrolled in a Phase II clinical trial. In discussing the research protocol with him, you have repeatedly emphasized there is no guarantee of therapeutic benefit. The patient, however, discusses the potential for long-term plans, now that he's "part of the study." How should you, as his clinician, communicate that the study may not change the prognosis?

Commentary

One can imagine the conversation:

Patient: I'm really glad you got me on this new medicine, Doctor. After I do the first 6 months, I'm going to go on an elderhostel trip to the Greek Isles. I've sent them my payment.

Doctor: Oh my, I'm not sure that's so good an idea, John.

Patient: Oh, don't you worry, Doctor. I'm going to do just fine.

We want to have our cake and eat it too, don't we? We want our patients to be hopeful enough to enlist for research protocols and yet "realistic" enough to accept our limited expectations for them. We mourn when our patient loses hope but when he has hopes that exceed ours, we say he is in denial. So how can we approach this patient whose expectations differ so greatly from ours? We must prepare ourselves to address this divergence of opinion.

First, look inward.

In preparing for all difficult encounters, our first task is to look inward, to consider our own ideas and feelings [1,2]. My self-analysis of this situation would sound something like this: I am concerned that my patient has unrealistic expectations about the benefit of this research protocol. I am worried: worried that the actual outcome will not please my patient or his relatives; worried that my patient may reject proven treatment because of inflated hopes for an experimental treatment with low probability of success; worried that I will have to tell him some bad news, hence threatening his hope; worried that I may have to endure his anger, should his disease continue to progress, at what he could perceive as a betrayal by me or the medical system. I surely don't want to replace his hopefulness with despair or anger. Perhaps I am also angry—angered that this study or perhaps that my research colleague has led

the patient on; angry that now my interchanges will take much more time. I may be sad, already grieving this patient's death. Yet I am glad that the patient is here, still coming to me, willing to work with me.

Besides my feelings, my picture of reality may include the observation that even our pessimistic estimates of life expectancy are often still far too optimistic. Physicians tend to overestimate time-left by a factor of 2 to 5 [3]. And our patients are often even more optimistic. Disappointing and unanticipated outcomes for patients often stem from the misalignment of expectations between physician and patient [4]. The unrealistic expectations that patients hold probably explain more unanticipated outcomes than do other phenomena such as biological variability, rare outcomes, and even errors of the individual clinicians and of the systems in which we work.

Ask the patient.

Once I have sorted out my own feelings, I want to learn more about the nature of my patient's hope. I know it is important and therapeutic to make efforts to understand my patient and to let him know that I have heard and understood him. So I will have to begin my response to his surge of hopefulness with acknowledgement of his feelings [5-7], I may say, for example, "Sounds like you're feeling a lot more hopeful since we discussed this research study." Only after demonstrating that I have observed his state of mind will I proceed to my concerns, and then I want to inquire about his specific hopes, beginning with, "Can you tell me more about your hopes for the future?"

Doctor: So John, can you tell me more about your hopes for the future?

Patient: What do you mean, Doctor?

Doctor: Well, I hear that you have a trip planned to the Greek Isles.

Patient: Yeah, me and my wife have always wanted to do that.

Doctor: I see. And you've probably got some other things you want to do.

Patient: Like what?

Doctor: Well, even though we're hoping that you have a lot of time left, what if your life were a matter of a few months? Are there people you'd want to talk to? Things you want to accomplish?

Patient: Oh, I see what you mean. Yeah, there's my sister in New York. I haven't talked to her for years.

Doctor: So maybe talking with your sister, going to Greece. What else?

Patient: Well, you know if this was the end, mostly I'd like to be at home with my wife.

Doctor: Those all sound reasonable. Any other hopes?

Patient: No, Just to be comfortable and not in a lot of pain.

Doctor: OK. I think I understand now.

I often recommend a policy of hoping for the best while preparing for the worst [8,9]. In this case I will recommend this policy to my patient and the person he has designated to make medical decisions for him if he is incapacitated, the person with “durable power of attorney for health care.” Using the “educational sandwich”—Ask, Tell, Ask—I will ask my patient to describe the scenarios he foresees and how he sees his options in all those situations. I will inquire about what other sources of comfort and hope he has. Maybe I will have little to tell him after I discover the various scenarios he envisions. If I do give him information about the course of his disease, I will ask him and his companion what they understood of my explanations and suggestions. I might phrase my post-explanation question like this: “I am not sure I explained my ideas very clearly. Can you tell me what you heard so I can clarify [10,11]?”

Doctor: John, perhaps it would help for me to tell you how I like to think about situations where we can’t be 100 percent sure, like yours.

Patient: Sure, Doc. Go ahead.

Doctor: Well, I like to suggest hoping for the best, like doing that Greece trip, while preparing for the worst, like if you were too sick to go on the trip.

Patient: Yeah, I can understand that. But are you telling me that I won’t last that long?

Doctor: No, I sure don’t know that. But it is really hard to predict the future. It could go either way.

Patient: I see. Well, OK, I’ll hope for the best and make plans but I will also contact my sister and talk to my wife about how I’d like to be taken care of if things get worse.

Doctor: Sounds like a good plan! So thinking about how things might go if they weren’t so good, what about talking with someone from our Hospice department so you and your wife would know what they had to offer just in case you needed their help in the future.

Patient: Yeah, I could do that. But I think I’m going to surprise you. I’ll send you a picture of the Parthenon yet!

Doctor: I sure hope so! And I’ll do whatever I can to make that happen.

Patient: Thanks, Doc. I’m really glad you’re my doctor.

Doctor: Me too. Oh, and there is one more thing that I don’t think we’ve discussed yet. If you are ever in a position where you couldn’t tell me your wishes, whom should I turn to to best represent your wishes?

Patient: Oh, that would be my wife. She’s my agent. She signs the checks, decides what we’re going to eat, everything.

Doctor: OK. Well, that's about all I've got on my mind. Can you sum all this up so I see if I said things that made sense?

Patient: Sure. You want me to hope for the best but plan for the worst. So I can plan the trip but better talk with my sister. You want us to talk with the hospice people and if I'm ever out of it, my wife will tell you what I would have wanted. Is that it?

Doctor: Perfect!

Breaking the News

Are we obliged to make efforts to “correct false hope?” I think not. I think our task is to hear the patient, understand the patient, communicate evidence of understanding, and ask the patient for his thoughts about our task, about what he would most like from us. But if we think he is expecting something from us that we clearly cannot deliver, we may have to tell him that, in the style of giving bad news. Most doctors are quite accustomed to the task of giving bad news. When asked how they do it, they frequently mention these strategies [12,13]:

1. Prepare yourself—gather the needed information, get your own feelings under control, be ready to be present when the patient expresses strong feelings. Make sure you have time and will not be interrupted (turn off electronic interrupting devices like cell phones.) Fire a “warning shot” to prepare the patient for upcoming bad news. Find a quiet, private place to have the conversation. Ask the patient if he would like someone else in on the conversation.

2. Sit down. Eye contact helps. Be able to touch the patient.

First ask the patient what he already knows and what his concerns are. Then deliver the news bit-by-bit and ask the patient for his understanding of what you said. (Use the ask-tell-ask model.)

3. Listen and watch for emotions, ideas, and the patient's values. Then try to let the patient know you heard and understood what he or she has said. Empathic communication requires not only that we listen, watch, and understand, but also that we reflect that understanding so that the patient knows it.

4. Recognize that the communication of bad news is not a one-time-event. Your patient will likely retain little of what you told him, and the conversation will have to be held again and perhaps several times. It is not done when the conversation ends.

Reassurance

Finally, we can reassure our patient. Not the false reassurance that suggests that things are not as bad as the patient thinks, or that they are not as bad as the patient is making them out to be. But we can reassure our patients that we will be back, that we will be present with them, that we will be available, and that we will not abandon them if their disease progresses. The promises we make must be those we can deliver on. If our patient is helping us in our research studies, we can repay him with our availability. We can provide our cell phone number, our home phone number, and a promise to

respond to him when he needs us. That promise may be all we can offer, but it is worth a great deal.

Doctor: John, of course I'm not sure of exactly what the future will bring.

Patient: No, of course not, Doctor.

Doctor: So what I'd like to promise you is that I'll be with you. In fact, I'd like to give you my phone numbers so you can get hold of me if you need to—my home number and my cell phone number.

Patient: That's kind of you, Doctor. I won't bother you unless I need you.

Doctor: I know. Here they are. Meanwhile, let's have you come back as this research protocol asks, in 2 weeks.

Patient: OK, Doctor. See you then.

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Suggested Reading

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