

# Virtual Mentor

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## ETHICS CASE

### When Patients Seem Overly Optimistic

Commentary by Jane deLima Thomas, MD

Dr. Beard was not surprised to see that Mr. Cohen leaned heavily on an ornately carved cane to walk the long corridor to her office. She had just been looking at images of his spine, to which his pancreatic cancer had now metastasized, sprinkling a long stretch of his lumbar spine with ominous grey holes.

Mr. Cohen had previously asked that Dr. Beard be direct with him, so she began as soon as she was settled in the chair in her office. “As you had been guessing from your new back pain, it looks like the cancer has spread to your spine.”

“I’d thought so,” said Mr. Cohen. “I’ve been reading more and more about new treatments, and I really think it’ll work out fine. I’ve just started a new chemotherapy, and I have a big trip planned around the world for next year. Besides, this is a great hospital, and I know you’re the best in the field.”

Dr. Beard hesitated. She had not anticipated this level of optimism. Mr. Cohen had been diagnosed 6 months before. Since then, several chemotherapy protocols had failed to reduce his tumors, and he was increasingly crippled by the metastasis.

“I’m glad you’re thinking so positively,” Dr. Beard said carefully. “But your disease is moving much more quickly than I’d expected. These CT scans show that it is now in your spine.”

“Oh, I know. But the more I read about these new treatments, I really think it’s all going to work out fine,” Mr. Cohen repeated. “Besides, if I don’t hope for the best, well....” His voice trailed off.

Later that day, Dr. Beard received a concerned phone call from Mr. Cohen’s daughter, a nurse in the ICU.

“Dr. Beard, I know what this disease is like, and it’s clearly progressing. My father’s not getting it. You need to make sure that he understands the reality,” she said.

## Commentary

The situation described in this case is not uncommon for clinicians who work with patients with life-limiting illness. The clinician has done the difficult task

of giving bad news, but the patient continues to express unrealistic optimism. What responsibility does the clinician have to make sure the patient accepts the gravity of the illness? What are the risks and benefits of being more explicit with the patient about the seriousness of the illness as opposed to allowing him or her to hold on to unrealistic hopes?

Clinicians often feel that the ethical precept of respect for patient autonomy requires that patients not only hear prognostic information but accept it in order to participate fully in making decisions. This approach has limited utility, however, since some patients cannot understand or come to terms with a poor prognosis for a variety of reasons [2]. In these cases, shared decision making is best done using a patient-centered approach, which involves making a careful assessment of the reasons a patient seems not to accept the prognosis, weighing the risks and benefits of being more explicit, using patient-centered communication skills to convey the information in a way that patients are more likely to accept, and using surrogate decision makers when necessary. What follows are four questions to consider when faced with a patient who seems not to accept a poor prognosis.

1. What is the patient's true understanding of the illness?

Sometimes patients receive direct information about prognosis but still don't understand. This can happen for several reasons, including underlying cognitive deficits, language barriers, medical illness (e.g., delirium), or the use of jargon or euphemisms by the clinician. A patient may have an underlying undiagnosed neurologic issue like mild dementia that is exacerbated by acute illness and interfering with the ability to process and remember information. Other patients may be cognitively intact but have emotional barriers to processing medical information. For example, one study showed that patients who did not acknowledge their prognosis had rates of depression nearly three times higher than those who did [1].

Assessing the patient's understanding and barriers to understanding is the first step in trying to decide what information still needs to be shared and the most effective method of sharing it. Is there need for an interpreter? Are there underlying medical illnesses that must be addressed first? Would emotional overload preclude giving more information? And if the barriers to understanding are insurmountable, does the patient have capacity to make decisions, or should a surrogate decision maker or health care proxy be involved? Answers to these questions help the clinician understand the patient's ability to process information and guide the plan for next steps.

2. If there are no barriers to the patient’s understanding prognostic information, are there specific reasons that he or she continues to appear hopeful?

There are several reasons why patients may continue to express optimism even as they seem to understand that the illness is serious. Some may be protecting family members, putting up a good front so that loved ones won’t worry that they are sad or afraid. Other patients express hopefulness for fear that the clinician may stop trying to treat the disease if they express doubt that the treatments will work. Yet others may be responding to social pressure to avoid the appearance of “giving up,” which can seem self-sabotaging or even suicidal. Lastly, most patients find it impossible to live with the reality of impending death at every moment and oscillate between realistic acknowledgement of the gravity of the illness and optimistic hopes. For most patients, this is simply a manifestation of healthy coping as they adjust to a new and difficult reality, although it can give the impression that they are in complete denial if clinicians only see them at moments of hopefulness.

3. What is at stake if the patient does not recognize the seriousness of the illness?

The answer to this question should be an important consideration when clinicians are deciding how much to push patients to acknowledge the seriousness of their prognosis. The baseline assumption—and what the data about good end-of-life care and bereavement outcomes shows—is that patients and their families have better outcomes when they are given the opportunity to prepare for the losses associated with advanced illness and death.

Even with that understanding, however, clinicians faced with patients who refuse to accept the gravity of their illness should pause before launching into a serious discussion about prognosis and ask themselves, “What good will come of having a frank discussion? What harm?” Clinicians should ensure that the motivation for discussing prognosis further is not simply to ease their own discomfort. Factors that might justify giving patients more leeway to sustain unrealistic hopes include a gently declining clinical course, a patient’s emotional fragility, or a code status that is already consistent with the patient’s values. Factors that might compel clinicians to be more explicit include a rapidly deteriorating clinical status, unresolved issues with high potential for harm (e.g., unclear guardianship for children or a family that is unprepared for the death), or a code status that is inconsistent with the patient’s values.

4. How can clinicians proceed if—after they have considered questions 1 through 3—they feel the patient will come to harm if he or she does not understand the reality of the poor prognosis?

After assessing (1) obstacles to the patient’s understanding, (2) reasons for continued unrealistic hopefulness in the face of clear understanding, and (3) the risks to the patient if he or she holds on to unrealistic optimism, clinicians may believe that significant harm will come to the patient if he or she does not acknowledge the seriousness of the illness. Often specific patient-centered communication skills can be helpful in those situations.

Using “hope and worry” statements can help preserve alignment with the patient even as difficult news is being discussed, e.g., “I hope we can find a way to stop the progression of your disease but I worry that we are seeing that it isn’t possible.” Using “I wish” statements can serve a similar purpose, e.g., “I wish we had an effective treatment for your disease but it looks like nothing we have used is working any more.” Using hypothetical questions can sometimes give patients an opening to talk about the reality of the situation, e.g., “Have you ever thought about what would happen if the disease weren’t treatable?”

Lastly, “naming the dilemma” can be helpful if the first three techniques are ineffective, e.g., “I find myself in a tough spot. I want to give you the very best care, but I am concerned that I won’t know how to do that if we don’t talk about what’s happening with your illness. Do you think we could do that?”

If patients persist in avoiding facing a poor prognosis despite the likelihood of harm if they continue to do so, clinicians can ask for permission to talk with surrogate decision makers. “I understand that it can be very difficult to talk about things going badly. I don’t want to force you to do something you feel isn’t right for you, but there are some decisions that have to be made. Is there someone you have named to make decisions for you if you can’t or choose not to? Would it be OK with you if I talk to that person so we can think together about how to ensure you receive the best care?”

In summary, clinicians faced with patients who hold on to unrealistic hopes in the context of serious illness often worry that they are responsible for ensuring that the patient accepts the gravity of the prognosis. The above considerations shift the nature of that responsibility. Clinicians are responsible for the following:

- Identifying and—to the extent possible—removing barriers to a patient’s understanding;

- Assessing reasons patients may hold on to unrealistic hopes despite clear understanding;
- Evaluating the risks and benefits to the patient of having more frank discussions about prognosis;
- Using patient-centered communication skills to try to offer information about prognosis in order to prepare the patient for continued decline; and
- Trying to obtain permission to use a surrogate decision maker if time is short and decisions need to be made.

Clinicians should also recognize that patients' acceptance of poor prognosis is a dynamic state that changes over time. They would do well to revisit the conversation at different points in the course of the illness to give patients the opportunity for discussion as they adjust to the progressive nature of the disease. Clinicians who follow these steps, however, have fulfilled their ethical obligation to respect patient autonomy and need not feel they have failed the patient if he or she continues to refuse to acknowledge a poor prognosis. In that case, good patient care includes respecting a patient's autonomy in deciding *not* to acknowledge it.

### References

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2. Jacobsen JC, Jackson VA, Thomas JD. Misunderstandings about prognosis: an approach for palliative care consultants when the patient does not seem to understand what was said. *J Palliat Med*. 2012 [In press.]

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