THE ART OF ONCOLOGY: WHEN THE TUMOR IS NOT THE TARGET

Setting Goals to Maintain Hope

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A 72-YEAR-OLD former smoker was referred to a medical oncologist by his general practitioner after evaluation for a persistent cough and arm pain. A chest x-ray, followed by a chest computed tomography (CT), revealed a right upper lobe mass and bilateral mediastinal adenopathy. A bone scan revealed multiple areas of uptake in the long bones and ribs, including the area of pain. A bronchoscopic biopsy showed adenocarcinoma. His Eastern Cooperative Oncology Group performance status was 2. The patient knew he had cancer before he and his wife met with the oncologist.

Oncologist: “You have stage IV lung cancer. Although that’s very threatening to you, there’s about a 40% chance the cancer will respond to chemotherapy. Some of my patients have done very well, much longer than anyone expected.”

Patient: “Of course there’s a chance. I’ll be with you every step of the way.”

Wife: “Won’t the side effects be bad?”

Oncologist: “Chemotherapy isn’t like it once was. We can control the nausea. You will lose your hair, but only temporarily. I’ll have my nurse come discuss what to expect in more detail.”

Patient and wife: “Oh, thank you doctor.”

We oncologists frequently encounter patients who expect their cancer to be “fixed.” In other words, they want hope—hope that the cancer will go away and never come back. They seem to want us to tell them that the cancer can be cured, even if we know it’s unlikely or impossible. If we’re honest, we also notice that we want to tell them what they want to hear—we, too, want to promise a good outcome.

Our responses to this need for hope can have unfortunate consequences. We talk in language that can easily be misinterpreted by patients. For example, we say “There is a 40% chance of response,” and the patient hears, “There is a 40% chance of cure.” We don’t explore their understanding about what this really means, because it already feels like enough bad news.

We use the problem-based method to manage care. As the problem list gets longer, we maintain hope (mostly our own) by making plans and being busy about what to do for each problem. In this example, the patient has several problems: a chest mass, arm pain, cough, multiple bone metastases, fatigue. This is a manifestation of the training we had as residents—it seemed that the resident with the longest problem list “won.” Particularly if we could not offer cure or substantial improvement in survival, solving smaller problems—making the mass smaller, making the pain better, correcting the potassium, balancing intake and output, subdividing the problem list—made us feel like we were doing something. If the patient died, we consoled the family and ourselves by saying we did everything we could. Further, the busy-ness of all that problem solving distracted us, and the patients and their families, from the bigger issue, that the patient will die and we can’t prevent that. In other words, this is a situation of not seeing the forest for the trees. In teaching this concept to other physicians, one of us frequently uses the twist on the old adage, “don’t just do something, stand there.” It’s a way to highlight how a physician’s need to be busy can get in the way of more important tasks and goals.

The admonishment to physicians to maintain hope, even false hope, is almost as old as the recorded history of medicine. Its most recent interpretation is that positive mental imagery is required for cancer to be cured.2 This diminishes the role of the physician as a person—one who can offer honest support.

Unfortunately, there are several reasons to think that this approach is not in the best interests of patients, or of ourselves. First, false hope leads to disappointment and disillusionment. If we are all hoping the cancer can be fixed, and it can’t, then it isn’t surprising that this leads to desperation and despair on the part of patients, and emotional distance and burnout on the part of oncologists. Second, we are subject to criticism from patients, families, and our colleagues outside of oncology when we engage in sustaining false hope and wishful thinking. Patients and families ask why they weren’t prepared. Colleagues mutter about the oncologist who won’t recognize the inevitable and insists on giving useless chemotherapy. Third, we tend to be overly optimistic about how much time a patient really has. As physicians, we seem to be systematically miscalibrated toward optimism. This may be a coping mechanism to prevent cynicism or nihilism. Unfortunately, it can have unintended consequences. When we think the patient has months, the patient usually has days or weeks. In other words, we often wait until it’s too late to tell the truth. This can rob patients and us of meaningful interactions, time to make necessary plans, and/or achieving a sense of accomplishment.

There’s a darker side to this attitude about hope on the part of oncologists. They think there isn’t any role for them when there isn’t hope for giving anticancer therapy. In their eyes, if they think chemotherapy will offer no further benefit, then there must

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be no further role for the oncologist. This descent into being mere technologists, chemotherapists as some of our colleagues call us, is reinforced both by the profit motive of giving chemotherapy and the reimbursement strategies in which we work. This shortchanges both our patients and us.

Planning gives a sense of future, and working toward something reinforces hope. When patients learn they have cancer, many first hope it isn’t true, then they hope they won’t die from it. Next, they think a bit about what they will do if either turns out to be likely. The point is, most adults cope and sustain hope by making plans for the future, even if the future isn’t what they would want if they could choose.

Most adults have room to hope and plan for several possibilities simultaneously. We can hope for the best, but prepare for the worst. Most of us can recall a variety of situations in which this is true. How many of us had a cherished hope as well as a plan if it didn’t happen? Getting the best score on the exam? Being named valedictorian? Starting for the football team? Getting our first choice for medical school?

We, as others, have observed that hope is quite resilient. It is different from wishing. Hope can be defined as the expectation that something good or anticipated will happen in the future. There are a variety of things for both patients and oncologists to hope for in cancer care. Patients and their doctors can hope the cancer will be cured, or that it won’t come back, or that its growth will be stopped, or that symptoms will be controlled, or that important business can be accomplished before a good death.

The following analogy can be helpful in trying to teach this concept to the person with cancer and their family. Many hope to win the million-dollar lottery while continuing to go to work and manage with the money they have. There’s nothing wrong with that. However, it would be wrong to live a life as if a person were going to win the lottery. For the patient with cancer and the oncologist, it’s fine to hope for a cure, even if there is a small likelihood of it happening. But we need to avoid crossing the line and behaving as if a cure is assured when it is not.

**SETTING GOALS TO MAINTAIN HOPE**

In the course of clinical practice, we have found an approach to decision making that promotes hope and avoids the pitfalls that unrealistic hope holds both for patients and ourselves. We set goals. When a patient comes to an oncologist, there are many possible goals: cure, prolonged life, to know what to expect, to be comfortable, to not be frightened, or to improve quality of life. We find it useful to be explicit about which goals are hoped for, which goals we are trying to achieve, and which goals are most important. We can act as cheerleaders and offer honest support in our role to help patients achieve those goals.

To set goals, you need to name them and understand how you are going to get there and how you will know whether they have been achieved. Another analogy illustrates this. If our goal is to drive to Oak Park, it’s nice when you have a map and the signs say, “Oak Park 3 miles.” “Oak Park 1 mile.” “Oak Park next exit.” Contrast this with driving without a map after someone has said “Oak Park is west,” and driving down a poorly marked road where the only sign for a change in direction is at the time of the exit. We can use what the transportation engineers have learned and apply it to oncology.

**PREPARE THE PATIENT FOR GOAL-ORIENTED CARE**

At the beginning of the therapeutic relationship, establish how information is going to be shared and what the relationship between physician and patient is going to be. Establish that truth telling will be the norm unless they prefer otherwise. If you always begin the therapeutic relationship by laying ground rules that you’re going to tell the truth, you set the stage for an easier future. When new information is available or difficult decisions need to be made, you can remind the patient (and yourself) about the ground rules you established: that you had agreed to be honest about where things stand in order to make the best decisions and plans.

**PREVENT SURPRISES**

Let patients and families know that you are going to talk about all possible eventualities, even if they don’t happen, to prevent surprises. To use the driving analogy, this is part of being oriented to the trip. Particularly if you are unfamiliar with the territory, or don’t like to travel, it helps if you have a guide that is going to give you accurate information. It’s reassuring to know what is likely to be encountered, or what is unlikely but important, when undertaking a trip.

It’s also helpful if the patient wants someone else to do the driving. There are some patients who want their doctors, or their families, to make all the decisions. This is ethical and legal but deserves exploration. Who should make what kinds of decisions? At what point should the patient’s opinions be sought?

Tell them who the players are and the roles they will play. For many patients, there are a host of physicians and other health care professionals. Who is making the decisions—the primary care physician? The medical oncologist? The radiation oncologist? The surgeon? Who is talking to whom and when?

**PREPARE FOR DECISION POINTS IN ADVANCE**

Share how and when decisions are made. Tell patients what you use to make decisions and when these decisions will be made. Indicate that you will say when you think that a particular approach is not working to achieve your mutual goals. Let patients know that when you think an approach won’t be effective, or when you think the burden exceeds the possible benefits, you will say so. Tell them you will then discuss it and come to a mutually agreed on plan.

**DEFINE LANGUAGE**

If you are going to use terms like cure, control, complete response or remission, partial response, stable disease, progressive disease, and recurrence, then explain what you mean in terms that patients and families can understand. Better yet, use a glossary (Table 1) for translation, and use common language when talking to patients and families. Reserve medical language for talking to colleagues.

**SET GOALS BY USING A FRAMEWORK FOR THE DISCUSSION**

Starting to use a goal-oriented approach with patients and families who have cancer may seem awkward at first. This is particularly true if you have never observed this approach. To
have a greater chance of achieving success, consider using the following modification of the six-step protocol for communicating bad news.\textsuperscript{4} In laying out this framework, we expect that you will have already established who the decision maker is, how much information will be shared, and that you will always tell the truth. It is useful to recall that the vast majority of people in the United States want all the details themselves.\textsuperscript{5}

1. Create the Right Setting

Establish that the purpose of the conversation is to determine goals for care. Sit down. Ensure privacy and time. Be sure the right people are present.

2. Ask What the Patient/Family Know

Start with an open-ended question such as, “I’d like to start by having you tell me what you know about your illness.” Although you know what is in the chart, or what the referring doctor said he told the patient, or what you have said in the past, first check out what they understand. Clarify their understanding of their current situation and the context in which decisions about goals of care should be made. For example, if the patient thinks he or she had a little colon cancer resected and you know that it has spread to the liver, the determination of goals of care will first have to include achieving agreement on the clinical facts.

3. Explore What They Are Expecting or Hoping For

Start with a question like, “Tell me what you are expecting in the future with this illness.” It helps to know what they are expecting before you start talking about what is possible. For example, if the patient has metastatic colon cancer and they say they expect to be cured, you will approach the conversation differently than if the patient says, “Oh I know I’ll die of this eventually; I’m hoping you can give me some extra time.” Focus on what you will do to achieve those expectations and hopes. As appropriate, identify those things that you cannot do, perhaps because they will not help achieve the goals or because they are not possible. For example, if the patient and family describe metastatic non–small-lung cancer that has progressed after first-line chemotherapy, and thus expect to be cured with another kind of chemotherapy, you can remind them that you said you’d be truthful. Tell them that you don’t know of a chemotherapy that will achieve that goal.

For situations where you need to give information that you aren’t sure they are expecting to hear, many advise using a so-called warning shot. For example, in the case of the person with progressive non–small-cell lung cancer after first-line chemotherapy who expects to be cured, you could say, “I’m sorry to have to tell you some bad news. I don’t know of any chemotherapy that can achieve that goal,” or, “You remember that I said I would always be honest. I don’t think that any kind of chemotherapy will achieve what you want.”

4. Suggest Realistic Goals

Given what you now know about what the patient and family understand and expect, you can suggest realistic goals. Oncologists often have a wealth of scientific knowledge about the patient’s illness, its expected natural course, the experience of patients in similar circumstances, and the effects that contemporary health care may have. It’s our role to share this to assist with decision making. After sharing this information, suggest realistic goals (eg, curing the cancer with more intensive combination therapy, shrinking the tumor with as few side effects as possible, extending life for a few more months than might otherwise be expected, taking a trip with good symptom control while there is enough stamina to do it) and how they can be achieved. Work through unreasonable or unrealistic expectations. Problem-solve about overcoming barriers to achieving the identified goals.

One of the most prevalent, but often implied, goals is wanting to be a fighter. We find that many value being a fighter, even in the face of overwhelming odds. Whether it is a feature of human nature, or sex, or culture, it is prevalent in both patients and oncologists. It conjures up visions of sports or war analogies of fighting valiantly against adversity. Perhaps that is why the legend of Don Quixote is persistently appealing—it represents the valiant pursuit of an ideal. Yet most can agree that pursuit of an illusion can be counterproductive if it leads to poor decisions.

If it is an important goal to be a fighter, even if the odds are slim, we find it helpful to make this an explicit goal—to feel like you’ve tried everything. Further, it helps to clarify whose goal this is: the patient’s, the family’s, or the doctor’s. Many patients will continue treatment not for themselves, but to pacify a family member or to avoid disappointing the doctor. For many people, making this an explicit goal, as well as laying the groundwork for deciding when enough fighting has been done, or when there is too much casualty helps to avoid the feeling of being a quitter.

Because of our better knowledge of likely outcomes, we can help patients observe when the goals of making final gifts, creating legacies, and preparing for the future of the family are more important than high-risk, low-yield chemotherapy. As oncologists, we need to listen to our patients, families, nurses, and other colleagues when it is we who are fighting windmills. One of the saddest situations is when a patient pursues therapy in order to not disappoint the oncologist.

5. Respond Emphatically to the Emotions That Will Arise

When information is shared in this way, various emotions can be expected: anger, sadness, and fear, for example. The most important clinical pearl is to listen quietly while the patient expresses emotion. Facilitating comments like, “I can see that this makes you sad,” or “You really seem angry about this,” can help the patient feel supported.

Responding to emotion is often the hardest part of a clinical interview for new oncologists. In our experience training fellows and residents, lack of preparation and skill leads to a prevalent fear that patient and family emotion will be overwhelming and
uncontrollable. Consequently, they structure conversations, if they have them at all, in such a way as to ensure that no emotion other than quiet assent is expressed.

In fact, the majority of emotions expressed in the oncologist’s office are short-lived. The fact that the oncologist was willing to listen is experienced as supportive and caring.

6. Make a Plan and Follow Through

Clarify what the overall goals are and the steps that will be taken to achieve them. This permits both patient and physician to be energetic and hopeful about achieving the goals. Be clear about how you will know if you are achieving those goals and how you will measure them. Examples are: “Our goal is to put the lymphoma into remission. We’ll give the chemotherapy twice and check the CT scan. If it’s smaller, we’ll give the chemotherapy again four more times and then repeat the scan. If it’s the same or larger, we’ll need to reconsider our goal.”

“Our goal is to shrink this lung cancer. We’ll give the chemotherapy twice and check the CT scan. If the cancer is better, we’ll continue. If the cancer is worse, then it means the chemotherapy isn’t working and we’ll stop the chemotherapy.”

“It sounds like our goals should be to get your pain controlled, see if we can increase your energy, and get you to your daughter’s graduation. I’d like to ask the hospice team to get involved because they are experts with these things and can help us achieve these goals. Their involvement is the best way I know to help us achieve the goals we’ve set.”

7. Review and Revise Goals Periodically

Identify key decision points in advance. The road sign analogy is very helpful here. If you know a decision to exit the highway is coming, it helps to have enough preparation ahead of time. The same is true for cancer therapy. What are the signposts to know if the goals are being met? Energy level? Pain? The size of the lump? The CT scan? Share the things you are looking for with the patient and family. This helps them cope and prepare and takes some of the drama and tension out of future conversations when decisions need to be made.

These signposts help us, too. For example, if the goals for this patient with metastatic lung cancer are to make him feel stronger, make the pain get better, and make the mass in his chest shrink, it is a lot easier to have made these explicit before starting chemotherapy. When the date to assess progress comes, it is much easier to take stock of those goals than to say, “The cancer is worse,” to an unprepared patient.

Let’s revisit the case and see how it might go if setting goals were the approach.

CASE REVISITED

Oncologist: “Before we talk about specifics, let’s establish an understanding of how you’d like our relationship to be. It’s something I ask all my patients. How do you like to hear medical information?”

Patient: “Well, I want all the information. I’ve got to know what I’m dealing with. Just give it to me in words I can understand.”

Oncologist: “OK. I’ll always be as honest as I can be, even if the news isn’t what we’d wish for. Is that OK?”

Patient and wife nod in agreement.

Oncologist: “Right. Well, I wish the news I had was different. You have lung cancer that has spread to your bones. That’s why your arm hurts. [pause] What does that mean to you?”

Patient: “It means I’m going to die.”

Oncologist: “Yes, that’s true, eventually. But, there are things we can do. Chemotherapy makes some patients feel a lot better for a time. They can get stronger and the pain can get better. In addition, we can use pain medicines to make your arm feel better right away. Radiation can also help your arm.”

Patient: “You mean there’s a chance I can beat it?”

Oncologist: “What do you mean by ‘beat it’?”

Patient: “Make it better for a while. . . go into remission. . . I’d really like to see my grandkids grow up.”

Oncologist: “It sounds like your grandchildren are very important to you. I’m not sure I can tell you that you will see them fully grown, but it may be important for you to spend more time with them now. Many people can gain a sense of accomplishment by preparing a legacy for their grandchildren—something to pass on to them like a tape-recording, a photo album, a videotape. While I don’t think it’s very likely that the cancer will go away completely, I do think there’s a chance we can make it better for a while.”

Patient: “How much of a chance?”

Oncologist: “Well, chemotherapy helps about one in three people.”

Patient: “How long do you think I’ve got?”

Oncologist: “Before I answer that, tell me why you want to know?”

Patient: “Well, me and my wife have always wanted to go to Las Vegas for a week. We were going to put it off until this cancer got into remission.”

Oncologist: “Well, it’s hard to predict the future. On average, people with lung cancer like you live 6 to 12 months. I’ll be able to give you a better estimate when we see how the cancer responds to the chemotherapy. My advice is that you make plans to make that trip soon. If the cancer gets better with the treatment, maybe you can go again. If it doesn’t, you’ll want to use the time you have now while you can go. We can either get the treatment started now, or wait for you to get back. Which would you prefer?”

Patient: “Oh, let’s get started, and we can start making plans.”

Oncologist: “Great. The chemotherapy is given every 3 weeks. Most people feel pretty good during the week before the next treatment. Maybe you should plan to go then.”

Patient: “Thanks, doc.”

Oncologist: “Whatever happens, I’m happy to take care of you. Now, let me ask my nurse to come in to discuss some of the details of treatment, including these pain medications I’d like you to start using.”
REFERENCES

ERRATUM


The abbreviation CHOP was expanded improperly. The correct expansion is cyclophosphamide, doxorubicin, vincristine, and prednisone.