

EPEEC-O

Education in Palliative and End-of-life Care - Oncology

Participant's Handbook

Module 9

Negotiating Goals of Care

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Abstract

There are many possible goals of cancer care, from prevention, to cure, to prolongation of life, to relief of suffering, to optimizing quality of life, to achieving a good death. No one goal is inherently more valid than another. Multiple goals may apply simultaneously. In general, attempts to treat the cancer or restore health can be pursued at the same time as efforts to manage the experience, ie, relieve suffering and improve quality of life. To establish what is important to the patient, specific clinical skills are needed for negotiating care goals. From the onset, the oncologist will want to identify what is reasonable for the patient to hope for, to adjust according to the patient's culture, to convey prognosis even with all its uncertainty, to use appropriate language, to set limits if necessary, and to manage care even when the patient lacks decision-making capacity.

Key words

Culture, decision making, goals of care, hope, hospice, incapacity, language, limit setting, palliative care, prognosis, quality of life, treatment priorities, uncertainty

Objectives

After studying this module, oncologists and other members of the cancer care team will be able to:

- Tell the truth while identifying reasonable hope.
- Discuss potential goals of care and treatment priorities, and how they interrelate and change.
- Use a 7-step protocol to negotiate goals of care and treatment priorities.
- Identify goals when patients lack capacity.

Clinical case on trigger tape

M.J. is a 50-year-old woman with stage II breast cancer, hormone receptor negative, treated with lumpectomy, radiation, and chemotherapy 5 years ago who returns to the office for evaluation. She was premenopausal at the time of diagnosis, although she hasn't menstruated since then. After the therapy was over, she kept up routine visits first every 6 months, then every year. Recently, she felt some pain in her ribs that will not go away. A bone scan was scheduled before coming to the office today. The bone scan was positive.

Introduction

Oncologists frequently encounter patients who expect their cancer to be 'fixed.' They are hoping 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 is unlikely or impossible. We may

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 may talk in language that can easily be misinterpreted by patients. For example, we may say “there is a 40% chance of response,” and the patient may hear, “there is a 40% chance of cure.” Often, we do not explore their understanding about what this really means because it already feels like enough bad news.

The problem-based method to manage care is highly prevalent.¹ As the problem list gets longer we may maintain hope (mostly our own) by making plans and being busy about what to do for each problem. If we cannot 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—may make us feel like we are doing something. If the patient dies, we console the family and ourselves by saying, “We did everything we could.” Further, the ‘busyness’ of all the problem solving can distract us, and the patients and their families, from the bigger issues.

Truth-telling and hope

One of the chief obstacles to negotiating goals of care in the face of life-threatening illness and poor prognosis is the issue of hope, ie, the feeling that what is wanted will happen. Hippocrates stated, and Osler continued to advocate for the medical convention that ‘physicians should express hope to the patient and family that the patient will enjoy a full recovery from the current illness, even if it is not true.’² Its most recent interpretation is that positive mental imagery is required for cancer to be cured.³ This principle has been mistakenly taken so far as to administer treatments that are known to be ineffective, even to cause harm, in the service of maintaining hope.

There are several reasons to think that this approach is not in the best interests of patients, or for us.

1. Patients say they want the truth.⁴
2. False hope leads to disappointment and disillusionment. If we are all hoping the cancer can be fixed, and it cannot, then it is not surprising that false expectations lead to desperation and despair on the part of patients and families, and stress, emotional distance, and burnout on the part of oncologists.
3. 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 were not prepared. Colleagues mutter about the oncologist who will not recognize the inevitable and insists on giving useless chemotherapy.
4. We tend to be overly optimistic about how much time a patient really has.⁵ As physicians, we seem to be systematically miscalibrated towards 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 is too late to tell the truth. This can rob patients, families, the oncologist and other members of the cancer care team of meaningful interactions, the opportunity to make necessary plans and realize our full potential. It can also erode autonomy and trust.

There is a darker side to oncologists' attitude about hope. We may think, perhaps subconsciously, there is not any role for us when there is not any anticancer therapy. If chemotherapy or radiation therapy will not help, then there must be no further role for the oncologist. This drift into 'chemotherapists or radiotherapists' as some of our colleagues call us, is reinforced both the reimbursement strategies in which we work that have favored administration of these interventions. But such dispositions can short change our patients, their families, members of the cancer care team and ourselves and often leave everyone feeling like a failure.

Planning that gives a sense of future and working towards a goal reinforces hope. When patients learn they have cancer, many first hope it is not true. Later, their hope shifts and they hope they will not 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 is not what they would want if they could choose.

Most adults have room to hope and plan for several possibilities simultaneously. They 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? Named valedictorian? Starting for the football team? Getting our first choice for medical school?

Hope is quite resilient, even in the face of hard realities. It is different from wishing. Hope can be defined as the expectation that something good or anticipated will happen in the future. There is a spectrum 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 will not come back for a long time, or that its growth will be stopped, or that symptoms will be controlled, or that important business can be accomplished before a good death, or that death will be comfortable and safe, or that family will recover from their bereavement.

An 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. However, the ones who get along well do not live a life as if he or she must or will win the lottery. For the patient with cancer and the oncologist, it is fine to hope for a cure, even if there is a small likelihood of it happening. But crossing the line to behave as if cure is assured when it is not is rarely helpful in the long run.

Potential goals of care

This module presents an approach for eliciting a patient's goals for care and clarifying his or her treatment priorities throughout the course of comprehensive cancer care.

Since the beginning of medicine, there have been two overall aims of care: to cure disease and to relieve suffering. Both strive to maintain the patient's capacity to live life to the fullest and realize her/his full potential. Within these two overall aims are numerous possible goals for health care, including complete cure, avoidance of premature death, maintenance or improvement in function, prolongation of life, relief of various types of suffering, improvement of quality of life, preservation of control, a good death, and support for families and loved ones. No one goal is inherently more valid than another; all are legitimate goals of medicine and each will be applied differently by the individual in his or her particular circumstances.

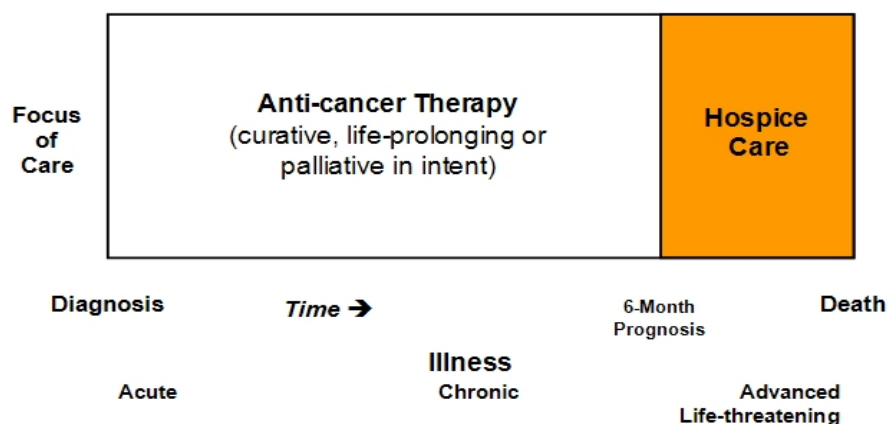
Historically, a dichotomous division of goals of care

In the last quarter of the 20th century there have been significant developments in cancer science and technology. In the fight against illness and death, modern oncology has focused primarily on curing cancer and prolonging life as it has fought aggressively against death.

In the 1960s and 1970s, the hospice and palliative care movements were born in the United Kingdom, the United States, and Canada to address the management of symptoms, the relief of suffering, and the care of dying cancer patients. Beginning in 1982, hospice care in the United States has been profoundly influenced by the Medicare Hospice Benefit requirement for a prognosis of 6 months or less in order to qualify for the benefit. Since Medicare provides about 80% of hospice revenue in the US, programs have tended to serve only patients with cancer when cure was no longer possible.

Figure 1 shows the division between goals of care if medical decision making occurs in a dichotomous way where the focus is first on therapies with a curative intent, and only when they are no longer effective does the intent shift to relief of suffering.

Figure 1: A dichotomous intent



This dichotomous approach does not adequately address many clinical situations. Some therapies aimed at cure and life-prolongation may be appropriate until close to the time of death. Moreover, studies show that patients with life-threatening illnesses, and their families, will experience multiple symptoms and have ongoing needs for psychological, social, spiritual, and practical support throughout their illness, from the time of presentation/diagnosis, not just in the period before death.

Do not wait to focus on the relief of suffering until all attempts at cure have been exhausted or the patient and family plead for such efforts to stop. With earlier access to symptom management and supportive care, patients and families may feel better, have the capacity to live their normal lifestyle, maintain more capacity to fight their illness, sustain more treatment, and live longer.

Multiple goals of care

As patients and families experience life-threatening illness, several aspects become apparent to the observant clinician.

Multiple goals apply simultaneously

Although goals may seem to stretch along a continuum in a linear fashion, in fact the patient and physician may want to both control/cure the cancer and manage the symptoms and other issues that cause them suffering, ie, treat the cause and manage the experience. They may not consider a therapeutic intervention, eg, chemotherapy, unless it addresses both goals. In clinical practice this is more the rule than the exception.

Goals may be contradictory

A patient may want prolongation of life as the overriding goal but also insist that nothing be done that increases discomfort. The oncologist knows, however, that treatments aimed at curing disease, such as a surgical operation or chemotherapy, may unintentionally cause temporary or permanent functional deterioration and suffering. It is the physician's role to help the patient and family understand the balance between the benefits, the risks of harm, and burdens of a particular treatment.

Explicitly include a goal of comfort along with the goal of cure from the beginning

From the time of presentation, offer both therapies that aim to treat the cancer (whether curative, life-prolonging, or palliation in their intent) and manage the experience. When curative goals are no longer appropriate, this concurrent strategy permits some aspects of the plan of care to continue until death, rather than necessitating a change from one goal to another with its implications for abandonment and 'giving up hope.'

Goals may change

Over the course of a lifetime, or the course of an illness, the relative weight given to each goal and each treatment may change in response to numerous factors. It is only in the context of an individual’s life that an adequate balance of goals can be achieved.

Some goals take precedence over others. As a patient’s prognosis and health status worsen, the goals of prevention, cure, and avoidance of death may become less important as they become less possible. At the same time, the goals of maintaining function, relieving suffering, and optimizing quality of life may become the focus of care.

Ideally, this shift in focus of care is gradual. It is usually negotiated over time. An abrupt transition in the focus of care from primarily curative care to primarily supportive care is rarely appropriate.

The shift in goals is an expected part of the continuum of cancer care. Clinical decisions routinely require prioritization among potentially contradictory goals. Such tradeoffs are an inevitable part of medical care. Changes occur throughout the patient’s life and illness. The oncologist plays a key role during all phases of the continuum. In all situations, use the nature and course of the illness, and the patient’s and family’s goals for care, to determine the relative emphasis on cure vs. palliation in the mix of therapeutics offered to the patient.

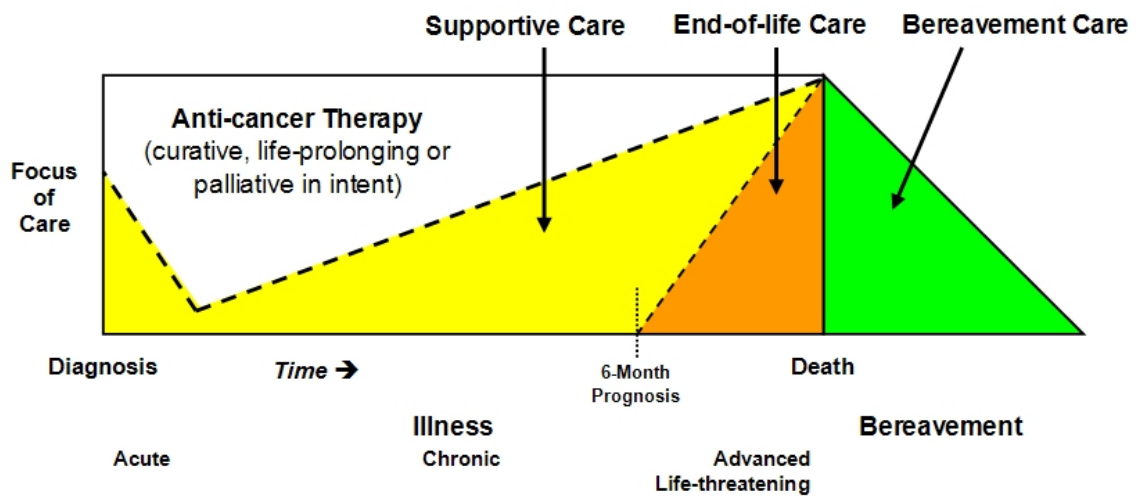
Table 1: Primary emphases of care for those with different goals related to life-threatening illness or injury

Aspect of care	Primary goal of care		
	Curative	Palliative/ life-prolonging	Palliative/ symptomatic
Impact on disease	Eradicate	Arrest progression	Avoid complications
Acceptable adverse effects	Major	Major-moderate	Minor-none
Psychological attitude	“Win”	“Fight”	“Accept”
Preference for CPR	Yes	Probably	Probably not
Hospice candidate	No	No	Probably
Symptom prevention/relief	Secondary	Balanced	Primary
Support for family	Yes	Yes	Yes
Advance care planning	Yes	Yes	Yes
Bereavement support	Not usually	Sometimes	Usually

Adapted with permission from Institute of Medicine: *Approaching Death: Improving Care at the End of Life*. Washington, DC: National Academy Press; 1997:83.

In contrast to the previous dichotomous model of care, Figure 2 below shows how the relief of suffering can integrate into the continuum of care desired and needed by the patient and family during an illness.

Figure 2: The interrelationship of therapies with curative and palliative intent



Initially, more focus may be on therapies intended to cure the illness or prolong life. Later, the relief of suffering may become increasingly important or even the total focus of care. But therapies with a palliative intent are not an alternative, to or an abrupt change from, the preceding care plan.

This ‘simultaneous’ care model has been tested in several comprehensive cancer centers.⁶ Many more cancer programs have developed palliative care services, frequently in collaboration with hospice agencies that have staff and expertise. Comprehensive cancer centers are being encouraged to develop this for certification.⁷ By doing so, the interdisciplinary care focused on symptom control and supportive care can be available to all patients with any cancer, at any time during their illness when they have symptom control or supportive care needs, and are prepared to accept such care.

Set goals to sustain hope

Setting goals, rather than listing problems, sustains hope. When a patient comes to an oncologist, there are many possible goals: cures, prolonged life, reduce suffering, to know what to expect, to be comfortable, to not be frightened, to improve quality of life, to prepare for the end of life. It is the oncologist’s job to find out explicitly what goals are hoped for, what goals are likely to be achieved and which goals are most important.

In order to set goals, name them and understand how you will know if they have been achieved. Another analogy illustrates this. If the goal is to drive to Oak Park, most like driving with adequate directions where exits on the highway are clearly marked with signs that 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 there is a poorly marked road where the only sign for a change in direction is at the time of the exit. Apply what the transportation engineers have learned to oncology.

Establish how information will be shared

At the beginning of the therapeutic relationship establish how information is going to be shared, and what the relationship between physician and patient is to be. Establish that truth-telling will be the norm, and who will receive the information, 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.

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, when talking to patients and families use the common language in Table 2 that follows. Reserve medical language for talking to colleagues.

Table 2: Common language

Medical language	Common language
Cure	The cancer is gone and will not come back.
Control	Slow or stop the growth for a time.
Complete response / remission	There is no evidence of cancer, but it could come back.
Partial response	The cancer is still there, but smaller.
Stable disease	The cancer is the same.
Progressive disease	The cancer is worse.

Prevent surprises

In order to minimize the risk of surprises, let patients and families know that you are going to talk about and plan for all possible eventualities, ie, the best, the worst, the

unexpected, even if they do not happen. To use the driving analogy, this is part of being oriented to the trip. Particularly if you are unfamiliar with the territory, or do not like to travel, it helps if you have a guide that is going to give you accurate information. It is reassuring to know what is likely to be encountered, or what is unlikely but important, when undertaking a trip.

It is also helpful if the patient wants someone else to ‘do the driving.’ There are some patients who want their families or friends to make all the decisions. This is ethical and legal, but deserves exploration. Establish who will make what kinds of decisions. Decide when the patient’s opinion will be sought.

Tell the patient and family who the members of their cancer care team are, and the roles they will play. Many patients are involved with a host of physicians and other health care professionals. Clarify who will making the decisions—the primary care physician? The medical oncologist? The radiation oncologist? The surgeon? Decide who will talk to whom and when.

Prepare for decision-points in advance

Talk about how and when decisions are made. Tell patients and families about the strategies you use to decide what therapy could be beneficial, ie, by considering the potentials for benefit and the risk of harm and burden. Indicate that you will say when you think that a particular treatment is not achieving your mutual goals. Let patients know that when you think an approach will not 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 upon plan. Ensure they understand that you will always provide them with the information you have, then discuss their goals of care and treatment priorities in order to come to a new mutually agreed upon plan of care.

7-step protocol to negotiate goals of care and treatment priorities

For many physicians, negotiating goals of care and treatment priorities with patients and families who are facing the end of the patient’s life can be difficult, particularly when there is a conflict between aspirations and what is medically likely or possible. To have a greater chance of achieving a successful outcome, use the following modification of the 6-step protocol, SPIKES, for communicating bad news (see EPEC-O Module 7: Communicating Effectively).^{8,9}

Step 1: Create the right setting

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

SPIKES+

7-step protocol to negotiate goals of care and treatment priorities

Setting. Getting started.

1. Create the right setting.

Perception. What does the patient know?

2. Determine what the patient/family know.

Invitation. How much does the patient want to know?

3. Explore what they are expecting or hoping for.

Knowledge. Sharing the information.

4. Suggest realistic goals.

Emotion. Responding to the patient and family feelings.

5. Respond empathically.

Subsequent. Planning and follow-up.

6. Make a plan and follow through.

+ Review. Reassess and revise periodically

7. Review and revise periodically.

Step 2: Determine what the patient/family know

Start with an open-ended question like:

- 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 are to 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 (see EPEC-O Module 8: Clarifying Diagnosis and Prognosis).

Step 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.” Explore expectations and hopes related to the cancer, symptoms or issues causing suffering, and their goals for work, life, family, pleasure, and end-of-life care.

Focus on what you will do to achieve those expectations and hopes. As appropriate, identify those things that you cannot do, either 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 expect to be cured with another kind of chemotherapy, you can remind them that you said you’d be truthful. Tell them that you do not know of any chemotherapy or radiation therapy that will achieve that goal.

Step 4: Suggest realistic goals

Oncologists often have a wealth of scientific knowledge about the patient’s illness, its expected natural course, the potential for therapies to benefit, harm or burden the patient and family, the experience of patients in similar circumstances, and the effects that contemporary health care may have. It is our role to share this to assist with decision-making. After sharing this information, based on your knowledge of the patient’s and family’s understanding and expectations, you can suggest realistic goals, eg, curing the cancer with more intensive combination therapy, shrinking the tumor with as few adverse 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. Problem-solve about overcoming barriers to achieve the identified goals and work through unreasonable or unrealistic expectations.

One of the most prevalent, but often implied, goals is of wanting to be a fighter. Many value being a fighter, even in the face of overwhelming odds. Whether it is a feature of human nature, or gender, 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—the valiant pursuit of an ideal. Yet, most can agree that pursuit of an illusion can be counter-productive if it leads to poor decisions.

The fighter

For many patients, it is an important goal to be a fighter, to know that ‘everything possible’ has been tried, even if the odds are slim.

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. If this is the patient’s goal, make it explicit. An open-ended thorough discussion will lay the ground work for deciding when enough fighting has

been done, or when there is too much casualty, and help to avoid the feeling of being a ‘quitter.’

Because of our better knowledge of likely outcomes, oncologists and the cancer care team can help patients and families 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 us who are fighting windmills. It is a sad situation when a patient pursues therapy in order not to disappoint the oncologist, and misses the opportunities to realize her/his full potential, give gifts, and say goodbye before s/he dies.

Step 5: Respond empathically

When information is shared in this way, various emotions can be expected, eg, anger, sadness, and fear. The most important clinical pearl is to listen quietly while the patient expresses emotion. The following facilitating comments can help the patient feel supported:

- I can see that this makes you sad.
- You really seem angry about this.

Responding to emotion is often the hardest part of a clinical interview for oncologists. Lack of preparation and skill leads to a prevalent fear that patient and family emotion will be overwhelming and uncontrollable. To avoid this, conversations are structured, if they occur at all, in such a way as to ensure that no emotion other than quiet assent is expressed.

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

Step 6: Make a plan and follow through.

Whenever possible make 3 plans. Plan for: 1) the best, 2) the worst, and 3) the unexpected.

Clarify what the overall goals of care are and the treatment priorities will be if everything goes as hoped for. Also create an alternate plan if things do not go well or the unexpected happens suddenly. Plan 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. Write down the key facts and goals and the outcomes to measure (See Appendix for Example).¹⁰ Examples are:

- Our goal is to put the lymphoma into remission. We’ll give the chemotherapy twice and check the CAT scan. If it is smaller we’ll give the chemotherapy again for 4 more

times and then repeat the scan. If it is 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 CAT scan. If the cancer is better, we'll continue. If the cancer is worse, it means the chemotherapy is not working. We'll stop the chemotherapy and reassess our goals.
- Our goals are to get your pain controlled, 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. Their involvement is the best way I know to help us achieve the goals we've set.

Step 7: Review and revise periodically

People do better when they anticipate change rather than if they are surprised. 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 oncologists, too. For example, if the goals for this patient with metastatic cervical cancer are to make her feel stronger, make the pain get better, and make the mass in her liver 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 and have the patient reflect on how s/he is doing than to say, "The cancer is worse," to an unprepared patient.

Language with unintended consequences

In any physician-patient communication, well intentioned oncologists may say things that will have unintended consequences. What the listeners understand may be quite different from what the oncologists intended. Some examples that may be significantly misinterpreted by patients include:

- Do you want us to do everything possible?
- Do you want us to be aggressive or not?
- Will you agree to discontinue care?
- We'll refrain from extraordinary measures.
- It is time we talk about pulling back.
- I think we should stop active therapy.

From each of these statements, the patient and family may interpret the unintended message that they are about to be abandoned. As a result, they may see only a stark choice between care and no care.

Language to describe the goals of care

In order to prevent unintended consequences, it is useful to develop facility with language that reinforces the goals of appropriate medical care for someone with advanced cancer. Some examples include:

- I want to give the best care possible.
- We will concentrate on improving the quality of your life.
- We want to help you live meaningfully in the time that you have.
- I'll do everything I can to help you maintain your independence.
- I want to ensure that your father receives the kind of treatment he wants.
- Your child's comfort and dignity will be my top priority.
- I will focus my efforts on treating your child's symptoms.
- Let's discuss what we can do to fulfill your wish to stay at home.
- Let's discuss what we can do to have your child die at home.

Cultural differences

Cultural differences may require the physician to modify his or her approach to determining goals for care. Some cultures prefer that medical information be given to the family and not the patient. Families may insist on this. Among other cultures, eg, some Navajos, it is not good to raise a negative prospect at all. Moving the conversation to the third person may circumvent this: "If you were hearing a story about someone who was facing an illness that could not be cured, how would you want that story to describe the best way to help?"

As cultural generalizations often do not apply to given individuals, it may be a useful approach to ask the patient early on in the relationship how he or she would like information to be handled, and who should be making decisions. It may be useful for this conversation to take place in the context of a family meeting so that all can hear the patient's disposition (see EPEC-O Module 8: Clarifying Diagnosis and Prognosis).

When the physician cannot support a patient's choices

Occasionally, the oncologist will be confronted with a situation where the patient, proxy, or parent has goals and treatment priorities that the physician cannot support. Typically, this occurs when goals are unreasonable or illegal. The challenge for the physician is to

set limits on what he or she will do, without implying abandonment or destroying the relationship of trust and loyalty that has developed.

If this situation occurs, it is generally more useful to make the conflict explicit and then offer to help find a solution. For example:

- I understand that your first priority is to live as long as possible by having a bone marrow transplant. Unfortunately, I'm not able to do that because a bone marrow transplant will not help kidney cancer. Is there an alternative way that I can help you achieve your goal of living as long as possible?
- I understand your goal is not to be a burden to your family and you would like me to assist you to die. Unfortunately, I cannot do that. Is there an alternative way that I can help you so that you will not feel like a burden?

More intractable differences are addressed elsewhere (see EPEC-O Module 13: Advance Care Planning; EPEC-O Module 14: Physician-Assisted Suicide; and EPEC-O Module 12: Conflict Resolution).

Decision-making capacity

Occasionally, choices that are insupportable suggest that the patient is losing decision-making capacity. Reassess your patient if this seems possible.

Decision-making capacity implies the ability to understand and make medical decisions for oneself. It can usually be determined by any physician. It does not require a psychiatrist or a court ruling. For a patient to have decision-making capacity, he or she must be able to:^{11,12}

- Understand the information.
- Use it in rational ways to come to a decision.
- Appreciate the consequences of the decision.
- Have that be a reasonable decision for him or her.

For example, consider a woman who refuses an amputation of a leg for treatment of osteosarcoma. She needs to demonstrate that she understands the information about the condition and the options for care, that she could die if it is not amputated, and that this is a rational decision for her. The patient can meet criteria for decision-making capacity for a particular treatment, ie, decision-specific capacity, and yet not be competent to handle her practical, financial, and legal affairs. Further, decision-making capacity may vary depending on the treatment decision (see EPEC-O Module 1: Comprehensive Assessment).

When a patient lacks capacity

When patients lack the capacity to express their own values and preferences for medical care, goals must be determined by others. For patients who lack decision-making capacity, find a proxy decision maker to help clarify the patient's goals and consent to specific care plans.

Generally, the appropriate proxy is a person selected in advance for this role by the patient (see EPEC-O Module 13: Advance Care Planning), or a person who has knowledge of the patient's values and preferences and is willing and able to serve in this capacity. When the patient has not preselected a proxy decision-maker, this usually falls to the next of kin. Legal criteria for proxy selection vary from state to state.

Guide the proxy/decision-maker to understand his or her role in determining what the patient would have wanted based on available information. Where information is lacking, it becomes necessary to try to determine what would be in the best interest of the patient. This is often, but not always, the same conclusion and often errs more toward life prolongation.

To the extent that they are known, use the patient's values and preferences to determine the goals of care. Written advance directives, the patient's verbal statements, his or her general values and beliefs, and how the patient lived his or her life can all be useful. Together they allow an assessment of what the patient would have judged, ie, a substituted judgment. Fundamentally, the process demonstrates respect for the patient, and builds trust that the physician and the health care team are acting in the interests of the patient. Further, by focusing on the wishes of the patient, there is reduced guilt or decision regret for the proxy, family members, physician, and health care team.

Here are some practical ways to elicit patient values and preferences in discussions with proxy decision makers:

- Help me to understand what your husband was like before he got sick. What was most important to him?
- Has he ever said anything about how he would want to be treated if he could no longer make decisions for himself?
- What would he say in this situation?
- Do you have any other family members or friends who have experienced serious illness? Did he or she express how he or she would want to be treated in that situation?
- Based on everything you know about him, what do you think he would have wanted in this situation?

Many of the approaches that work for an advance care planning discussion also work for establishing immediate goals of care, whether working with the patient or a proxy. In

particular, it can help to go through a worksheet again, using predrafted scenarios, goals, and treatment options, prior to returning to the situation at hand. Often clarity and perspective return with this exercise for getting a broad perspective and allow a comfortable settling into current goals.

Summary

It is important to determine the goals of care with patients and families from as early a stage as possible in the course of cancer care. The patient, with the help of the family, determines the goals with guidance from the physician and the health care team. Hospice and palliative care goals can be integrated with other goals, which may appropriately change over time. A 7-step approach to negotiating goals has been offered, along with suggestions for identifying reasonable hope, for adjusting care to the patient's culture, for setting limits when goals are unreasonable, for helpful language that avoids unintended communication of abandonment, and for handling goal choices when the patient is no longer competent to decide.

Key take-home points

1. Setting goals sustains hope.
2. Goals are based on diagnosis, prognosis, the potential benefits, burdens, and risks association with various therapies, and personal priorities.
3. Over time, goals for care and treatment priorities will change.

Potential goals of care

1. There are 2 overall aims of medical care: to cure disease and to relieve suffering. More personal and specific goals also exist within these overall aims.
2. Many physicians have been trained to focus on diagnosis and treatment of the patient's disease by using a medical problem-oriented method. They have not been trained to pay attention to relief of symptoms and other issues that heighten patient suffering as an explicit goal of medical care.

The interrelationship among goals of care

1. Many patients, families, and professionals are not prepared to give up therapies aimed at cure and/or life prolongation, and totally focus on relief of suffering.
3. Early access to symptom management and supportive care may help patients and families feel better, continue more of their normal lifestyle, and maintain more capacity to fight their illness and sustain treatment.
4. Multiple goals may apply simultaneously.
5. Goals may appear to be contradictory.
6. Some goals take priority over others.

7. Goals may change near the end of life.

7-step protocol to negotiate goals of care

1. Create the right setting.
2. Find out what the patient/family knows.
3. Find out how much they want to know.
4. Explore what they are expecting or hoping for.
5. Suggest realistic goals.
6. Respond empathically.
7. Make a plan.

Identify goals to hope for

1. When surveyed, most Americans (>80%) said they would rather know the truth about their illness.

Cultural differences

1. Some cultures prefer that medical information, particularly that of a life-threatening prognosis, be given to the family and not the patient.

Clarify goals and treatment priorities

1. In addition to helping patients and families establish overall goals for care, assist them to clarify priorities for treatments and care.
2. Review goals when patients have a significant change in their health status, have limited life expectancy, change their setting of care, or change their treatment preferences.
3. If the physician cannot support the patient's choices, it is generally more useful to make the conflict explicit and then offer to help find an alternate solution.

When a patient lacks capacity

1. When a patient lacks the capacity to express his or her own values and preferences for medical care, goals must be determined by a proxy decision-maker based on either the patient's previously expressed preferences, or what would be in the best interest of the patient if expressed preferences are lacking.

Pearls

1. No one goal is inherently more valid than another.
2. Set goals *before* determining treatment plan.

3. Ask early in the relationship how the patient would like to handle information sharing.
4. Always expect hopefulness—the object of hope changes with time.

Pitfalls

1. Failure to discuss expectations.
2. Giving unwanted interventions. Most of us will become angry and lose trust if things are done to us that we do not want.
3. Thinking that the ‘problem-oriented’ approach is the same as setting goals.
4. Failure to refer to hospice or palliative care programs. The majority of Americans (80%) are never referred to hospice or palliative care programs.
5. Language with unintended consequences.
6. Offering a false sense of hope. The collusion of a lie may only push patients and families apart.
7. Excessively optimistic estimates of prognosis.

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- ¹ Weed LL. What physicians worry about: how to organize care of multiple-problem patients. *Mod Hosp.* 1968 Jun;110(6):90-4. [PMID: 5705976](#).

This commentary from a medical educator tells how doctors must change teaching and record systems to make practice more precise and effective.

- ² Adams F. *The Genuine Works of Hippocrates Translated from the Greek*. William New York, NY: Wood & Co.; 1986:195.

- ³ Simonton OC, Simonton C, Matthews S, Creighton JL. *Getting Well Again*. New York, NY: Bantam;1992.

This book shows people with serious illnesses how they can participate in getting well again. It suggests how those who are not ill can participate in maintaining their health. The ideas and techniques described in this book are the approach employed at the Cancer Counseling and Research Center to show cancer patients how they can participate in getting well again and live a rewarding and fulfilling life.

- ⁴ Baile WF, Beale EA. Giving bad news to cancer patients: matching process and content. *J Clin Oncol.* 2003 May 1;21(9 Suppl):49-51. [PMID: 12743192](#). [Full text](#)

- ⁵ Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. *BMJ.* 2000 Feb 19;320(7233):469-72. [PMID: 10678857](#). [Full Text](#)

To describe doctors' prognostic accuracy in terminally ill patients and to evaluate the determinants of that accuracy. 343 doctors provided survival estimates for 468 terminally ill patients at the time of hospice referral. Doctors overestimated survival by a factor of 5.3. Few patient or doctor characteristics were associated with prognostic accuracy. Doctors in the upper quartile of practice experience were the most

accurate. As duration of doctor-patient relationship increased and time since last contact decreased, prognostic accuracy decreased.

⁶ Meyers FJ, Linder J. Simultaneous care: disease treatment and palliative care throughout illness. *J Clin Oncol*. 2003 Apr 1;21(7):1412-5. [PMID: 12663735](#). [Full Text](#)

⁷ Commission on Cancer Standards for Accreditation, <http://www.facs.org/cancer/>. Accessed March 11, 2005.

⁸ Garg A, Buckman R, Kason Y. Teaching medical students how to break bad news. *CMAJ*. 1997 Apr 15;156(8):1159-64. [PMID: 9141988](#). [Full Text](#)

This article describes a program for teaching medical students how to break bad news. An evaluation of the program by the participants over a 5 year period is presented.

⁹ Baile WF, Buckman R, Lenzi R, Glober G, Beale EA, Kudelka AP. SPIKES—A six-step protocol for delivering bad news: application to the patient with cancer. *Oncologist*. 2000;5(4):302-11. [PMID: 10964998](#). [Full Text](#).

A protocol for disclosing unfavorable information-"breaking bad news"-to cancer patients about their illness is described.

¹⁰ American Society of Clinical Oncologists. Optimizing cancer care – the importance of symptom management, vol. II. Making written plans, ASCO Curriculum, 2001 Kendall/Hunt, Dubuque: IA

¹¹ Huffman JC, Stern TA. Capacity Decisions in the General Hospital: When Can You Refuse to Follow a Person's Wishes? *Prim Care Companion J Clin Psychiatry*. 2003 Aug;5(4):177-181. [PMID: 15213780](#). [Full Text PDF](#)

¹² Appelbaum PS, Grisso T. Assessing patients' capacities to consent to treatment. *N Engl J Med*. 1988 Dec 22;319(25):1635-8. [PMID: 3200278](#). [Abstract](#).

The right of patients to accept or refuse recommended treatment requires careful reassessment when their decision-making capacities are called into question. Patients must be informed appropriately about treatment decisions and be given an opportunity to demonstrate their highest level of mental functioning. The legal standards for competence include the four related skills of communicating a choice, understanding relevant information, appreciating the current situation and its consequences, and manipulating information rationally. Since competence is a legal concept and can be formally determined only in court, the clinical examiner's proper role is to gather relevant information and decide whether an adjudication of incompetence is required. Treatment for impairment of mental functioning can sometimes restore patients' capacities, making it unnecessary to deprive them of their decision-making powers.