

The Role of Palliative Care in Cancer Care Transitions

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INTRODUCTION

Transitions are difficult for everyone. In the course of cancer care, many transitions occur for patients, families, and the care teams. The "transition" to palliative care is perceived to be one of the more difficult, but it need not be. Psycho-oncologists are well positioned to support patient, family, and oncologist while they navigate changes in goals of care throughout an illness course.

Palliative care is an approach to the relief of suffering. It grew out of, and includes, hospice care for the terminally ill. It is now clear that it applies to the entire course of illness—from diagnosis to death.¹ As in the situation for Phase I studies of new cancer agents studied first in the terminally ill, palliative care was first demonstrated effective for those near the end of life. However, just as with new anticancer agents, it may be even more effective when it is used earlier in the course of an illness.

Suffering from cancer is substantial. Suffering can have physical, psychological, social, and spiritual components.² Of the more than one-third of Americans who will be diagnosed with some type of malignancy during their lifetime, all will suffer in some respects,¹ often beginning with the diagnosis. Attention to the suffering caused by cancer and its treatment is fairly recent, despite the myriad reports describing its manifestations and significance.³⁻⁷ Of all patients with cancer, only 50% will be cured, meaning the cancer is gone and will never come back. Even those that find cure will often continue to suffer in some respect. Despite the many advances in cancer care, the proportion cured has not increased over the past 40 years.⁸⁻¹⁰ Over the same period, there has been an increased interest in the field of psycho-oncology. Recently, there have been calls for the seamless integration of palliative care with anticancer care that mirror the calls for integration of psycho-oncology.¹¹

It is the purpose of this chapter to describe a model of palliative care that can be woven into oncologic care from diagnosis. When palliative care is seen as extending throughout the course of illness and overall goals of care determine the treatment plan, then transitions can be straightforward and transparent. First, palliative care will be defined. Then, several conceptual frameworks for its role in the comprehensive care of patients with cancer will be presented. Finally, an approach to structuring the conversation for setting goals of care and making transitions when goals of care change will be described. All of these issues are well within the realm of the oncologist and psycho-oncologist in support of the entire cancer care team.

PALLIATIVE CARE

Since the time of Hippocrates there have been two overall goals of medical care: relief of suffering and cure of disease.¹² These goals are shared by the patient as well as healthcare providers. The relative emphasis on cure versus relief of suffering is best determined by, both, the underlying illness and the overall goals of the person who has the illness, within the context of his or her family and culture.

The term "palliate" originated with the Latin term *pallium* which means "cloak" or "cover."¹³ While at one time the term palliative care was used as a pejorative for "covering up" the real problem; it is now a superlative; "covering up" the suffering and letting the patient experience the best quality of life possible. The field of palliative care encompasses a wide range of therapeutic interventions that aim to prevent and relieve suffering caused by the multiple issues that patients, families, and

caregivers face at any stage during an acute or chronic life-threatening illness. In providing whole-person care to relieve suffering, palliative care attends to all domains of the human experience of illness that may be involved: physical, psychological, social, and spiritual.¹⁴ Quality of life rather than quantity of life is most often the chief aim of those engaged in the delivery of palliative care. Since suffering is experienced by persons, its existence, character, and criteria for relief are best defined by the patient rather than by the physician.¹²⁻¹⁴ As persons do not exist in isolation, the relief of suffering requires attention to the care of patients within their framework of beliefs, culture, and loved ones. Suffering is caused by many factors that are rarely limited to the physical domain. As such, tending to the relief of suffering in these domains cannot possibly be accomplished by a single medical discipline—a team approach is required.

Palliative care can be delivered at primary (generalist), secondary (specialist), or tertiary (academic) levels.¹⁵ At the primary level, all physicians, nurses, and other health professionals need basic skills in relieving suffering. In this sense, the palliative care skills one would expect of every medical, radiation, surgical, or pediatric oncologist qualify as primary palliative care. One might expect oncology professionals to even have exemplary skills in this area. Secondary levels refer to specialist physicians and services. Palliative Medicine is the term coined to denote the physician subspecialty concerned with the relief of suffering within the larger interdisciplinary model of palliative care.

Palliative medicine is now a recognized specialty. The Royal College of Physicians in Great Britain recognized palliative medicine as a physician specialty in 1987.¹⁶ This recognition came only after it had been demonstrated that there was an established body of medical knowledge that uniquely pertained to a distinct patient population. Later, the Royal College of Physicians and Surgeons in Australia recognized the specialty. The Royal College of Physicians and Surgeons and the College of Family Physicians of Canada established 1-year postgraduate training programs in the field in 1999. Similar recognition as a subspecialty followed in the United States in 2006.¹⁷

CONCEPTUAL FRAMEWORK

The mental model of the cancer professional treating patients with cancer is of critical importance. Treating cancer is not equivalent to treating a person with cancer. Failure to recognize this has led, in some circumstances, to cause increased suffering while administering anticancer treatment. An exclusively "cure-oriented" approach to cancer can be conceptualized in the following diagram where the time course and goals of such treatment are illustrated (Fig. 37-1).

A patient is first evaluated for some constellation of symptoms for which a diagnosis of cancer is made. Evaluation and treatment is directed toward the eradication, reversal, or substantial control of the disease. Symptoms help elucidate the diagnosis and course of treatment. This model of treatment can be characterized as disease-oriented and pathophysiologically based. Clinicians are engaged in a "war on cancer" and the patient dies in spite of "doing everything" and maintaining a "fighting spirit" to the end. The death is often viewed as a "casualty" in the war on the cancer.

Unfortunately this model leaves many patients and the doctors feeling as if they have failed if the cancer "wins" and the patient dies. Following the logic of this model may actually cause suffering. Working within this

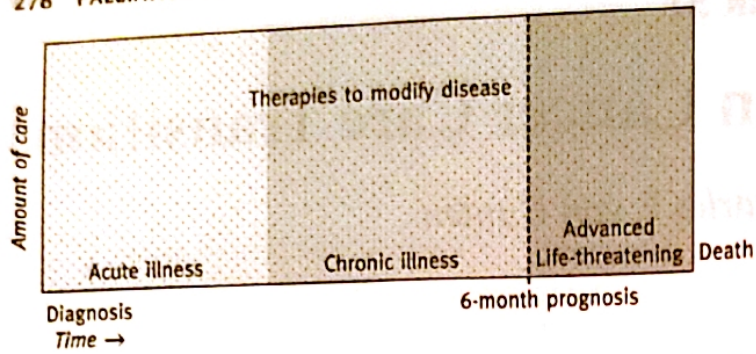


Fig. 37-1. Model of cancer care where only therapies directed at the disease are considered as part of standard care.

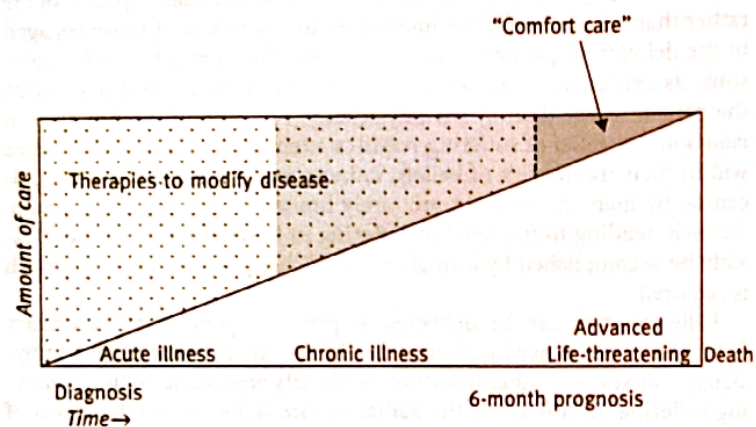


Fig. 37-2. Model of cancer care where anti-disease therapy diminishes over time as it becomes less and less effective.

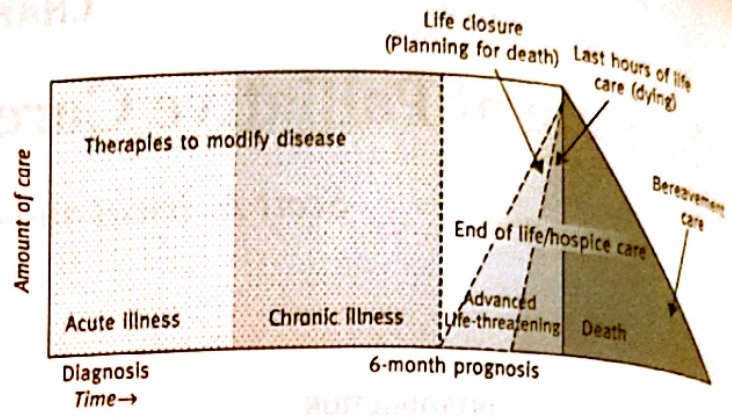


Fig. 37-3. Model of cancer care where palliative care begins after efforts directed at the cancer end.

framework, well-meaning clinicians may administer anticancer or other therapies of which there is no evidence of benefit as a way to demonstrate their character as "fighters" and demonstrating rejection of the possibility that they are "quitters" often with substantial adverse effects.

For oncologists who try to modify the approach diagrammed in Fig. 37-1 to include only medical care for which there is evidence of efficacy for the stage of disease and the likely outcomes of treatment, the patient and family may perceive the care to be more like that shown in Fig. 37-2.¹⁸ In recognition of the situation when the disease is progressive and treatment modalities are no longer effective, "comfort care" measures may be instituted. This last period, if it occurs at all, is often of short duration (sometimes hours to days) and may consist only of analgesics, sedatives, and a private room. Quite often, this model does not include explicit consideration of nonphysical aspects of a person's illness experience or that of the person's family. Further, once "comfort care" has been recommended, there can be a perception that the oncologists are no longer engaged in the care of the patient. That is to say, the patient and family often feel that the oncologist shows diminished attention to the patient over time. Unfortunately, in many instances, this is true, as the oncologist struggles with feelings of failure and discomfort with the death and dying.¹⁹

This can lead to a major cause for patient and family dissatisfaction with the healthcare system—a feeling of abandonment. Although the severity of illness may be increasing, within this framework the attention of the oncologist and other healthcare providers often diminishes when the evidence shows there is "nothing more to do" for the disease.

In addition, the implication of abandonment may lead to strident demands from patients and families to "do more, do everything." In the absence of a better treatment framework that addresses these issues, the oncologist may give in to patient demands and revert to the model in Fig. 37-1, offering treatment that is of no medical benefit in the service of patient autonomy. Such treatment results in increased suffering for the patient and family independent of adverse events, as important issues that surround death and dying are ignored.

In appreciation that the models of care diagrammed in Figs. 37-1 and 37-2 do not adequately address issues of patient suffering, Dr. Cicely Saunders in England introduced the hospice model of palliative care.²⁰ Working primarily with cancer patients, she recognized that suffering might be produced not only from the cancer, but also by medical efforts to control the disease. She also recognized that the physical, psychological, social, and spiritual aspects of suffering were inadequately addressed. Dr. Saunders founded St. Christopher's Hospice in 1967 to pilot a new model of inpatient care for patients for whom curative therapy was not available or was no longer desired. It is useful to note that she tried to advance these ideas in standard hospitals and hospices at the time. However, because she was unable to influence contemporary patterns of care for these patients, she developed her own facility where she could test her ideas. She demonstrated that an interdisciplinary team approach to the care of the patient and family that continues into a bereavement period after the patient's death is effective for the relief of suffering. The hospice concept has been widely adopted because of its demonstrated benefits for patients and families.

Sadly, this model leaves a sharp demarcation between disease-oriented therapy and hospice care. Fig. 37-3 shows the most common position of hospice care in the overall scheme of cancer patient care introduced in Fig. 37-1. This model suggests that the goal of medical care is first cure of cancer, then relieve suffering. Although hospice care aims to address aspects of patient suffering not usually addressed during "standard medical treatment," the period of hospice care espoused in Fig. 37-3 is often short and comes at the end of a long care process. The median length of hospice care for 1.3 million patients in the United States in 2006 was 20.6 days with about one-third of patients receiving hospice care for 7 days or less.²⁰ Only approximately one-third of eligible patients received hospice care in the United States that year. With this model there is a sharp discontinuity between the previous cancer care and hospice care, which can leave patients feeling abandoned by their oncologists. Another problem with this model is it suggests a dichotomy between curative/life-prolonging care and palliative care. Yet good sense dictates that the two goals are not mutually exclusive and can be pursued simultaneously. Integrating curative or life-prolonging treatments with the relief of suffering should be the goal. Palliative treatments are not adjuncts or complementary to "conventional" cancer care, but are an essential part of good cancer care. In fact, when oncologists integrate palliative care in their practice, the role of the palliative care specialist is only to help with the difficult cases. When considered carefully, no care provider would suggest waiting to introduce measures for alleviating suffering and improving quality of life until either all attempts at cure have been exhausted or the patient and family plead for such efforts to stop.

Many palliative care approaches to illness can and should precede the point at which referral to a hospice program is appropriate. For example, aggressive control of pain and other bothersome symptoms, setting goals of care, and addressing the psychosocial effects of a cancer diagnosis should co-dominate the very beginning of contemporary cancer care.^{1,21-24} Where the oncologist feels uncertain with addressing these symptoms, a palliative care specialist can be helpful as a consultant or in a co-management role. Palliative care specialists can be especially helpful when it comes to setting goals of care, both for curative

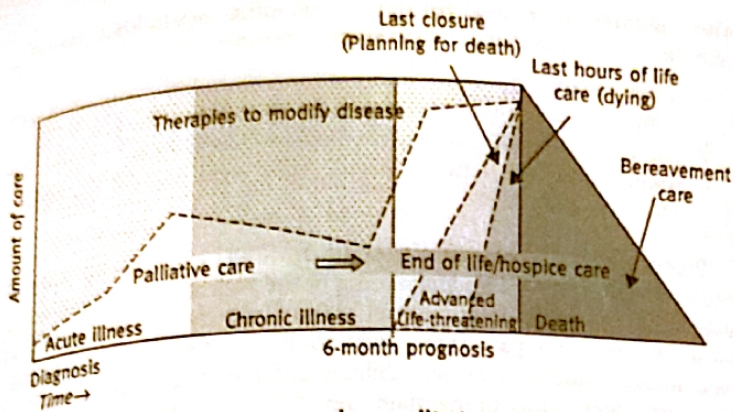


Fig. 37-4. Model of cancer care where palliative care begins at diagnosis and is integrated throughout the course of cancer care.

treatment and symptom relief, though the whole illness experience. A psycho-oncologist can facilitate these discussions as well. In addition to their disease status, a patient's goals and priorities should determine which treatment approaches will be most valuable to them. A treatment plan that is directed by those goals should be provided and adhered to by the care team.²⁵ These goals and treatment plans will usually evolve as the illness changes and should be reevaluated often. This care scheme is shown in Fig. 37-4.

In this model, palliative care is given simultaneously with curative care, and hospice care represents the completion of comprehensive cancer care, not an alternative to, or an abrupt change from, the preceding care plan.²⁶ Thus abrupt transitions are avoided and the best of all types of care are provided throughout the illness.

NEGOTIATING TRANSITIONS AND GOALS OF CARE

Clearly, negotiating goals of care throughout an illness process is the important clinical skill rather than conceptualizing care as abrupt transitions. In other words, an abrupt transition from curative care to palliative care suggests earlier communication and conceptualizing were omitted or were incomplete.

Along the trajectory of cancer care, several trigger situations invite the patient and healthcare provider to reflect upon and discuss goals of care. These include general advance care planning^{27,28} (1) at the time of diagnosis, (2) at first and subsequent episodes of progression or relapse, and (3) when initiation of hospice care is recommended.

Evidence shows that patients are open to such discussions. Studies done in North America and Europe show that between 85% and 95% of patients want to have honest discussions with their healthcare providers regarding life-threatening diseases.^{29,30} Evidence also suggests that oncologists struggle with and often avoid such discussions.^{31,32} Some studies suggest that oncologists generally fail to adequately address their patients' emotional concerns and often are deficient in the skills necessary to handle the emotional component of discourse with patients. Fortunately, research shows oncologists and others can learn these skills.³³⁻³⁶

A six-step approach to structuring such conversations can be used for any situation during the disease trajectory such as advance care planning, discussing treatment options, or when introducing hospice care. This protocol has been adapted from a widely used communication model for the delivery of bad news.^{35,36} Specific examples for the discussion of resuscitation orders or when introducing hospice care have been described elsewhere.^{37,38}

The protocol uses the general principle of shared decision making. Shared decision making as a process puts great emphasis on patient autonomy while acknowledging the physician's responsibility to make treatment recommendations that are based both on the patient's stated overall goals of care as well as the physician's medical expertise and evidence-based medicine. Psycho-oncologists and palliative medicine specialists are well poised to facilitate such conversations.

This approach for determining goals of care discussions reflects common communication patterns in North America. Studies of healthcare decision making in other parts of the world show that different cultures

prioritize these values differently. The most common variation is to place less emphasis on autonomy in favor of family-centered decision making (examples of beneficence and nonmaleficence). For example, more than 90% of U.S. oncologists share a new diagnosis of cancer with their patients.³⁹ In contrast, only 44% of hospital-based and 25% of outpatient oncologists in Great Britain have been shown to do so.^{40,41} A study of European physicians showed that, in northern and western parts of Europe, they generally feel that a new cancer diagnosis should be shared with patients whereas their colleagues in southern and eastern parts of Europe considered withholding information regarding the diagnosis of a life-threatening condition as part of their duty to protect their patients, even if patients expressed a wish to be informed. A study from China indicates that patients there are only rarely informed of a new diagnosis of cancer.⁴² In African countries such as Nigeria, Egypt, or South Africa, the type and amount of information shared seems to depend on patient factors such as level of education or socioeconomic status. Only 18% of South American oncologists think their patients would want to know a diagnosis of cancer.⁴³⁻⁴⁵

Asking patients and families what they want to know before giving information can be helpful in guiding further discussion while staying within cultural norms and the wishes of the patient.⁴⁶⁻⁴⁸ In some cases, patients quite happily prefer their families to hear the news and to make decisions for them. Even in North America, there is nothing to prevent a patient from giving his or her autonomy to others.

USING GOALS OF CARE TO NEGOTIATE TRANSITIONS

Eliciting patient preferences is at the center of goals-of-care discussions. Empathic listening, a highly underestimated skill in medical practice, is required to negotiate goals of care. Therefore, it is imperative to start the conversation with an open-ended question followed by active listening. This allows the patient to focus on his or her major concerns and sets the stage for patient-centered care. Active or empathic listening then includes nonverbal communication skills that show full attention such as good eye contact and leaning toward the patient as well as verbal empathic listening techniques such as reflection, paraphrasing, and validation.⁴⁹

Psychooncologists and palliative medicine specialists can be of great help in these discussions, as there exists evidence that oncologists struggle with these discussions. For example, it has been shown that oncologists, on average, interrupt their patients only 20 seconds after they begin to speak. It has also been shown that oncologists often miss empathic opportunities⁵⁰ and tend to use close-ended questions in an attempt to retrieve information as fast as possible. This risks that patients never get to address their major concerns. Unfortunately, under these circumstances, the majority of patients leave the office without ever having their concerns addressed or with a feeling that they have been "heard."⁵¹

It is helpful to give medical information in short phrases using words that the patient can understand, with frequent pauses to check for patient response and understanding. The higher the emotional impact of the given information, the less likely the patient is to hear what is being said. It might therefore be necessary to repeat the information at a later time and more than once. Not only can psycho-oncologists and palliative medicine specialists facilitate these discussions, they might also be able to reflect back to their oncologist colleagues these facts in the service of educating and improving oncologist skill and sense of competence in having these discussions.⁵²⁻⁵⁵

6 STEPS TO SETTING GOALS

A step-wise approach to goals-of-care discussions helps to remind the clinician to include all major components of the discussion. This is particularly true for those who are inexperienced or early in their training where this skill has generally not yet been learned.⁴⁸ The six steps include (1) preparing and establishing an appropriate setting for the discussion, (2) asking the patient and family what they understand about the patient's health situation, (3) finding out what they expect will happen in the future and what they want to know, (4) discussing overall goals and treatment options, (5) responding to emotions, and (6) establishing and implementing a plan.⁵⁶

Prepare and establish an appropriate setting for the discussion. Preparation for a goal-setting conversation by knowledge of the clinical facts of the case and the evidence-based outcomes regarding stage specific prognosis, chemotherapy, radiation, surgery, and cardiopulmonary resuscitation is a must. In general, patients are more interested in concrete descriptions of abilities ("Life is not worth living if I won't be able to speak.") than in the details of interventions ("That means that we would have to put a tube down your throat that is about as thick as your finger."), where often functional consequences are omitted.

Reflection upon the expected emotional responses and possible identity issues that might arise for the patient or the physician before entering the discussion is helpful. The phrase, "I'm a fighter" or "I always fight for my patients" are expressions of patient identity, not expressions of desire for a specific plan of cancer care.

The meeting should occur in a private and comfortable place when those who need to be present can be present. The atmosphere should be unhurried and undisturbed, with the clinician sitting at eye level. After general introductions, the purpose of the meeting should be made clear. Examples of introductory phrases are

- I'd like to talk to you about your overall goals of cancer care.
- I'd like to review where we are with your cancer and make plans for the future.
- I'd like to discuss aspects of your cancer care today that I discuss with all my patients.

Before continuing, asking if anyone else should be present for this discussion can avoid serious pitfalls. If others need to be present, the meeting can be postponed accordingly.

Ask the patient and family what they understand. Starting with an open-ended question to elicit what the patient understands about his or her current health situation is the best approach. This is an important question, and one that many clinicians skip as their nervousness drives them to speak first. If the physician is doing all the talking, the rest of the conversation is unlikely to go well. Example phrases are

- What do you understand about the cancer?
- Tell me about how you see things are going.
- What do you understand from what I and the other doctors have told you about your cancer?

Open-ended questions have been shown to establish trust and set the tone for patient-centered decision making. Structured this way, the answers help the care team assess and address misconceptions or conflicting or missing information. They also allow a quick glimpse into the patient's emotional response to his or her current health state, such as fear, anger, or acceptance. More time might need to be spent to clarify the current situation before the patient is able to address future medical decisions.

Find out what they expect will happen. For the patient who has a good understanding of the status of their disease, the third step is to ask the patient to consider their future. Examples of how to start are

- What do you expect in the future?
- Have you ever thought about how you want things to be if you were much more ill?
- What are you hoping for?

This step allows the care provider to listen while the patient contemplates and verbalizes his/her goals, hopes, and fears. This step creates an opportunity to clarify what is likely or unlikely to happen. Follow-up questions might be needed to better understand the patient's vision of the future, as well as his or her values and priorities. If there is a significant discrepancy between what the physician expects and what the patient expects from the future, this is the time to discover it.

Some cancer care teams find they are speaking for the first time with a patient and family late in the course of treatment. Consequently, this should be acknowledged, and often, before proceeding, it is wise to ask how much the patient wants to know about his/her condition. This provides a protection against giving unwanted information to a patient

whose culture or personal preferences are either not to know or not to take the decision-making role. Examples include

- Some patients like all the information, others like me to speak with someone else in the family. I wonder what is true for you.
- Tell me how you like to receive medical information.
- Some people are detail oriented, some want just the big picture, which do you prefer?

Discuss overall goals and specific options. Now that the stage has been set with a mutual understanding of the patient's present and anticipated future, a discussion of overall goals of care and specific options can ensue. Allowing the patient to reflect upon goals that might still be realistic despite reduced functional abilities and a limited life expectancy can be a very effective tool to maintain hope.^{36,49} Insight into the patient's values and priorities will help structure the conversation of medical options and guide expert opinion. Using language that the patient can understand and giving information in short phrases is best. In general, patients prefer a focus on treatment outcomes rather than the details of medical interventions. Stopping frequently to check for emotional reactions, to ask for clarifications, and to clarify misunderstandings will improve the communication between patient and care team.

As an introduction to specific treatment options, summarize the patient's stated overall goals and priorities. In following the principle of shared decision making, clarify that recommendations are based, both, on the patient's stated overall goals of care as well as medical expert opinion. For example

- You have told me your goal is to try for a cure while staying pain free.
- I understand your goal is to feel like you are a fighter and not a quitter. You also said you understand that you can both hope for the best, but plan for the worst.
- You have told me that being at home with your family is your number one priority and that the frequent trips to the hospital have become very bothersome for you.
- If I heard you correctly, your first priority is to live to participate in your granddaughter's wedding in June.
- I heard you say that your goal is not to be a burden to your wife and children.

Beginning the discussion of treatment options from the patient's perspective and evaluating treatment options according to their potential to achieve the patient's overall goals can be a great help in building trust between the patient and healthcare provider. Working to achieve realistic goals is inherently hopeful. The goals may change over time, but the hopeful attitude about achieving them can be sustained.

Respond to emotions. Patients, families, and healthcare providers may experience profound emotions in response to an exploration of goals of care. It shouldn't be surprising that patients, when confronting evidence that initial therapy didn't work or that the end of their life is sooner than they thought, might cry, become angry, or myriad other responses. Parents of children with life-threatening diseases are especially likely to be emotional and will need extra support from the healthcare team. In contrast to common worries in the healthcare community though, emotional responses tend to be brief and therapeutic. Psychoncologists should be well versed in providing this type of support and can help both the oncologist and patient to deal with the emotional response.

Responses should be sympathetic. The most profound initial response a physician can make might be silence and the offering of a facial tissue. Consider using phrases such as

- I can see this makes you sad.
- Tell me more about how you are feeling.
- People in your situation often get angry. I wonder what you are feeling right now.
- I notice you are silent. Will you tell me what you are thinking?
- Many people experience strong emotions. I wonder if that is true for you.

A common barrier to this step is the physician's fear to precipitate overwhelming emotional outbursts that they might not be able to handle. As such, conversations between physicians and their patients often remain in the cognitive realm where emotions are not addressed. The best way to overcome this barrier is to learn how to sympathetically respond to patient emotions and to learn to be comfortable with silence. The majority of patients are embarrassed by being emotional and keep their expressions brief. This is because most patients have adequate coping skills and appreciate the presence of a doctor while they work through the experience and their emotions. As with most aspects of being a physician, a sense of competence and confidence imparted to the patient leads to a willingness to engage in the challenge on the part of both parties.

Establish and implement the plan. Establishing and implementing a plan that will meet the agreed upon goals, aids in coping, sets goals and expectations, and lays out the tasks at hand. The plan should be clear and roles and responsibilities should be understood by everyone involved. Consider using language like the following:

- You said that it is most important for you to continue to live independently for as long as possible. Since you are doing so well right now and need your current breathing machine only at night, we will continue what we are doing. However, when your breathing becomes worse, you do not want to be placed on a continuous breathing machine. We will then focus on keeping you comfortable with medicines to making sure that you do not feel short of breath.
- The different regimens we have used to fight your cancer are not working. There is no other anticancer therapy that I think will be effective. We discussed your options at this point including getting a second opinion from one of my oncology colleagues or asking a hospice program to get involved in your care. In light of what you told me about your worries about being a burden to your family, you thought that hospice care might be the best option at this point because you would get extra help at home from the hospice team members that come to see you at your house. I am going to call the hospice team today and arrange for them to call you in the morning so they can see you and explain more about what they offer. We can talk more after you see them.
- We'll start combination chemotherapy and radiotherapy next week. We won't know whether it's working for about 2 months when we repeat your scans. If it is not working at that time, we will have exhausted all of our anticancer therapy options. I'll ask the palliative care team to see you after you're admitted so they can help me with your symptoms and to give you and your family some support. They can continue to see you when you follow-up with me as an outpatient.
- I'll ask our social worker to help you finish those advance directive forms I gave you at your next office visit. She can then make copies and get them into the medical record.
- From what you've said, I think getting hospice care involved at home seems to be the option that best helps you to realize your goals.
- Let's try this third-line chemotherapy and treat your nausea with a different drug regimen. We'll repeat the scans after the second cycle. If the cancer is smaller or the same size, we'll continue. If it's bigger, we'll stop chemotherapy and get the hospice program involved.
- You don't feel you need the help, but the hospice team can help your family cope through the support from the nurse, chaplain, and social worker. In addition, the bereavement team will look out for them after you are gone.
- It is clear you want to try all options to extend your life as long as possible, even if there is a small chance they will work. So, we'll start fifth-line chemotherapy. If you develop an infection that is serious, we will care for you in an intensive care setting with maximal support. However, if you are unable to communicate, and there is no reasonable chance of recovery, you want life support to be stopped and for us to let you die comfortably.

It is often helpful to ask the patient or family member to summarize the plan and underlying reasoning in their own words to ensure

understanding. Especially for the emotionally overwhelmed patient, it is important that there is good continuity of care. Ensuring this continuity, for example, by arranging for follow-up appointments, speaking to the referring clinician, or writing the appropriate orders, is part of the oncologist's and care team's responsibility.

COMMON PITFALLS IN GOALS-OF-CARE DISCUSSIONS

There are a number of common pitfalls that fall into several categories. These are outlined below.

Inadequate preparation

- **Having an agenda:** If a physician enters a room with a predetermined agenda (e.g., to "get the DNR" or to "stop this futile treatment") trouble may ensue.⁵³ By trying to understand patient values and priorities first, the care team can make appropriate medical recommendations which are most likely to achieve the patient's goals. An awareness of possible agendas of all parties involved in a goals-of-care discussion such as the physicians, patients and families, consultants, or even hospital administrators assists in understanding the different perspectives and can help prevent adversarial outcomes.
- **Stakeholders not identified:** A picture-perfect goals-of-care discussion might have occurred and everyone seemed to have agreed upon a reasonable plan, but then the "cousin from out of town" flew in and threw out the whole plan. Before starting a goals-of-care discussion, make sure that all stakeholders are either physically present, included over the phone, or otherwise represented to the extent possible. Stakeholders also include other healthcare providers involved in the patient's care.
- **Homework not done:** Be prepared to answer questions regarding the outcomes and evidence of discussed interventions, such as resuscitation survival data, prognosis, and the risks and benefits of various of treatment interventions. Just as in any other informed consent discussion, patients need accurate information to make good decisions.

Inadequate discussion of overall goals and specific options

- **Inadequate information giving:** Each person handles information differently. While some patients want to understand the numerical probability of success or failure of specific interventions, most people do not comprehend statistical information. Many clinicians share an excessive amount of medical details (because its familiar or interesting to themselves) using language that the patient cannot understand. The actual information given should be tailored to the patient's needs and learning style. It might be helpful to ask the patient to repeat the information back using his own words.

Improper shared decision making, informed consenting, and decision-making capacity assessment

- **The person either does not have, or is inappropriately denied, decision-making capacity:** Before asking someone to make a decision regarding goals of care, assess if that person has decision-making capacity. This is usually the case if a person can summarize the decision in his or her own words, including weighing the risks and benefits and demonstrating appropriate underlying reasoning. Patients with delirium, dementia, depression, or other mental health problems may be able to demonstrate decision-making capacity. Since decision-making capacity is specific for each decision and at a specific point in time, patients might very well be able to make consistent decisions regarding their care. This right should not be taken away from them inappropriately. Nor should a choice that was stable while the person had decision-making capacity be reversed if they lose that capacity but other stakeholders have different opinions on that decision. Furthermore, simple "yes" or "no" answers do not imply understanding, and decision-making capacity should never be assumed.

- **"Restaurant-menu medicine":** The process of shared decision making strongly values patient autonomy but also recognizes the duty of the healthcare provider to make recommendations, based on his or her medical expertise, that are most likely to achieve the patient's stated goals. Many physicians skip the step of giving an expert opinion, often leaving themselves frustrated as the "waiter," offering a wide array of all possible medical options, as if they were items on a restaurant menu for the patient to choose. This can leave the patient feeling lost and overwhelmed as well. Physicians are under no obligation to offer any single therapy, especially if there is no belief of benefit to the patient and possible risk of harm. Only those options with potential benefit and within the patients goals of care should be offered.

PEARLS REGARDING THE DISCUSSION OF GOALS OF CARE

- **Start with the "big picture":** Many healthcare providers skip steps 2 and 3 (finding out what the patient understands and expects to happen) and lunge straight into detailed descriptions of medical interventions. These two simple steps help set the stage. They show that the clinician is interested in the patient and his/her experience and wants to support them to achieve their goals. Starting from the patient's perspective not only establishes trust and a feeling of safety for the patient, it also makes giving recommendations much easier later on. When the "big picture" goals are clearly understood, the discussion of specific medical interventions most commonly fall quickly into place.
- **Pay attention to nonverbal language:** Approximately 50% of communication between people happens nonverbally. Sitting down, maintaining eye contact, leaning forward, and a nod of the head in response to a patient talking all communicate interest and concern.⁵⁷ Similar behaviors in the patient or family member suggest they are listening. Standing, pacing, breaking eye contact, scowling, or whispering to other family members suggest there may be a problem.
- **Deferring autonomy is an act of autonomy:** Concerned family member sometimes ask that healthcare information not be disclosed to the identified patient. This can make clinicians feel very uneasy, as it interferes with their understanding of patient autonomy. Less skilled oncologists tell the truth over the objections of patient or family in a misplaced sense of duty. More skilled oncologists verbalize understanding for the family members concerns and then convey a need to check with the patient if this is how he/she would like to proceed (if the care team hasn't done that already). When the patient is seen alone, he/she can be asked how they would like to handle medical information and decision making. Questions such as: "Some people want to know all medical information as we find it and discuss all options with the doctor. Others would rather have their children make decisions and do not want to have to deal with the medical information. Where do you stand?" can be helpful.
- **Cultural competence:** In multicultural societies, such as the United States, physicians are apt to care for patients and families from many different backgrounds. The term culture is used here in the broad sense and includes ethnic, religious, and social. Each culture has its own values and language. Sensitivity to differences in cultural background helps to facilitate communication and understanding. When inquiring about cultural backgrounds sentences such as: "People from different backgrounds handle medical decision making very differently. Is there anything that we should be aware of regarding your care?" might be appropriate. It can also be very helpful to be sensitive to the "culture" of the facilities or other medical specialties involved in the patients' care to help avoid conflicts or misunderstandings.
- **Validate "unrealistic" or conflicting goals:** Physicians are sometimes frustrated by their patients' "unrealistic" goals. "They just don't get it." is a common reason for palliative care consultation requests. Many people have some hopes that might not be very

realistic ("I wish I could win the lottery."), but still valid. The great difference lies in how these hopes are handled: are people leading a life counting on what seems an unrealistic hope? An often cited example of this is a terminally ill parent who is unable to make the necessary arrangements for his/her minor children. A useful strategy is to support hope, but at the same time assist in making appropriate plans for future needs with a "Plan B" approach: "While we hope for plan A, lets also prepare for plan B, just in case." Another useful way to validate the patient's hope is the "I wish" statement, for example: "I wish that were possible. Whatever happens we will be there for you."⁵⁸ It is often similarly distressing to healthcare providers when patients verbalize conflicting goals over time. "I want to be aggressive but I don't want to keep coming to the hospital" is an example. Acknowledge that conflicting goals are common, for example, "I wish I could eat ice cream three times a day and still be as slim as I was when I was 20." In end-of-life care especially, intermittent denial of terminal prognoses verbalized as unrealistic hopes can be an effective way of coping. As long as patients are not making decisions that will harm them or others, it can be accepted and worked with as a coping mechanism.

- **Pay attention to emotions and identity issues:** Promoting understanding, comfort, trust, and thereby successful discussion and decision making is of the utmost importance. Emotional awareness is at core of empathic healthcare and allows for a true, authentic, and ultimately successful relationship between clinician and patient.⁵⁹

SUMMARY

The mental model of the relationship between palliative care and anticancer care is important to negotiating transitions in care. For most patients with cancer, transitions can be predicted at four times: (1) diagnosis of cancer, (2) recurrence of cancer, (3) worsening cancer despite therapy, and (4) lack of efficacy of cancer treatment. A model of integrated anticancer and palliative care can help smooth these transitions. Preparing for and addressing goals of care periodically over the course of a patient's illness is an important part of patient-centered care and has been shown to increase patient satisfaction and decrease patient stress and anxiety. Simple steps can be taken to ensure good goals of care discussions. Psycho-oncologists are well poised to assist oncologists with these discussions and educate physicians about improving such interactions. Goal-oriented care sustains hopefulness for both patient and clinician.

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