

# A Communication Approach for Oncologists: Understanding Patient Coping and Communicating About Bad News, Palliative Care, and Hospice

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## Key Words

Communication, end-of-life, palliative care, hospice

## Abstract

Oncologists frequently approach patients to discuss difficult topics, such as bad news about cancer progression and referrals to palliative care and hospice. To communicate effectively in these difficult situations, it is helpful to assess what the patient knows and wants to know about their disease in general and, specifically, their prognosis. Although some patients fully accept the diagnosis of cancer and cope well, most patients struggle with how best to cope. This struggle often manifests itself with the patient vacillating between unrealistic hopes for longevity while also indicating prognostic awareness by talking about funeral plans. Although this coping is normal, it is difficult for most clinicians to interpret. This article presents a framework for understanding normal patient coping and gives specific examples of how to talk with these patients during difficult transitions, such as times of disease progression, and about referral to hospice and palliative care. (*JNCCN* 2009;7:475–480)

Understanding what patients know and want to know about worrisome information, such as cancer progression, can be stressful for clinicians<sup>1,2</sup> because patients have a broad range of information preferences. Some pa-

tients want to discuss prognosis and their inevitable decline in health and function,<sup>3,4</sup> some do not,<sup>5,6</sup> and some may never be ready to hear such information.<sup>7</sup> Others are provided information but do not seem to hear what is said<sup>5</sup> and many have contradictory desires, such as for physicians to be both honest and optimistic.<sup>4</sup> Oncologists struggle with the issue of balancing being honest and straightforward with not discouraging hope,<sup>8–10</sup> and how best to communicate that further disease-modifying treatments are unlikely to be helpful without causing patients to feel abandoned.<sup>11</sup> Communication difficulties or miscommunications can also arise from a tendency to avoid negative topics in an effort to protect the patient and family. Although few oncologists have been trained in basic communication tasks,<sup>12</sup> and most fellowships do not have a formal curriculum for teaching communication skills,<sup>13</sup> successful teaching models exist for improving communication skills.<sup>14–16</sup>

## What is the Spectrum of Normal Coping?

When faced with a terminal illness, patients rely on coping habits that they have used throughout their lives. A few patients have exceptional coping skills and are able to discuss their prognosis openly and balance the possibility of death with realistic hopes (e.g., “I used to hope for cure, but now what’s important to me has changed. Now I hope for other things.”).<sup>17</sup> These patients are generally rewarding and satisfying to care for because they are able to accept support from family or medical staff, and their emotions are accessible but not overwhelming.

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In contrast, a small number of patients have an extremely limited tolerance for talking about prognosis, and cope best by focusing on the present or on treatment possibilities. These patients can sometimes make oncologists feel uncomfortable. As one oncologist explained, “he knew he was dying, and could talk about it for a few minutes. He agreed to be DNR/DNI, but he could not keep thinking about it for very long. I left the room and when I came back, he was asking about the next chemotherapy. Everyone knew what was happening, but he needed us to pretend that it wasn’t.” These patients can be difficult to care for because their views about their prognosis do not change as they become more ill<sup>7</sup> and because they do not always hear prognostic information when it is communicated.<sup>5</sup> Outside consultation with palliative care and social work can be critical to assist the patient, family, and medical team with coping, communication, and decision making. Care is often focused on supporting family and staff as they struggle with patients who seem to be suffering but are emotionally and intellectually inaccessible (i.e., they cannot talk about it). Oncologists should be sure to uncouple their own self-evaluation of their abilities as physicians from the coping reactions of these patients.<sup>18</sup> Despite skilled, caring communication, a small number of patients may never be able to communicate in a meaningful way about their illness.

Between the 2 extremes of patients who are coping well and those unable to tolerate discussion of prognostic information are the coping styles of most patients. Some patients process information (facts and details) intellectually, yet lack emotional connection to what is happening. Others are visibly emotional yet unable to discuss their thoughts and feelings. Still others are able to understand emotionally and intellectually what is happening, yet can only tolerate discussion for brief amounts of time. A brief assessment of patient coping during an office visit (e.g., “how are your spirits?”) can be a meaningful way to build rapport and broadly gauge the patients’ understanding of the severity of their illness. Fundamentally, clinicians want to facilitate good coping by providing information in a caring, respectful manner. However, this information is sometimes difficult to provide, particularly when patients struggle to come to terms with their prognosis and vacillate between unrealistic hopes for longevity and acceptance of the illness.

## Flip-Flopping is Normal but Confusing for Clinicians

As patients struggle with denial and acceptance, their coping can flip between these 2 extremes. In one part of the conversation, patients may seem to accept the illness. They may talk about worries for the children, refer to funeral arrangements, or say they hope to make it to an important date, such as a birthday or holiday. In other parts of the conversation, patients seem to be in denial. They may talk about “beating the cancer,” explain plans to resume work after treatments finish, or act surprised when a clinician refers to the illness as advanced or serious. Avery Weisman<sup>19</sup> called this flip-flopping phenomenon *middle knowledge*. “Patients seem to know and want to know, yet they often talk as if they did not know and did not want to be reminded of what they have been told.”<sup>19</sup> How then can oncologists discuss difficult topics in a manner that is both caring and realistic? The first step is assessing and then addressing a patient’s ambivalence.

## Assessing and Addressing Ambivalence

Information preferences are best assessed by asking patients directly, “How much do you want to know about your illness? Some people want lots of details, some want the big picture, and others prefer that I talk to their family. What would be best for you?”<sup>20</sup> Some patients will want explicit information, some may not, and others will be ambivalent. Occasionally patients who are ambivalent are able to articulate their conflicting feelings and may have seemingly conflicting priorities, such as wanting to remain hopeful despite receiving bad news.<sup>8,9</sup> For patients who are ambivalent, it can be helpful to 1) explore the pros and cons of knowing and not knowing, 2) acknowledge the difficulty of the patient’s situation, and 3) name the ambivalence (e.g., “It sounds like you have some reasons you want to know and reasons you don’t. Do I have this right?”).<sup>21</sup> Naming emotions can be a helpful tool to clarify what patients are feeling and to introduce feelings explicitly into the discussion so they can be discussed openly.

Another approach to assess a patient’s information preferences and ensure that information given is appropriate for the patient is the Ask-Tell-Ask technique.<sup>22</sup> This technique is particularly helpful when patients are asking for prognostic information, but cli-

nicians are unsure how much information they want to hear. To use this method, oncologists bracket information given to patients with questions that explore reasons why they or their family want information:

**Patient:** Can you tell me how long I have?

**Physician:** That is an important question and we can certainly discuss the answer, but first can you tell me a little bit more about what is on your mind. Why is important for you to know how much time you have left?

**Patient:** My family is traveling to my house for Thanksgiving and I want to make sure that we will be able to celebrate together.

**Physician:** It is always difficult to say for certain how much time a patient has. I think that there is a good chance that you will be able to celebrate Thanksgiving with your family. However, it is hard to know this for certain. If there are important things that you need to accomplish or people you need to talk with, you might want to do them sooner. If you like, we can talk in more detail about how much time you have remaining. Is there any more information that would be helpful to you right now?

**Patient:** Thank you, this is enough for now.<sup>23</sup>

By asking the patient to explain what is on their mind, the clinician gives the patient time and opportunity to pause and reflect about their intentions, and avoid giving information that is unwanted or potentially harmful.

## Breaking Bad News

Once a patient's information preferences have been evaluated, the discussion can transition to talking about bad news. Numerous publications give practical advice for how to approach this topic.<sup>24</sup> The SPIKES protocol<sup>25</sup> (Table 1) is an easy-to-remember guide that summarizes standard recommendations. When used by oncologists and oncology trainees, it increases confidence and ability to disclose unfavorable medical information.<sup>25</sup>

Whenever possible, bad news should be communicated in a private location with significant others present for emotional support. This can often mean that when scans are ordered, patients are instructed to bring family or a significant other to the next appointment for support. After patient understanding and information preferences are assessed, bad news should be communicated clearly using nontechnical

**Table 1 SPIKES Protocol for Breaking Bad News**

### **S – SETTING up the Interview**

Arrange for privacy

Involve significant others

Sit down

Make connection with the patient by maintaining eye contact, touching as appropriate

### **P – PERCEPTION**

How does the patient perceive the medical situation

“What have you been told about your medical situation so far?”

### **I – INVITATION**

Assessing preferences for information disclosure

### **K – Giving KNOWLEDGE and Information to the Patient**

Include a warning shot (e.g., “Unfortunately I have some bad news to tell you...”)

Use non-technical words

Avoid excessive bluntness

Give information in small chunks and periodically check for understanding

### **E – Assess the Patient’s EMOTIONS with Empathic Responses**

Observe for any emotion

Allow for silence

Use empathic statements (e.g., “I know this isn’t what you wanted to hear. I wish the news were better”)

### **S – STRATEGY and SUMMARY**

Check for understanding

Make a plan for the future

words. Most authors suggest prefacing bad news with a warning to give patients a few moments to prepare before the actual news is delivered (e.g., “I am afraid that I have some disappointing news.”). Once news is delivered, emotions should be assessed and responded to using silence or empathic statements, which reflect the emotions behind the patient's statements (e.g., “I know this is disappointing, I wish the news were better.”).

With patients who are ambivalent about information or struggling to cope with illness, it can be helpful to check in with patients and assess how they are coping with the conversation (e.g., “It looks like this is tough to talk about. How does it feel to continue?”). Because patients may have trouble cognitively processing information when they are emotionally stressed, it is important to address emotions that

arise so that patients or family can process medical information.<sup>26</sup> Processing information and making a plan for the future helps facilitate problem-focused coping, a strategy that fosters hope by focusing on what can be done.<sup>10</sup>

### Referring Patients to Palliative Care

Patients struggling emotionally with their illness or are ambivalent about hearing prognostic information may benefit from referral to palliative care services. Palliative care can be consulted at anytime during the disease course. However, early referrals, ideally at diagnosis of metastatic disease, provide patients the best opportunity to optimize both the physical and psychological symptoms associated with the disease and its therapy. Palliative care consultation offers patients the opportunity to process emotions and consider treatment options, needs that are often difficult to accommodate in busy oncology practices. Some patients are also reluctant to express their emotions to oncologists; they worry about taking excessive time, feel that listening to emotions is not the role of the oncologist, or are focused on appearing well and full of energy so that they can have more chemotherapy.

Often, referrals to palliative care must be introduced in different ways for different patients. Experts recommend that clinicians consider how patients are able to cope with explicit prognostic information when choosing the approach.<sup>17,27</sup> Patients who are struggling to cope with their prognosis and unable to talk about the possibility of dying are unlikely to be able to have an explicit conversation about palliative care. These patients may be more accepting of a referral if it is explained in terms of symptom management. The symptoms may be obvious, such as pain, dyspnea, nausea, or constipation, or subtle, such as difficulty coping or feelings of grief, anxiety, sadness, or depression. Palliative care clinicians can perform a psychological assessment and provide supportive counseling, and can refer patients in need of additional services to social work or psychiatry as appropriate.

Although some patients may be more accepting of palliative care when it is explained in terms of symptoms, others can handle a more direct approach. These patients have a more integrated understanding of their prognosis and can tolerate and want more explicit prognostic information.<sup>17</sup> Although even in this situation, patients want truth-telling to

be balanced with hope.<sup>8,9</sup> Experts recommend that this can be accomplished if 1) the physician is sensitive to what information the patient is ready to hear and how this information is affecting them, and 2) emphasizes what can be done<sup>23</sup> (e.g., “I am recommending that you have an appointment with palliative care. They can help assure that your symptoms are well controlled, and can give emotional support to you and your family”).

### Referring Patients to Hospice

Despite its benefits, hospice conversations can be difficult and should be approached with care. Maintaining hope can be achieved by focusing on what hospice can do: provide high quality pain assessment and management,<sup>28,29</sup> improve bereavement outcomes,<sup>30</sup> and support families.<sup>31</sup> The SPIKES protocol can be modified to introduce hospice by expanding the assessment of patient perceptions to include a discussion of their goals for the future.<sup>32</sup> If needed, goals should be refocused or reframed to increase the possibility that they might be achieved. This reframing also gives patients important prognostic information (e.g., “I wish I could guarantee that you would be alive for your 50th wedding anniversary but I am worried that there is a possibility that you may not be. Perhaps there is a way that you could celebrate with your family now while you are feeling well?”).

Once realistic goals are established, the conversation can shift to focus on how to achieve those goals. In many cases, patients are hoping to spend quality time at home with friends and family and hospice can be introduced as an additional support (e.g., “Hospice is a team of people that can help improve your quality of life while you are at home, and help support your family as they care for you”).

Patients will often react with surprise or sadness at hearing the mention of hospice and clinicians will need to pause to acknowledge the emotion. Allowing for silence, empathizing with the patient, and exploring concerns can help patients process some of the strong emotions they experience during the discussion. Patients may also wish to hear more about hospice’s goals: that hospice helps people live as well as they can for as long as they can, and that the goal is to improve quality of life as much as possible for the time remaining. The language of “hoping for the best, preparing for the worst” can help patients

maintain hope while allowing them to make practical plans (e.g., “I am hoping that you will be able to live a long time with this cancer, but I wanted to put some plans in place to support you and your family just in case things don’t go as we hope”). Expressions of nonabandonment (e.g., “the hospice will help care for you at home, but I will still be your doctor and involved in your medical care”) can also reassure patients that their care will not be compromised by choosing hospice.<sup>11</sup>

## Making Recommendations

After discussing difficult news with patients, whether about cancer progression, decisions about future treatments, or referral to palliative care or hospice, oncologists must decide whether to make a recommendation to the patient about what they should do. Often clinicians can feel that making recommendations to patients is tantamount to medical paternalism. In fact, increasing data suggest that decision making is stressful for families,<sup>33</sup> families are more satisfied with communication if clinicians make explicit recommendations,<sup>34</sup> and patients want their physicians to tell them the best treatment option.<sup>3,35</sup> Making a recommendation can relieve the patient and family from some of the burden of decision making.<sup>36</sup>

In many cases, making a recommendation to patients makes clinicians’ preferences clear but allows patients and family to make the final decision. For example, when referring patients to hospice, the recommendation can be followed by an offer for an informational visit, allowing the patient and family to learn more about the services that hospice provides. Similarly, when referring patients to palliative care, the recommendation can be followed by an offer to book an appointment, which the patient can then accept or decline. In general, patients must be aware of the benefits and burdens of a given course of action and to know that the physician has carefully considered these risks and benefits in the context of the patients overall values, goals for treatment, and preferences for care.<sup>37</sup>

## Conclusions

As patients struggle to cope with cancer, many remain largely ambivalent about medical information. They want to know, yet fear the worst, and are not

sure how they will cope with information once it is delivered. Oncologists struggle with these mixed signals and how to inform patients without overwhelming them and taking away hope. Although skilled communication cannot lessen the sadness and grief that patients experience with a terminal diagnosis, it can soften the blow. Through sharing hope while being clear and honest, the oncologists can align with an ambivalent and vacillating patient who then does not face an uncertain future alone.

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