

The Cultivation of Prognostic Awareness Through the Provision of Early Palliative Care in the Ambulatory Setting: A Communication Guide

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Abstract

Early, integrated palliative care delivered in the ambulatory setting has been associated with improved quality of life, lower rates of depression, and even prolonged survival. We outline an expert practice that provides a step-wise approach to cultivating prognostic awareness in patients cared for by a palliative care clinician early in the course of the patient's disease. This approach can be used by both novice and more experienced palliative care clinicians.

Introduction

EARLY, INTEGRATED PALLIATIVE CARE delivered in the ambulatory setting includes consultation and management throughout the entirety of the illness for patients with advanced cancer. This approach has been associated with improved quality of life, lower rates of depression, and, even, prolonged survival.^{1,2} Many patients with cancer hold an inaccurate view of the goals of treatment and their prognosis.^{3,4} These patients have a low "prognostic awareness." We define prognostic awareness as a patient's capacity to understand his or her prognosis and the likely illness trajectory. Improving a patient's prognostic awareness is an important component of early palliative care because a more accurate understanding of prognosis is associated with earlier enrollment in hospice and lower rates of resuscitation for patients with incurable cancer.^{5,6} Palliative care clinicians can facilitate enhanced prognostic awareness in patients with cancer through the use of advanced communication techniques.¹

Our clinical experience in caring for patients early in the course of illness is that although most are provided with statistical information about their prognosis by their oncologist, many patients react to the information they have received in ways that leave them unable to make personal or medical decisions. Some patients react by not wanting to think or talk about their prognosis. Others feel the information does not apply to their situation or cognitively integrate the information but feel too emotionally burdened and decide to put off dealing with their mortality until a future point. We classify these patients as having a low level of prognostic awareness.

Over the course of receiving care from a skilled palliative care clinician, we have found that many of these patients seem to develop an increased capacity to tolerate discussions about prognosis and accept what this information means to them personally. Many of these patients develop the ability to hear, process, and draw on prognostic information to make medical decisions that match their own values—and are grateful to the clinician who worked with them to reach that point. In summary, we observe patients gradually develop prognostic awareness through an incremental cognitive and emotional process that can be cultivated over time through interaction with a skilled clinician.

We outline here an expert practice that provides a step-wise approach to cultivating prognostic awareness in patients cared for by a palliative care clinician early in the course of the patient's disease. We illustrate our approach with a case that unfolds over months. This approach can be used by both novice and more experienced palliative care clinicians. It requires the clinician to assess the patient's level of prognostic awareness, coping, and clinical status. The patient's clinical status is a key component of this approach. Thus, we believe this communication approach will be most useful for clinicians who can draw on both medical and psychosocial skills.

Case (a): Dan Murphy is a 54-year-old man with metastatic non-small cell lung cancer diagnosed 3 months prior to his first palliative care clinic appointment, now on first-line chemotherapy. He is a successful businessman who is married and has three children. His oncologist, Dr. Anna Simpson, is concerned that his disease is progressing but that "he just doesn't get it."

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In his first visit, Dan tells Dr. Linda Hancock, the palliative care physician, that, "I am fine. I mean, I know this is bad but I have to beat this no matter what Dr. Simpson says. I have a family, you know. I want you to help me feel well while I get all this chemotherapy. Just like I told Dr. Simpson, I want you to always be straight with me and hopeful. If you can do that, we will get along just fine."

Challenges in Enabling Patients To Cultivate Prognostic Awareness

What is the prognosis?

Clinicians commonly question their ability to accurately prognosticate about life expectancy. Christakis has shown that clinicians systematically overestimate their patients' life expectancy by a factor of five.⁷ Although these data suggest that a clinician's ability to estimate prognosis is an inaccurate science, studies show that patients prefer clinicians to relate the best information they have in a timely fashion.⁸ Patients will make different plans for the future if they have a sense that their life expectancy is on the order of days to weeks or weeks to months.^{5,6}

Discussions of prognosis should not only address life expectancy but also include information about the likely disease trajectory. Both pieces of data provide important information to the patient. Unless patients have witnessed another person navigate the same illness, they often have little idea about what to expect either from the treatment or the disease itself. Providing information about the likely disease trajectory helps patients plan and hope for things that are likely possible within the context of the illness.

How much prognostic information has the patient integrated?

Clinicians must first have a sense of what the patient already knows and is able to articulate about the prognosis. This assessment is best accomplished by using open-ended questions that make no assumptions about what information the patient has integrated thus far.

One challenge that referring oncologists commonly note is that, despite having detailed conversations about prognosis, patients are often unable to articulate an understanding of what was said. Clinicians often assume that the reason the patient has not integrated the information is either because they were not clear in the communication or that the patient "just doesn't get it."⁹

It is vital for clinicians to appreciate that a patient's inability to integrate prognostic information after one or even multiple conversations is typical and should be expected. Patients integrate prognostic information at a pace that they can tolerate and that preserves their ability to function in the world.^{10,11} This process can be incredibly confusing to clinicians who have worked hard to clearly discuss prognosis only to have a patient seem to have very little recall or understanding of the information delivered by the clinician. This reality makes the question "what does the patient know?" a significant challenge for oncology and palliative care clinicians who are collaborating in the care of a patient.⁹

What does the patient want to know?

Patients are often ambivalent about receiving prognostic information. In survey studies, a majority report contradictory wishes, as did Dan in our case example, wanting their clinicians to be hopeful and also honest.¹² Patients may request prognostic information but then become angry when the in-

formation is provided. These experiences can lead clinicians to avoid conversations of prognosis and illness trajectory.

What if the patient doesn't want to discuss prognosis?

Another challenging situation occurs when the patient's medical condition is declining yet the patient is still providing cues that he or she is unwilling to discuss prognosis. In this situation, clinicians often feel that whatever approach they take will have undesirable consequences. If the clinician does not initiate a prognostic discussion, it is possible that the patient will not have the information to make fully informed medical decisions and may choose high-burden, low-benefit interventions, or fail to prepare for the final stage of life. If the clinician does initiate a prognosis discussion, the fear is that the relationship could be irreparably damaged.

Case (b): Dr. Anna Simpson (Oncology) and Dr. Linda Hancock (Palliative Care) meet jointly with Dan Murphy to inform him that his scans revealed tumor progression. Dr. Simpson discusses the CT results clearly and recommends a new chemotherapy. Dan asks how many more chemotherapies are available to treat his disease. Dr. Simpson informs him that many other treatment options exist, however each with a smaller chance of response. Dan replies, "Dr. Simpson, listen, I know this isn't good and that I won't live forever. I have done my will and everything but you have to figure out how I can see all my kids get into college. You can't let me die from this now."

After the visit, the clinicians debrief. Linda Hancock (PC) reflects to Anna Simpson (Onc) that despite having given the CT results in a clear and empathic way, Dan was not able to tolerate the thought that his disease was incurable. Linda makes a mental note to re-assess Dan's self-assessment of his prognosis at the next palliative care visit.

At the next palliative care visit, Dr. Hancock asks Dan his thoughts about their last visit. He replies, "Well...I was just glad to hear that there are many other treatment options available to me. You know I think Simpson is just really negative. I really think I will beat this thing."

Linda Hancock notes to her self that Dan has incorrectly recalled the essence of the conversation she and Anna Simpson had with him and appears unable to contemplate anything but positive information. Linda wonders if Dan may be a patient for whom the cultivation of prognostic awareness is particularly challenging or if this is just a day when he needs to see only the positive.

A Normal Pattern: Coping That Swings between More and Less Realistic

The proposed approach to cultivating prognostic awareness is informed by Dr. Avery Weisman's observations of how patients cope with life-threatening illness. Weisman is a psychiatrist who studied hundreds of patients and observed their patterns of coping with terminal illness. A fundamental concept of his work is that denial is not a sign of unhealthy coping but rather a tool for patients to safely and slowly integrate the reality of death over time.¹³ Unlike Kubler-Ross's¹⁴ concept of coping with illness in which denial is an early stage and acceptance is a final stage, he observed that patients move in and out of both denial and acceptance of impending death frequently and often in one conversation. He calls this phenomenon "middle knowledge." A patient with weeks to live may, for example, discuss his funeral and in the next moment describe his excitement over the birth of a grandchild who is due to be born in 6 months: "I can't wait to hold that child!" This can be incredibly confusing for the clinician who thought the

patient understood that his life expectancy was on the order of weeks and was even able to plan his funeral. Weisman believes that the patient may have the ability to integrate some aspects of his death but has not fully integrated the loss he feels at not being able to meet this new grandchild.

We conceptualize this normal coping as a swinging pendulum of awareness, from more integrated and realistic to less integrated and less realistic (Fig. 1). This kind of coping is not “denial” in its traditional sense, but rather a healthy, paced integration of information that, from the patient’s perspective, would otherwise feel unimaginable.

In practice, patients frequently swing between a more and less realistic understanding. It is important for clinicians to tolerate this variability and remember that a patient’s need to use denial as a coping mechanism changes over time. As the patient’s disease progresses, and he or she has the opportunity to slowly explore the likely outcomes of the illness, expressions of middle knowledge often become less frequent. In the case, Linda Hancock as the palliative care clinician is early in her relationship with Dan and does not know whether his optimistic interpretation of the data is an example of middle knowledge or a sign that Dan will have difficulty cultivating prognostic awareness.

It is important to note that family members exhibit similar coping and this approach to cultivate prognostic awareness can be used with them as well. Family members with good prognostic awareness can promote prognostic awareness in the patient. If the key caregivers have low prognostic awareness, it can make the patient’s coping and integration more challenging.

Over time, our communication goal is to enable the patient and family to engage in discussions that more openly explore the likely course of the illness and to aid the patient in the psychological integration and stabilization of prognostic data. Patients who have integrated this difficult information can more effectively engage in shared medical decision making with their clinicians.

A Communication Process for Cultivating Prognostic Awareness

Clinicians can help patients cultivate prognostic awareness by taking a step-wise and partnered approach. This approach

begins with the clinician determining the likely prognosis, then assessing the patient’s current understanding of the illness and inviting discussion of attainable hopes, and providing a place to grieve hopes that are likely unattainable. It is important to remember that the patient’s current clinical status will be a critical factor in the timing of these discussions. The clinician’s role is to help the patient understand how the likely clinical path maps onto the patient’s hopes and goals. The clinician can help the patient understand both what is possible and what plans might need to be changed so the goal can be met.

Step 0: Preparing: A subspecialist-level knowledge of prognosis

Clinicians first need to prepare themselves with accurate information about the patient’s likely life expectancy and the course of illness. The patient may prefer not to receive this information, but in order to accurately assess the patient’s prognostic awareness the clinician should possess the most accurate information available.

Case (c): Because Dr. Linda Hancock wants to be sure she has a subspecialist-level understanding of the patient’s prognosis, she asks Dr. Anna Simpson for her best estimate of what she expects will happen with Dan’s cancer. Anna reports that she thinks his survival is on the order of 6 to 9 months. Anna is worried that his extensive pleural-based disease will cause dyspnea that will adversely affect Dan’s quality of life soon.

Step 1: Assessing the patient’s prognostic awareness: “What’s your sense of how you are doing?”

This self-assessment question offers a window into the patient’s illness understanding and willingness to discuss the future. The patient’s response can provide a useful guide (Fig. 2) for the discussion of prognosis. The response to this simple question often varies greatly. Patients may state emphatically, “I am fine! I am fine!” or quietly dissolve into tears as they express how worried they are about all that is happening. This patient self-assessment not only gives the clinician a sense of the patient’s coping in the moment, but also often provides an

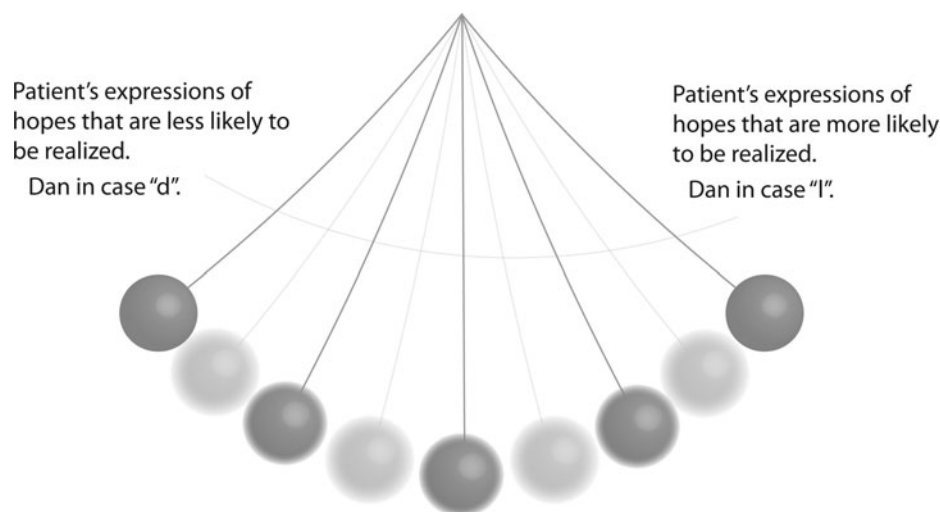


FIG. 1. Model of coping with serious illness: a pendulum in which the patient’s expressions swing through varying degrees of prognostic awareness.

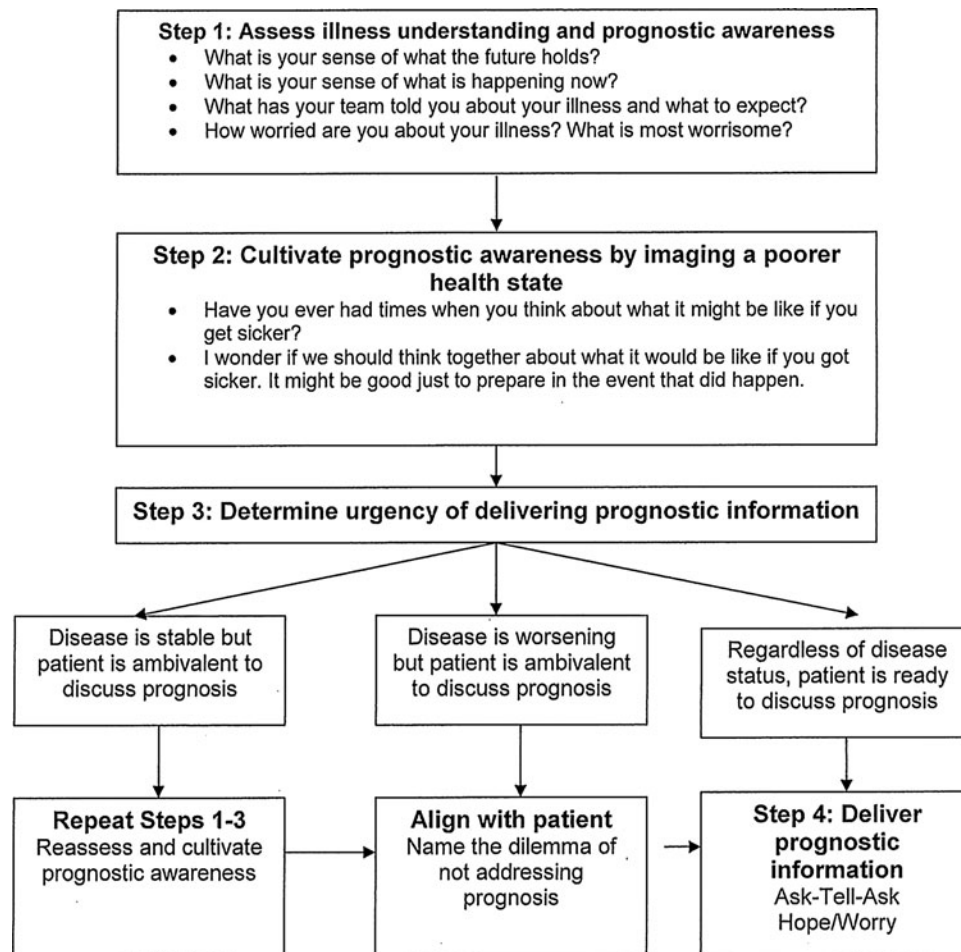


FIG. 2. The step-wise process to help patients cultivate prognostic awareness.

indication of the patient's readiness for discussions of prognosis. For example, the patient who is trying to convince the clinician that she is fine is giving clear cues that she is not ready to discuss weighty prognostic information.

In responding to the patient's self-assessment, clinicians have the opportunity to consciously model that discussion of prognostic information is something that is possible for both the clinician and the patient. When the clinician attends to the patient's cues and is able to sit with the patient's affect, patients often feel more in control and are empowered to ask for more detailed prognostic information on their own.

Case (d): In her third palliative care appointment with Dan, Linda Hancock finds him appearing more ill. She asks several open-ended questions to assess Dan's illness understanding. "How worried are you about what is going on right now?" she asks. He responds, "I am not that worried. I mean, don't get me wrong, I feel like crap but I am 54 years old. I don't really see how I can't bounce back from this." Linda then asks how his children are doing with him feeling so poorly. Dan becomes quiet and then after a bit of silence says, "I guess that is the place I find it hard to just stay positive. It is hard to see them worried and if I am going to die from this like Simpson says, I will need to plan for the kids [pause]. I have to believe I will beat this!"

Linda notes to herself that he is vacillating between wanting only to discuss that he will be cured and preparing his children for his eventual death.

Step 2: Inquiring whether the patient can imagine a poorer health state: "What would it be like if you got sicker?"

When patients articulate only positive interpretations of their clinical status, one way that the clinician can test the patient's willingness to contemplate other interpretations is to ask the patient to imagine a poorer health state.

A clinician may introduce the discussion in the following way, "I know we are hoping that things will go well for a long time but I wonder if we should prepare in case things don't go as well as we hope. Do you ever imagine what it would be like if things did not go so well?" This is a variation on the technique of hoping for the best and preparing for the worst.¹⁵

Encouraging a patient to imagine a poorer health state is one step removed from the difficult reality. This exercise allows the clinician and the patient to partner in hope-based coping while beginning a discussion about goals and values in the event that what we are hoping for does not come to fruition.

Case (e): Linda Hancock responds to Dan and asks, "I hear that it sounds impossible to believe that you won't beat this. Is that right?" He nods yes. Linda continues, "I wonder if you ever have times when you find yourself imagining what it would be like if you did get sicker from this illness?" Dan becomes very quiet and his eyes fill with tears. "Yes at night when I can't sleep, I find my mind going there. I

always stop myself and push it out of my mind. I have to be hopeful. It is the only way to beat this."

Linda Hancock documents in her palliative care note that today Dan can articulate a deeper awareness of his prognosis as evidenced by his sadness at the thought of becoming sicker and his sense that he may need to prepare his children for his death. Linda notes to herself that Dan has partially integrated important prognostic information, and she believes he will be able to tolerate deeper conversations in future visits.

Step 3: Judging patient readiness and clinical urgency: "Do I need to discuss prognosis now?"

In this step, the clinician must consider the role that the patient's clinical status plays in the assessment of the patient's readiness.

3a. For a patient who demonstrates readiness (regardless of clinical status): Indicate that you will discuss the information. Any patient who has asked for more detailed information about his or her prognosis should be given the information regardless of clinical status. When providing this information, it is again helpful for the clinician be aware of what the patient believes is likely to happen. It can be useful to ask, "What is your body telling you?" (Illustrated in case f below.)

3b. For a patient who is ambivalent or resistant and clinically stable: Hold off on giving the information and re-assess. If the patient is ambivalent or resistant but doing well clinically, the clinician may decide to repeat the self-assessment in an effort to help the patient become more comfortable with the discussion (Fig. 2). The goal is not to have the patient talk about difficult topics for the sake of talking about them but rather to be able to engage in more fully informed shared medical decision making. This is especially true in cultures where patients abdicate the role of decision making to a family member. We want to have either the patient or family member have the ability to engage in informed decision making, not to be forced to talk about prognosis when it is counter to the cultural norm. (Return to Step 1.)

3c. For a patient who is ambivalent or resistant and clinically declining: "Name the dilemma." This approach will be illustrated in step 4b, but the next episode of the case will show how Dr. Hancock assesses readiness.

Case (f): *At the next palliative care appointment, Linda Hancock remembers the last visit and asks Dan his thoughts about their last meeting. Dan says, "You know I have been thinking more about what might happen if I get sicker. Do you really think that could happen? What would it look like? I mean I guess it is good to know how I would feel. I still find it hard to believe I will die from this."*

Although Dan has been resistant in the past, he is asking for prognostic information at the moment, so Linda interprets this as Dan exhibiting readiness and she decides to deliver the information. Dr. Hancock says, "Dan, this is important, could we have a serious talk about this?" He nods yes.

Step 4: Delivering prognostic information tailored to patient readiness and clinical urgency

4a. For the patient who demonstrates a degree of readiness. When a clinician delivers prognostic information, Ask/Tell/Ask can be a useful approach.^{16,17} This strategy

allows the clinician to ask the patient what type of information he or she would find helpful. Some patients prefer to know the estimated life expectancy, whereas others would rather receive information about the likely functional disease trajectory. Asking the patient which type of information would be most useful can help set the stage for the conversation. After delivering the information, the clinician should check in with the patient to ensure that the question was answered satisfactorily.

Clinicians are often concerned that providing prognostic information will prevent patients from feeling hopeful about the future. Pairing hope and worry is a technique that facilitates the delivery of prognostic information in a kind way allowing the clinician and patient to maintain an optimistic stance. A clinician might say, "I hope you do well for a long time, and I am also worried because the scans look so much worse." Patients feel supported when they believe that their clinicians want them to do well and hope that this will happen. Pairing hope and worry allows for clinicians to be honest about what they believe will happen clinically and also partner with the patient in hoping for a different outcome.

After the clinician delivers prognostic information, he or she must be prepared for the patient's expression of emotion. The patient's display of emotion is a normal response to a conversation about prognosis. This is a critical juncture in the clinician's relationship with the patient in which the clinician needs the skill to tolerate the patient's emotion and not retract the information provided. The sadness or anger that often accompanies these conversations does not indicate that the clinician was not skillful but, more likely, that prognostic information was integrated on both a cognitive and emotional level.

Instead of reassuring the patient or back-pedaling, the clinician must find a way to respond to the patient's emotion. The use of silence, empathic touch, re-statement of realistic hopes, and "I wish" statements can all be helpful in sitting with the patient's emotion.^{18,19}

Case (g): *Because Dan has just said, "I have been thinking more about what might happen if I get sicker. Do you really think that could happen?", Linda Hancock decides to offer prognostic information to Dan. She asks, "What specific information would be helpful to you? Just so I know, are you asking about the trajectory of illness in terms of your function or time?" Dan looks very serious. "I want to be able to plan how I will feel. I mean do I need to take a wheelchair on our summer vacation to the Grand Canyon? Just to be clear, I don't want anyone to tell me how long I have to live. I think I will just give up if I find out I only have a couple of months to live." Linda responds, "Dan, I hope you will feel well enough to go on the family vacation, and also I worry that as the disease progresses your shortness of breath will also worsen, making a trip like going to the Grand Canyon a challenge." Dan starts to cry quietly.*

Linda consciously leaves a bit of silence. She waits until Dan looks up and then Linda says, "It sounds like that was hard news to hear." He nods yes. Linda says, "Dan, I really wish I had better news." He shakes his head, and says "OK, doc." Linda decides that this is as much prognostic information as Dan can absorb today, and decides not to discuss code status.

Linda documents in her palliative care clinic note that Dan is slowly integrating prognostic information about function. She notes that he is able to do this both emotionally and cognitively. She is feeling less worried about Dan and how he is navigating his illness. She documents Dan's prognostic awareness in her note so other collaborating clinicians can view her assessment.

4b. For a patient who is ambivalent or resistant and clinically declining.

Case (h): Three months later, Dan returns for another one of his regularly scheduled visits with oncology and palliative care. Prior to the visit, Anna Simpson finds Linda Hancock in the hallway and expresses her concerns. "You know he is declining fast. His performance status is terrible. I don't want to give him more chemotherapy. I am afraid I will harm him, but I don't think that would go over well if I suggested it. I wish I could talk to him about the 'big picture' but he won't do it. He just gets angry with me. I really feel like I need to talk about his code status with him but how can I? He won't even let me talk about stopping the chemotherapy."

Linda Hancock suggests that they meet together with him.

"Naming the dilemma"

In this approach the clinician empathizes with the patient about how hard it is to discuss prognostic information but also articulates the disadvantages of avoiding it. The clinician can do this by saying, "I hear that it is very hard for you to talk about the possibility that you might get sicker or even die from this illness. On the one hand, I don't want to do anything that would be upsetting, and on the other hand I feel like I won't be being a good doctor to you if we don't talk about the possibility that you might get sicker. Can we think together about a way to talk about this?"

Case (i): At the beginning of the joint visit, Linda Hancock asks Anna Simpson to lead. Anna asks Dan how he is feeling. He states he has been fatigued and on the couch most of the day. His wife states she is worried about him. Anna says, "I am worried about you too, Dan. I am worried that the chemotherapy may be doing more harm than good for you." Dan replies, "I am fine. I need to get chemotherapy or I can't fight this cancer, you know that. Are you giving up on me?"

Linda Hancock steps in: "Dan I know that it is really hard to talk about the fact that you might be getting sicker from this cancer. I wish it wasn't something we needed to talk about, but I worry that if we don't, we won't be able to make good decisions together. Can you help us think about a way to talk about this with you and your wife for a little while?" Dan states, "I get it, you know. It just makes it so real to talk about it, and I am afraid once we start talking, we will have to talk about it all the time. I don't want all my visits to be about my dying." Linda says, "No we just need to think about it to be able to make these decisions. Not all the time."

Dan is quiet and then says, "Dr. Hancock you know it is all about my kids. Will having more chemotherapy give me more time with my kids?" To which she replies, "I am not sure, what I hear Dr. Simpson saying is that she is worried it might actually make you worse." Dan says, slowly, "I understand what you're saying."

Conclusion

A key communication skill for clinicians providing early, integrated palliative care is the ability to help patients cultivate prognostic awareness over the course of the illness. In this setting, there is the luxury of time and different approaches are possible. When clinicians assess prognostic awareness, offer the possibility of discussing prognostic information, and allow for the swinging pattern of normal coping, patients can develop prognostic awareness at a pace that is less pressured. The goal of this approach is to allow a safe exploration of the likely course of the illness and to assist patients to psychologically manage and integrate prognostic information. Prognostic awareness allows for medical deci-

sion making that is based on realistic goals, incorporates patients' values and wishes, and matches values to treatments.

This approach has been distilled from expert practices, and should be refined and tested further. Our hope is that it provides a roadmap for clinicians starting early palliative care practices for patients with cancer and other life-threatening illnesses.

Author Disclosure Statement

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