Palliative Care

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EDITOR'S NOTE

Through this column, we hope that practitioners in general medical settings will gain a more complete knowledge of the many patients who are likely to benefit from brief psychotherapeutic interventions. A close working relationship between primary care and psychiatry can serve to enhance patient outcome.

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Palliative care becomes a relevant consideration once a severe medical illness is diagnosed. Palliative care represents the switch in focus from steps to cure the underlying illness to a concentration devoted to the comfort of the patient. In the hands of one of us (J.F.), it involves stressing goals of care, asks what it is that the patient wants, and discusses a fear of dying, among other issues. In the hands of another (D.S.), it explores the mindset of the patient with severe illness, stresses the strategic value of thoughts that relate to living and not dying, and examines the strategies of the individual in this phase of his or her life. These are complementary approaches. Neither is right or wrong, but both are designed to work in tandem. The first is the approach of a psychologically minded internist. The second is the approach of a medically informed psychiatrist. When a patient is referred to the palliative care team at our Veterans Affairs hospital, he or she often gets the benefit of both. The objective of this article is to describe both approaches to palliative care in detail.

The field of palliative medicine has had increasing recognition over the past few decades (including subspecialty status), as well as a significant increase in evidence-based knowledge. Despite these developments, considerable misunderstanding about palliative medicine persists among patients, families, and even clinicians. For patients and families facing chronic, serious, life-limiting, or life-threatening illness, palliative medicine seeks to improve quality of life, reduce suffering, be a source of support and information, and help with difficult decisions. Palliative care can be offered anywhere along the disease trajectory, and it is best initiated at the time of diagnosis of serious illness. It is consistent with curative intent and comfort-based treatments and has no limitation with regard to life expectancy. Pain relief is a critical element, but so are adequate sleep, reasonable appetite, and preservation of weight. Fatigue is combated, along with diarrhea and constipation and anxiety and depression.

Palliative care is not about giving up, throwing in the towel, or withdrawing care, nor is it a sign of no hope or "You're telling me that I'm dying." It is about living well, with the best quality of life, the least amount of suffering, and the most support and comfort for however much time the patient has to live. Perhaps the most succinct and accurate description of palliative care is provided by Smith[1]:

> The focus of palliative care is not browbeating patients into accepting hospice and avoiding resuscitation or hospitalization, as some might assume. Palliative care is at its heart a relationship-centered profession. Palliative care clinicians build strong relationships with patients and families in the hope of finding a way through the symptoms and distress, a way to cope with the illness experience, and a way to make each day as good as it can be.(p292)

DR FRANKLIN'S APPROACH TO PALLIATIVE CARE

I provide palliative care consultations on an inpatient and outpatient basis and remotely via telemedicine technology. Before answering a consultation, I discuss with the requesting provider the questions that he or she has and how I can help. Frequently, a provider will have significant information about the patient in his or her mind that may not be available in the chart. Before seeing the patient, I will review the chart to understand as much as I can about the patient. This includes diagnosis, treatment, symptom burden, hospital admissions, and emergency room visits. I also look for conditions that portend a specific limited prognosis (for example, malignant hypercalcemia, malignant pleural effusion, malignant pericarditis, multiple brain metastases, malignant ascites, and malignant bowel obstruction). On the basis of this information, I frequently have a sense of the prognosis before speaking with the patient.

The only agenda I have is to engage the patient and family and to understand who the patient is as a person, including his or her strengths and weaknesses, the journey thus far, what the goals of care are, and how I can help reach these goals. If any other agenda creeps in, I make a conscious effort to leave it at the door. My diagnostic and therapeutic tools include my eyes, ears, hands, and tongue. When I finish a consultation, I should be able to answer the following questions:

1. Who is the patient? What are his or her strengths, weaknesses, and social supports?
2. What is the diagnosis? What is the patient's understanding of the diagnosis, and how much information does he or she want revealed?
3. What is the symptom burden, including total pain (physical, spiritual, emotional, social, economic, and existential), fatigue, nausea, vomiting, shortness of breath, pruritus, anorexia, constipation, or diarrhea?
4. What is the patient's functional status? (In cancer patients, function is one of the strongest predictors of life expectancy.)
5. What, if any, advanced directives or advanced care planning is in place?
6. What are the patient's goals of care?
7. How can I improve quality of life and help the patient reach his or her goals of care?
8. Are there any specific recommendations?

Prior to discussing goals of care, it is important to determine what the patient understands with regard to the illness and how much he or she wants to know. Clues to denial may be gleaned from statements such as "They say I have cancer" or the presentation of a very unrealistic life expectancy. It is difficult for the patient to formulate realistic goals if he or she does not have an accurate understanding of the illness and its prognosis. To elicit goals of care, I find the following questions helpful.

1. What do you hope for? If the patient's hope is unrealistic, I will ask, "And, if that isn't possible, what do you hope for?"
2. What do you worry about the most now?
3. Knowing what you know about your situation, what is most important now?
4. What gives your life meaning? What makes life worth living for you?
5. What has been the hardest thing to deal with related to your illness?

The answers to these questions often will reveal the patient's goals. The goals of medical care are like a destination. If you drive your car and don't have a destination, then you don't know where you are going, you don't know how to get there, and you won't know when you have arrived. Defining goals of care is similar.

In addressing resuscitation, artificial hydration, and nutrition preferences, patients sometimes do not understand what resuscitation means. I elicit this information by asking patients, "When the end of life comes, do you want it to be peaceful, comfortable, and natural without machines?" Then, I will ask the patient where he or she would like to be at the end of life.

I formulate a plan to help the patient achieve the goals of care based on his or her personal preferences. When the goals are unrealistic, I offer alternatives to increase comfort and maintain dignity. Periodic follow-up is critical as circumstances change. At the end of a consultation, patients and their families will thank me and often say, "You have been more helpful than all the other doctors we have seen in the last 6 months combined!" I believe that this is a reflection of their desire for open and honest communication, with a specific plan to achieve the goals of care, which can be an important source of hope.

DR SCHUYLER'S APPROACH TO PALLIATIVE CARE

For me, it is crucial to establish a relationship with the palliative care patient. I stress that I have "lots of time." I take a comprehensive history, covering birthplace, family of origin, education, and work. I ask about marriage and relationships. Then, I move on to cover health and illness. All of this occurs before we consider together the patient's major illness.

When we consider the illness, I ask about initial symptoms and dwell on the patient's understanding of what caused the symptoms. Typically, causality is initially assigned to something benign. Only later does a test or examination pinpoint a more serious cause. Clearly, most persons are afflicted with thoughts much of the time.[2] When the diagnosis of serious illness is conveyed to the patient, this problem is added to his or her concerns.[3]

When someone is diagnosed with, for example, cancer, a question of strategy arises. Given what most people know, is it sensible to focus on the problem posed by the disease most of the time? The general answer is "no," because little of benefit is likely to accrue from this approach. Since most of us inappropriately spend time focused on the medical issue, it is not unusual to do this, merely typically nonproductive. I tell patients that they are in charge of where to focus their concern. Most patients say that "The thoughts come to my mind and I don't know what to do to combat them." Options include distraction and engagement, and this problem is a worthwhile concern for the provider to address.

Invariably, I ask the patient how he or she spends time. Some patients find little to do and see their period of work in younger days as "over with" and yet persistent in terms of identity. (Many doctors in their 90s have not seen a patient in many years and yet still refer to themselves as "MDs.") For many, identity is formed during their work years and never updated thereafter. I stress the importance of the patient spending time in an area of interest.

When there is evidence of anxiety or depression, the treatment of these entities is indicated, along with the usual palliative concerns of pain relief, sleep, appetite, fatigue, diarrhea, and constipation. Sometimes, the treatment of psychoactive problems may involve the patient's thinking (for example, cognitive therapy), and, sometimes, the treatment is pharmacologic.

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