

[Palliative Care Is About the Life That's Left, Not the End of Life](#)

Arefa Cassoobhoy, MD, MPH: Whenever I hear about palliative care, it's synonymously with hospice, but the two are obviously different. Let's discuss the difference between the two. I'll start with Diane.

Distinguishing Between Palliative Care and Hospice

Diane E. Meier, MD: It's a common confusion and misconception. The short answer is that all hospice is palliative care, but not all palliative care is hospice. That is the elevator speech version. The more nuanced version is that the Medicare Hospice Benefit, which was written into law about 25 years ago, was designed to reduce the number of people who would use it. They put strict eligibility criteria around access to hospice. One of the criteria is that two doctors have to agree that a patient is likely to be dead in 6 months in order to be eligible, which is already ridiculous because we have no idea who is going to be dead in 6 months. Second, the patient, or their decision-maker if they cannot decide for themselves, literally has to sign a piece of paper agreeing to [give up regular insurance coverage in return for hospice](#). It's like you cannot have medical treatment, but you can have hospice.

That is called "the terrible choice." That created the misconception that you could only get palliative care if you were dying and ready to give up. And that is a myth. The problem with that is that most people who need palliative care are not dying. They are living, and often for a very long time—10 years, 15 years—with serious illnesses like chronic obstructive pulmonary disease, heart failure, dementia, or end-stage renal disease. They have a tremendous burden of suffering and caregiver distress, but they are not dying. Palliative care was an answer to that gap. It was recognizing that living with a serious illness nowadays is almost always a chronic disease. No matter how long people have to live, they deserve the same attention to quality of life, treatment of symptoms, management of depression, support for their families, and support for social issues like financing and housing. It should be based on need, not prognosis.

The modern palliative care movement is a needs-based field. We take care of people who are going for lymphoma or leukemia cures, or who are getting a transplant or waiting for a transplant. They are not getting ready to die and they are not likely to die soon, but they have enormous palliative care needs.

Differing Views of Palliative Care

Dr Cassoobhoy: What is your experience in the hospital with other coworkers, other physicians, and healthcare providers as well as patients and their families?

Suzanne E. Zampetti, RN, MSN, FNP-BC: As a consulting service, what we hear often from other services is sort of, "We are not there yet. We are not ready for you yet." To Diane's point, it's that perspective that we are just end-of-life care. It's really important that we continue to educate other services and other physicians and nurses across the board about what palliative care does, so that we can be useful to them and we can reach out to the patients who need us.

Dr Meier: Let me give an example. For a very long time, oncologists at my medical center would say, "She's not ready for that." Although the patient was not dying, she was in excruciating pain and could not breathe, and all the rest. Then, in a pilot project, palliative care became something that every cancer patient was screened for; it did not depend on the attending physician thinking that "it's time." As a result, a much higher proportion of cancer patients received palliative care. And 6 months later, the oncologists now say, "We don't know how we ever practiced without you."

Oncologists are really busy and stretched, and they have more patients in the waiting room. And having a non-rushed conversation about what having a disease means, what to expect in the future, and what to do for a pain crisis in the middle of the night... they need help. We work side-by-side as an added layer of support to what the specialist does. Once they figured out what a huge benefit we were to them, they were like, "We need more."

How Sick Does a Patient Need to Be to Receive Palliative Care?

Dr Cassoobhoy: How sick does a patient need to be for a palliative care consult? What are the spectrums of illnesses that a patient may have that would qualify them for a palliative care consult?

Ms Zampetti: I don't think it's ever too soon to call in a palliative care consult, particularly if you have a potentially life-threatening illness. If you have a diagnosis of cancer, no matter what that may be, there is never an inappropriate time to talk about goals of care—what is important to that patient, what they are hoping to get out of the treatment, and what they would want and hope for if things did not go the way that they wanted.

We do this with our patients who get left ventricular assist devices. They come in looking for this life-saving cardiac device and their hopes are great, and they *should* be great. We are not there to take away their hope. We are there to discuss

what they want if things do not go the way they hope. What would they then hope for at that time? What is important to them, and how would they want to live their life if things were not going the way that they wanted?

Dr Cassoobhoy: It's interesting, because different patients are going to give different answers. Your role is to respect and encourage the real answer to come out so that it can be respected and honored.

Ms Zampetti: Exactly. Those conversations are very important to have with the family members present because it's important for everyone to hear what the patient is saying and to really be able to register and resonate with that. At the other side of things, the patient may not be able to speak for themselves anymore, and it takes a tremendous burden off of family members to know what their loved one wanted beforehand.

In palliative care, we are not about end of life; we are about the life that you have left.

Dr Meier: I would just add another story. A medical resident who had worked with our palliative care team was pregnant and delivered a baby a few months after she finished residency. Two weeks later she became extremely short of breath and thought that she may have developed a pulmonary embolus from a deep vein thrombosis as a complication of the delivery. She went to see her primary care doctor and he did a chest x-ray in the office.

She said she knew the minute he opened the door that she had cancer, just from looking at his face. She is a doctor, so she could read the body language. She had a massive mediastinal lymphoma that required a bone marrow transplant at the major cancer hospital in New York City. The hematologist asked her if she had any questions before he began treatment and she said, "I assume you have palliative care on your team." He said, "You don't need that; you're not dying." She said back to him, "I'm not going through this devastating treatment without support from a palliative care team." She could not get it at the cancer hospital, so she got her cancer care at the cancer hospital and her palliative care from us. She now says to whoever will listen that she could not have made it through the treatment without that support. She had terrible insomnia. She had terrible anxiety and depression. She was not allowed to touch her baby for quite a while because of the toxic treatment and radiation she was getting. She said it was hell, and that it was our team who managed her mood, physical symptoms, and addressed her existential and spiritual questions: How could this have happened to me? I just finished my residency. I just had my first baby. What did I do wrong? How did this happen?

She got great cancer care and she now appears to be cured, but it was a very difficult period in her life. This is an example of someone for whom the goal was always cure. She was to receive very aggressive treatment. She was an informed consumer, she was a doctor.

Dr Cassoobhoy: She could ask for palliative care.

Dr Meier: Yes.

Dr Cassoobhoy: It's hard to imagine going through something like that without palliative care. It seems like that should not happen anymore.

Dr Meier: Right. The doctors and the public should take notice of someone who is facing a life-threatening illness with a realistic hope for cure. She understood what the treatment was like because she had witnessed it as a trainee. She knew that there was no need to go through this without very meticulous and sophisticated professional attention to suffering. It's not just people who are going to die who need this kind of care. In fact, it's way more people who are not going to die, but are either chronically ill or are pursuing a cure, who need this kind of care.

Ms Zampetti: In palliative care, we are not about end of life; we are about the life that you have left. It is really exploring with the patient what they would like to do with that time and helping them realize that.

We have a patient right now who is in the intensive care unit who had a heart transplant and was doing very well for a while, and things have taken a turn for the worse. He said to our social worker that he thought he was dying. She astutely asked him, "If that were true, what would you want to do? What's important for you in that moment?" He asked to have his brother called and he asked to have certain people come to visit him, and we made that happen for him. It's about exploring what they want to do with the rest of their life.

How Can You Set Realistic Expectations for Patients?

Dr Cassoobhoy: What expectations should patients have for palliative care?

Ms Zampetti: The expectation would be that they are going to get expert pain management. They are going to get expert symptom management. Palliative care looks at the person as a whole. They are going to address their social issues, their existential distress. One of the things that I love about the palliative care team is that it is made up of many different

disciplines—social work, chaplaincy, nurses and nurse practitioners, and physicians—that are all working together to address all of the needs of the patient at one time. The patient should expect to be treated as a whole person and not as an illness.

Dr Cassoobhoy: I like that the social worker and the chaplain add so much to complete the addressing of the whole person.

How to Direct Patients to Palliative Care

Dr Cassoobhoy: How can patients find palliative care, and what if there is no provider close by?

Ms Zampetti: That is a real dilemma.

Dr Meier: First of all, there is a website called getpalliativecare.org. You can put in your city, state, or ZIP code and all of the programs in that area will drop down with the phone numbers. The second thing is that it is sometimes possible for palliative care teams to provide teleconsulting, which is the willingness to talk a colleague—who may be 1000 miles away—through a situation such as complex pain management or a complex family dynamic. This is increasingly common because there are so few palliative care professionals or specialists and so much need in areas of the country that do not have good access. If I were working in an area where there was not good regional palliative care specialty expertise, I would reach out to my nearest big city and ask to establish a telephone consulting relationship.

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