Help for patients... and providers

In Palliative Care, the Talk Turns from the Disease to the Patient

For Jeanie Youngwerth, the secrets of good patient care very often lie far from the research labs, exam rooms, surgical centers and clinics that make up the visible terrain of modern medicine. The answers instead reside in worlds at once obvious and remote: the patients themselves.

To unlock the mysteries requires the most basic of skills, says Youngwerth, a medical doctor and hospitalist who directs the hospital’s Palliative Care Consult Services. With a team of colleagues, Youngwerth helps patients and their caregivers who are battling difficult medical conditions identify their goals for quality of life, symptom improvement, pain management and other criteria. Their goal is not to cure illness, but to relieve those suffering from it.

A palliative care consult is a face-to-face meeting that can take hours, Youngwerth says. Emotions can run high. But her team sticks to one simple strategy for helping patients. “It’s more about listening than us doing the talking. We facilitate the discussion, but most of the time it’s listening to them because it’s about the patient and the family, not about us.”

It’s a job the consult service performed informally for more than a decade before it became a formal program in 2005, Youngwerth says. After consulting with the patient’s primary physician, UCH providers can request help from Youngwerth’s team by calling a dedicated hospital pager number (see below).

Search for answers. Far from a programmed presentation designed to guide the patient to a foregone solution, Youngwerth adds, the palliative care consult is closer to a fact-finding mission that uses eyes, ears and empathy to supplement clinical information in the medical record.

“It’s basically learning about [the patient] as a person,” she says. “We know about their medical illness, but what we don’t know is who they are... We need to remember that we’re not treating a disease; we’re treating a person who has that disease.”

“What we’re bringing to the equation is [to ask] ‘Who is this person? What’s important to them? What are their values and goals?’” By answering these questions, Youngwerth explains, the team can help the patient match medical therapies with his or her treatment goals.

The team also provides much-needed assistance for time-pressed clinicians who treat large numbers of patients with severe or terminal illnesses, notably cancer.

A clinical benefit, too. “A dedicated palliative care team is very helpful,” says Thomas Flaig, MD, assistant professor of Medical Oncology at the University of Colorado School of Medicine.

Instead of lab values and medication doses, he notes, Youngwerth’s team concerns itself with “palliation of symptoms. It’s something we also do as medical oncologists, but they have it as a focus. They help provide a better level of care in a collaborative manner.”

“It plays a vital role,” agrees Flaig’s Medical Oncology colleague Stephen Leong, MD. He estimates about half of the patients he sees while he’s on service on the hospital’s Oncology Unit have had palliative care, which he says helps patients define their goals, manage symptoms, and make decisions on post-discharge care.

Continued
Growing in importance. The American Board of Medical Specialists has recognized palliative medicine as a subspecialty since 2006.

And a growing body of evidence, including a study of lung cancer patients published in August in the *New England Journal of Medicine*, indicates palliative care not only helps patients feel better, but also could help to prolong their lives.

“Patients who get early and aggressive palliative care tend to do better because we manage their symptoms better,” says Flaig, who notes his patients often mesh palliative care with active chemotherapy.

Not end-of-life care. Even so, palliative care remains a concept that is imperfectly understood and sometimes clouded in controversy. The most common misperception: palliative care equals end-of-life care.

“There is a stigma attached,” Leong asserts. “[Patients] may think that [a palliative care consult] means the end is near and that we are giving up.”

Misperceptions about hospice itself also complicate the issue, Flaig says.

“People may see hospice as not doing anything,” he notes. “In fact, hospice is doing a lot of things, including nurses visiting regularly and physicians looking in on patients daily to treat pain and focus on symptoms, including dealing with the psychological burden of [disease]…It’s all active care.”

Not either-or. Hospice care is actually only one of many options a patient and his or her family may choose after a palliative care consult, Youngwerth emphasizes.

“Palliative care is not dependent on prognosis,” she states. “They do not need to be end of life to receive palliative care. And it doesn’t mean that he or she has to stop curative therapies. Palliative care can be delivered, and normally is delivered, right in line with curative treatments and therapies.”

Introducing palliative care early in a patient’s course of treatment could help counter misperceptions about it, Leong believes.

“If things don’t go well, they already know what hospice is,” he explains. “It’s not a shock”

Moreover, he adds, a patient’s goals may change over time as his or her disease progresses. “A patient may decide, for instance, to focus on symptom management instead of going after the cancer.”

The goal of palliative care, Youngwerth concludes, is to look at each case individually at a particular point in time. “No matter where [patients] are in the course of their illness, it’s really about improving their quality of life and relieving their suffering.”

To schedule a consult, call pager 303-266-7629.