Palliative Care Programs Still Face Obstacles in Mainstream Cancer Care

By Steven Benowitz

By all accounts, the past several years has seen palliative care leap into the nation’s health care headlines and perhaps its consciousness as never before. Many point to 2010 as a turning point, when Massachusetts General Hospital oncologist Jennifer Temel, M.D., reported a landmark study in the New England Journal of Medicine showing that terminal lung cancer patients given palliative care at the time of diagnosis, along with curative cancer treatment, not only had a better quality of life but also lived a median of 3 months longer. And in 2012, the American Society of Clinical Oncology (ASCO) released a report concluding that according to available evidence, all patients with metastatic cancer can receive palliative care—defined as symptom and pain management, and psychosocial and other supportive care aimed...
at improving quality of life—at the time of diagnosis.

“All of this interest in palliative care is related to the fact that more people are living with cancer than ever before,” said medical oncologist Edith Mitchell, M.D., professor of medical oncology at Jefferson Medical College of Thomas Jefferson University in Philadelphia. “Years ago, we had fewer drugs, and patients didn’t live as long, and fewer survived cancer. Now patients live longer and there are short- and long-term effects of therapy. With newer drugs and toxic effects, patients may be staying on treatments longer, and symptom management has become a major part of what we do. It is important for the oncologist to know about supportive care and how it really fits in with other care for the patient.”

Yet, while medical center palliative-care programs continue to gain visibility and grow in number across the country, experts say, many obstacles remain to integrating such programs into mainstream cancer care, particularly early in treatment.

One reason, some say, is that palliative care has an image problem and is misunderstood.

“The Temel study was our game-changer,” noted Rebecca Kirch, J.D., director of Quality of Life and Survivorship at the American Cancer Society. “Very rapidly after that clinical trial, the Joint Commission (the nation’s preeminent health care-accreditation agency), the Commission on Cancer, and ASCO began to pay more attention and to endorse quality care standards and guidance supporting palliative-care integration in oncology. But our biggest hold-up to wider acceptance has been public perception. Most people are not knowledgeable about palliative care. In contrast, many health care providers and the public continue to believe that palliative care is what you do when there is nothing left to do. They think that palliative care is the same as hospice. It’s not.”

“It seems that no matter what we do, people see palliative care as the end of life,” said geriatrician Ann Berger, M.D., chief of pain and palliative care at the National Institutes of Health. “Palliative care should begin at diagnosis, even if the patient is going to be cured. It’s not only about end of life—it’s about quality of life, including symptom management, and the physical, social, psychological and spiritual aspects of care.”

“Messaging and language matter a great deal—for purposes of public perception, for NIH grants, for professional training, and public policy,” said Kirch. “To change the psyche of the nation to think of quality of life as a priority alongside treatment, we need to find a way to get oncologists to think of palliative care specialists as colleagues and not last resorts.”

**Resources, Training Lacking**

Misconceptions aside, Jennifer Temel, who sees the ASCO report as a strong statement supporting early and universal palliative care, worries that resources are lacking and hindering its widespread use.

“Realistically, the nation does not have sufficient palliative-care staffing and infrastructure to provide care for all patients,” she said. “The ASCO provisional clinical opinion (PCO) brought the issue to the forefront in medicine and presents it as an option for all patients with metastatic cancer. We need to train more physicians to specialize in palliative medicine, and the PCO helps more people understand that palliative care isn’t necessarily end-of-life care. It’s a wake-up call for more funding and training, and additional infrastructure on both local and national levels.”

Improved physician training in medical school and residencies will help change the image of palliative care among doctors and increase its everyday use, said Jamie Von Roenn, M.D., professor of medicine at the Feinberg School of Medicine and director of palliative care at Northwestern University. Although it is a specialty, “we need physicians and oncologists to be trained in primary palliative care, including skills in pain management, and in the basic assessment of anxiety and depression.”

Von Roenn has another concern: Too often, physicians and oncologists think they know how to provide palliative care, when in reality, they may not.

“We can’t change perception and increase the use of palliative care unless we change the standards of what we expect physicians to have competencies in from medical school, residencies, and fellowships,” said Diane E. Meier, M.D., professor of geriatrics and palliative medicine at the Mount Sinai School of Medicine. Meier, also director of the Center to Advance Palliative Care, a national advocacy organization, said that currently, there are few “requirements for physicians to demonstrate skills in patient communication, in the management of pain and other symptoms, and in coordinating care across settings in the course of an illness.” One result of this lack of training, she said, is that patients too often “deal with untreated pain, a lack of communication with doctors and families about what to expect as a disease progresses, and a high rate of hospital readmissions.”

Although Mitchell acknowledged that many oncologists possess variable palliative-care skills, others contend that many are very well trained.

“I think that most experienced oncologists understand that palliative care is not end-of-life care and that it should be integrated into the care of patients almost from the beginning of treatment,” said Richard Schilsky, M.D., who recently left the University of Chicago to join ASCO as its chief medical officer. “Most well-trained oncologists have significant skills in palliative and supportive care as part of daily practice and are comfortable prescribing pain and antinausea medications.”

Still, few receive formal training in palliative care, he admitted, noting “it’s mostly on-the-job training.” Not only are there too

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JNCI | News 373
few palliative-care specialists to meet patient and family needs, he said, they are frequently unavailable to most oncologists in community clinical practice. “The emphasis should be on training more specialists to support oncologists, and be sure that the oncologists themselves have the necessary knowledge. We’ve all seen that patient who has refractory pain or unrelenting nausea; those are situations where access to palliative care specialists can be extremely valuable.”

Making Palliative Care Mainstream

Although improved training may help increase the use of palliative care, Von Roenn suggested emulating a model developed by Cancer Care Ontario in which newly arriving cancer patients are screened through questionnaires. “Every patient who walks into a cancer center there fills out a questionnaire about his or her care, asking about . . . dealing with psychosocial issues, dietary concerns, and other issues related to quality of life,” she said, which becomes part of the patient’s record.

Meier supported this approach. “Adopt the stance that palliative care is a core element of quality care,” she said. “We need to screen all patients for depression symptoms, for possible pain issues, caregiver stress, family understanding of the illness and what to expect, and ask if there are adequate resources at home. If palliative-care needs are identified, there should be protocols automatically triggered by the screening.”

The Joint Commission this year released a new certification in medical centers and hospitals for palliative care, she noted. She said that roughly two-thirds of U.S. hospitals have a palliative-care team on staff, and perhaps in the next several years, this will become a condition of Joint Commission accreditation. “I hope that having a qualified palliative-care team becomes a necessary step for accreditation. When that happens, it becomes a more universal approach.”

Although the field continues to struggle somewhat with wider acceptance by oncologists, and a lack of needed training programs, financial barriers remain to contend with. Temel’s New England Journal study and a subsequent Journal of Clinical Oncology report she cowrote suggested potential cost savings from early palliative care.

At the 2012 annual ASCO meeting, her group presented data showing that overall, there were cost savings from cutting the use of chemotherapy in the last few months of life, along with fewer, and briefer, hospital stays and in referring patients to hospice. Although these savings were offset somewhat by increasing outpatient expenses, savings averaged about $2,000 per patient.

Yet paradoxically, despite overall savings, oncologist reimbursement for palliative-care services continues to lag behind that for other treatments, such as chemotherapy. “They are nowhere near being on par with fee-for-service cancer treatment,” noted Kirch, from the American Cancer Society.

We have to train health professionals, change the payment system, and change the awareness of the nation to demand this type of integrated and patient-centered care because that is what will motivate change,” she said. “Patients, families, and caregivers need to be asked about what is important to them, and health professionals need to consider the implications of that information in helping patients make informed decisions and focus on what is happening in the course of their illness, treatment, survivorship, and death. There’s a steady drumbeat of interest now building in palliative care, and we have to seize the moment and get people to embrace it.”

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