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NCCN Expert Panel Sets the Record Straight on Palliative Care and its Value in the Cancer Care Continuum

The NCCN 21st Annual Conference kicked off with a look into the world of palliative care, exploring barriers to patient access and means to establish multidisciplinary palliative care teams.

FORT WASHINGTON, PA — The number of people being diagnosed with cancer in the United States is increasing year over year, reaching more than 1.6 million in 2015. As the cancer death rate also continues to rise, an increasing amount of attention has been focused on the unique challenges of patients, care teams, and caregivers facing a transition from active treatment to palliative care.

On Thursday, March 31, 2016, the National Comprehensive Cancer Network® (NCCN®) hosted the opening roundtable of its 21st Annual Conference entitled, “Palliative Care: Providing Comfort from a Patient and Provider Perspective.” Moderated by Toby C. Campbell, MD, MSCI, of the University of Wisconsin Carbone Cancer Center, the session featured a multidisciplinary panel of experts: Maria Dans, MD, Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine; Shirin Malekpour, PhD, Family Member Advocate, University of Wisconsin-Madison; Carri Siedlik, APRN, ACHPN, Fred & Pamela Buffett Cancer Center; and Sophia Smith, PhD, MSW, Duke Cancer Institute.

Thursday’s roundtable commenced with Dr. Malekpour describing her mother’s experience with palliative and hospice care. A renowned women’s health advocate, Dr. Malekpour’s mother was an Iranian pediatric hematologist/oncologist who was diagnosed with stage III ovarian cancer.

“After her passing, we realized that her initial medical team was unprepared to meet our needs for palliative care issues. We were never offered any palliative care options outside of chemotherapy or surgery,” she said.

After her mother’s initial palliative care experience, Dr. Malekpour was able to
connect with Dr. Campbell and his team through whom her mother was able to identify her
priorities and values at end of life. Fortunately, after Dr. Campbell’s intervention, Dr. Malekpour’s
mother was able to act on these priorities before her passing.

End-of-life decision-making can be a difficult, uncomfortable process for all parties involved—
patients, their caregivers, and their physicians. The first barrier to access to proper palliative care
planning is that physicians may not be equipped to have end-of-life discussions with their
patients, the panel noted. In order to best support patients with cancer who are making choices
about their long-term care options, programs exist now that help physicians address not only
physical symptoms, but the patient’s psychosocial well-being.

According to Ms. Smith, who is an associate professor of nursing at the Duke
School of Nursing and a social work researcher, Duke Cancer Institute is testing
an educational curriculum around shared decision-making for patients and their
providers whereby patients engage in four conversations around their personal
preferences in order to clarify their personal values, maximize their quality of life,
and promote solution-focused thinking.

A second barrier is that palliative care planning is a deeply personal choice based on patient
preference—a process that is difficult to achieve in a typical 15-minute appointment window.

When a treating physician refers a patient to palliative care, it is because these conversations
require a lot of specialized advanced directives, symptom management, and psychosocial issues,
and it is helpful to integrate these entities into the clinic, said Ms. Siedlik, a nurse practitioner
working in an inpatient/outpatient palliative care service with Nebraska Medicine.

Third, the panel suggested that the term “palliative care” may itself be a barrier, noting that
“supportive care” might be a more palatable name among the patient population.

“Changing the name doesn’t change the concept,” Dr. Campbell said. He added that most
patients know very little about palliation so specialists are free to describe the care as they see
fit.

Another barrier to access to palliative care is the misunderstanding that physicians who suggest
palliative care are giving up on their patients. In many cases, the panel remarked, quite the
opposite is true.

Oftentimes patients have spent months—even years—establishing a trusting relationship with
their oncology team and when it comes time to transition to palliative care—or even survivorship
for that matter—patients may feel rejected, explained Ms. Smith.
The panelists agreed that successful palliative care programs come down to important and timely communication and the ability to allow the patient to take their own values into consideration.

Dr. Campbell described that all oncologists, in some way, practice palliative care. The three modalities for palliative care, he said, are:

- **Primary**: the type provided by primary care physicians who don’t often practice palliative care;
- **Secondary**: routine circumstances in treating people with cancer and their symptoms—both physical and psychosocial; and,
- **Tertiary**: Expert-level palliative care that is referred following recognition that a patient’s palliative needs extend beyond regular appointments with their hematologist or oncologist.

Dr. Campbell encouraged the audience to continue to provide palliative care at all of the above levels, noting that although there are patients who warrant referral to tertiary palliative care, secondary palliative care indeed is an integral part of everyday oncology practice.

It’s important to integrate palliative care into the overall care team—into the clinics and, in some cases, into the home, he said. The palliative care specialist does not need to be a physician, as long as a patient’s oncologist is aware of the ultimate decisions being made, he added.

“The team approach to care is not a substitution—it’s an addition to the care that is being provided in the clinic,” said Dr. Dans, who is the director of the palliative care program at the Siteman Cancer Center at Barnes-Jewish Hospital and Washington University School of Medicine.

Oncologists tend to talk about symptoms, and palliative care providers tend to talk about psychological and emotional symptoms—things that may be considered part of advanced care planning, explained Dr. Campbell.

“Oncologists can ensure themselves that their patients will not be talking about the same things with palliative care specialists as in their clinics,” added Dr. Campbell.

In addition to the physical symptoms treated as part of integrated, comprehensive palliative care programs, care teams need to monitor patient distress. One cause for patient distress, noted Ms. Smith, is financial distress. She explained that many physicians are not equipped to have
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conversations with patients about the cost of care; however, social workers can counsel patients on financial—and other—worries as part of a coordinated care team.

The panel agreed that, as palliative care garners more recognition and acceptance in the treatment spectrum, it is important to be honest with patients about their place in their treatment.

With regard to the progression to hospice, as an oncologist Dr. Campbell noted that his strategy is to discuss the perspective of hospice early in diagnosis and again at each stage of disease progression. Then, when it is time and the door to hospice is open, this is no longer a surprise for the patient.

Prognosis, explained Dr. Dans, has a much broader definition than relative probably of death—it is the relative probably of any number of potential outcomes.

“One way to reconfigure that discussion is a discussion of functional status. I’m less interested in how patients want to die than how they want to live,” said Dr. Dans.

For additional coverage of the NCCN 21st Annual Conference: Advancing the Standard of Cancer Care™, visit NCCN.org/news.

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