Cancer Health™

Closing Perspective Gaps Between Cancer Patients and Healthcare Providers

NCCN Patient Advocacy Summit examines the patient perspective on delivering value and high-quality care.

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The National Comprehensive Cancer Network (NCCN) hosted its annual NCCN Patient Advocacy Summit: Delivering Value for Patients across the Oncology Ecosystem in Washington, DC, on December 11, 2019. The summit brought together patients, advocates, clinicians, policy-makers, and others to share diverse perspectives on the meaning of value in cancer care. The event also featured a keynote address on incorporating the patient voice into evidence-based care from Paul G. Kluetz, MD, deputy director, Oncology Center of Excellence, U.S. Food & Drug Administration (FDA).

“We must always keep in mind that no two individuals will define value in exactly the same way,” explained Ilana Feuchter, MA, senior manager for national advocacy, National Ovarian Cancer Coalition. “Therefore, patients must be included in any discussion of value at the beginning of their diagnosis and throughout each step of the process as that definition may change following treatment or if there’s a change in prognosis.”

Representatives from some of NCCN’s member institutions shared their experience from the clinical and institutional perspective with lessons learned from their high volume of cancer patients.

“Improving patient experience is an essential task for clinicians and hospitals,” said Justin E. Bekelman, MD, associate professor and director of the Penn Center for Cancer Care Innovation, Abramson Cancer Center of the University of Pennsylvania, who delivered a keynote address titled “High-value cancer care: what’s in it for patients, clinicians, hospitals, industry, and payers?” “It’s part of our mission, right up there with improving treatment outcomes and affordability, to ensure that each patient is approached with humanity and humility and feels the care they received was the best it could possibly be.”

“Personalized care for people with cancer is not only driven by clinical algorithms, but also includes a care design for each unique patient and their families, starting with access, finances, social service support, and one-on-one relationships with their clinical support team. Personal care design allows every patient's voice to be heard so their goals for care can be achieved," said Kimberly Bell, BSN, MBA, administrator of cancer services, Cleveland Clinic Taussig Cancer Institute. "The value-based payment models being developed by payers and providers must consider the patient's perspective on quality, care continuum, and finances. As we evolve in this area, this perspective needs to be integrated so patients feel the positive impact on care."

Financial toxicity was a recurring topic throughout the summit, including issues like fee transparency, lost wages, and auxiliary costs of care.

"We know that behind the words 'patient,' 'sick,' and 'cancer,' there is a family," said Carla Tardif, chief executive officer, Family Reach. "That family's only worry should be getting to the other side of cancer, but when financial barriers get in the way of treatment that is simply not the case."

Shame and silence around a type of cancer, or as a member of a marginalized community, can pose additional barriers to high-quality care.

"LGBT people fear homophobia and hetero-normative values will crowd out inclusive consideration of the healthcare needs for our communities regarding value-based care," said Darryl Mitteldorf, LCSW, executive director, The National LGBT Cancer Project. "LGBT people can have different configurations of what a family is, and our families are rarely considered by the healthcare system in the United States. The National LGBT Cancer Project, along with our partner, Malecare, facilitates the world's largest anxiety support group, with over 43,000 active members, because LGBT people present with higher incidence rates of anxiety than most groups."

"You have to be your own best advocate. If you believe something is wrong, press on, because you are probably right," said Lillian Kreppel, patient ambassador, The Anal Cancer Foundation. "Don't ignore symptoms like bleeding, lumps, bumps, or hemorrhoids. Don't be so embarrassed that you won't seek medical help. And don't necessarily think that doctors have all the answers or know everything, especially when you are the one who lives in your body. Get a second and third opinion, and get educated on the HPV vaccine."

Sexual health was also a key topic of conversation.

"One big issue for colorectal cancer patients regardless of age, but especially younger patients, is that physicians need to better address intimacy, fertility preservation, and overall sexuality," said Ronit Yarden, PhD, MHSA, senior director of medical affairs, Colorectal Cancer Alliance. "Treatments for colorectal cancer often come with debilitating side effects that can reduce a patient's quality of life. We not only want patients to survive, but we want them to thrive. They need open and honest conversations about their different options and the impact that their treatment will have on their everyday lives. Having these conversations before treatment—not afterwards, when patients are often surprised and overwhelmed—will help ensure that survivors can live their best lives."

"Maintaining quality-of-life specific to sexual health and intimacy is important to prostate cancer patients post treatment," agreed Chuck Strand, chief executive officer, Us TOO Prostate Cancer Education & Support. "Erectile dysfunction and urinary incontinence can be temporary or ongoing treatment side effects from surgery or radiation. It's important to patients and their partners to address this with their healthcare team during the process of making a shared decision on a treatment pathway, and be prepared to address management of these issues, if necessary, while recognizing the difference between intimacy and sex."

Several panelists reiterated that new laws and policies can serve as an important motivation for improvement, as long as they are implemented with the end goal of improving the patient experience, and not simply a checklist to cross off. Increasing use of shared decision-making and patient-reported outcomes can result in care that better meets the needs of the people receiving it.

The panel discussions were moderated by Clifford Goodman, PhD, senior vice president, The Lewin Group, and included the following additional participants:

- Alan Balch, PhD, CEO, National Patient Advocate Foundation
- Kristin L. Carman, PhD, MA, director of public and patient engagement, Patient-Centered Outcomes Research Institute (PCORI)
- Brian Connell, executive director, federal affairs, The Leukemia & Lymphoma Society (LLS)
- Andrea E. Ferris, MBA, president and CEO, Lungevity
- Elizabeth Franklin, LGSW, ACSW, executive director, Cancer Policy Institute, Cancer Support Community
- Miranda Goff, LICSW, support services manager, GO2 Foundation for Lung Cancer
- Edward Kim, MD, chair, NCI Central Institutional Review Board, Adult CIRB — Early Phase Emphasis (EPE) Board
- Molly McDonnell, director of advocacy, Fight Colorectal Cancer

The NCCN Patient Advocacy Summit follows the recent NCCN Policy Summit on Defining, Measuring, and Applying Quality in an Evolving Health Policy Landscape and the Implications for Cancer Care. In 2020, NCCN Policy will host summits on how to accelerate advances in cancer care research, drive down healthcare costs, and improve patient access to quality cancer care across the lifespan. For dates and other information, visit NCCN.org/policy, and join the conversation online with the hashtag #NCCNPolicy.

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