NCCN POLICY SUMMIT: ADDRESSING THE BARRIERS TO CARE LGBTQ+ COMMUNITIES FACE

December 13, 2022

This is the first post in a blog series on the National Comprehensive Cancer Network (NCCN) Patient Advocacy Summit: Best Practices and Policies for Addressing the Health Needs of LGBTQ+ Cancer Patients and Survivors. This event was held virtually and in person in D.C. on Friday, December 2.

The elegance and prestige of those who have walked its halls permeates through the National Press Club in D.C.—as their images decorate its walls. The building's unique history made it a fitting venue for the NCCN's annual policy summit series, closing out 2022 with a patient advocacy summit focused on sexual orientation and gender identity that highlighted the barriers that can prevent lesbian, gay, bisexual, transgender, queer and/or questioning, and other community members (LGBTQ+) with cancer, as well as survivors, from accessing high-quality, equitable care. It was equally fitting that Admiral Rachel L. Levine, MD, assistant secretary for health at the Department of Health and Human Services (HHS)—who is the first openly transgender, four-star officer across the eight uniformed services of the United States—delivered the day's welcome message to virtual and in-person attendees.

"As healthcare professionals, we learn to treat patients without discrimination. We work every day to benefit the sick, to protect people from harm, and…to make our community whole," Dr. Levine said. "We can do that with medicine, and we can do that as well with warmth, empathy, compassion, and understanding." According to Dr. Levine, there are health inequities that cause LGBTQ+ patients to experience cancer differently, compared to the rest of the oncology population. "LGBTQI+ people with a cancer diagnosis need culturally appropriate and affirming care," Dr. Levine said. "Providers and advocates should understand the unique challenges of these communities." (The addition of the "I" in the commonly used LGBTQ+ acronym ensures the inclusion of the intersex community.)

Unique LGBTQ+ Care Challenges

The summit's opening panelists for "Breaking Barriers: Identifying and Addressing Unique Cancer Care Needs of LGBTQ+ Patients" shared more than just a stage. Each of them identified as a member of the LGBTQ+ community, and their backgrounds in healthcare, as either patient or provider, coupled with their personal experiences made them uniquely qualified to identify the cancer care-related needs of LGBTQ+ patients. "I believe that implicit bias almost cost me my life, so I am here to share my story," said Paula Chambers-Raney, hope coordinator at Fight Colorectal Cancer. Chambers-Raney is a survivor of Stage I colon cancer, who advocates for effective cancer screening practices directed toward LGBTQ+ communities of color. "I am an advocate for change because I know it can happen, and I know it will happen," she said.

Chambers-Raney was continually misdiagnosed for nearly one year before a visit to the emergency room revealed a tumor. “I was misdiagnosed by my PCP [primary care provider] several times. When I started to see red in my stool [and] when I started to lose weight, nobody gave me a screening,” she said. “I could not be on my wife’s insurance because we were not legally married in Texas. One doctor told us, ‘I can’t treat you because you are going to hell.’ I got used to being treated badly in healthcare systems.”

As Chambers-Raney’s powerful story demonstrates, Archana Pathak, PhD, interim director, Q Collective; special assistant, Programs and Initiatives; and associate professor of Gender, Sexuality, and Women’s Studies at Virginia Commonwealth University, believes healthcare organizations need to be aware of the trauma from previous healthcare-related experiences patients walk through their doors with. Like Chambers-Raney, Dr. Pathak has been the subject of bigoted remarks from healthcare providers. “I have had nurses walk out and say, ‘I won’t treat you,’” Dr. Pathak said. “There are two people on a panel, who have never met each other, but have gone through the same experiences.”

Dr. Pathak believes that any issues involving LGBTQ+ patients should be approached with assumptive compassion. “Does that bathroom just say male and female? All these things add up,” she said. “I don’t understand how we have healthcare systems where everyone isn’t treated as a whole human being. That is a failure of the health system.”

Chastity Burrows Walters, PhD, RN, senior director of Patient & Community Education at Memorial Sloan Kettering Cancer Center, asserts that many LGBTQ+ community members do not visit a physician due to fears of discrimination. According to the National LGBT Cancer Network, “LGBT patients often face a combination of ignorance and discrimination in accessing healthcare,” and a history of experiencing or fearing negative responses from healthcare professionals may prevent LGBTQ+ individuals from obtaining routine care and cancer screenings. “I don’t want anyone to miss a screening because they are scared to go to the doctor,” Dr. Burrows Walters said. “They are worried more about how they will be treated instead of what the screening would say.”

Reports also indicate that lesbians without an established and trusted reproductive health physician obtain routine mammograms, colonoscopies, and Pap smears at a lower rate than heterosexual women. In addition, gay men who have not disclosed their sexual orientation to their healthcare provider are less likely to be screened for cancers that are not as prevalent in the heterosexual population (e.g., anal cancer). “We are dying from these things. When we delay our screenings, there are consequences, and death is one of them,” Dr. Burrows Walters said. “Access, awareness, and acceptance, that is all we are asking for.”

A Lack of Awareness and Representation

According to Wui-Jin Koh, MD, senior vice president and chief medical officer at the NCCN, healthcare providers may lack the education and awareness on how best to navigate LGBTQ+-related issues. Dr. Burrows Walters echoed this sentiment, arguing that healthcare providers get nervous when outside of their comfort zone. “We know our comfort zones. We know what we know,” Dr. Burrows Walters said. “We make mistakes when we are panicked.”

Mandi L. Pratt-Chapman, PhD, associate center director for Community Outreach, Engagement and Equity at the George Washington Cancer Center, and associate professor of Medicine and Prevention and Community Health at The George Washington University, highlighted the importance of staffing a greater number of LGBTQ+ providers on cancer care teams. “I believe the driver of change is going to be physician representation,” said Dr. Chapman.

Representation of LGBTQ+ individuals in data sets will also be key. “Data is everything. When we don’t have data, we can’t get funding. And, when we can’t get funding, we cannot do the research we need,” said Dr. Burrows Walter. “The reality is, until we have standard systematic data collection across different centers, we will never have the information to develop the targeted strategies to effect change.” Dr. Pratt-Chapman expressed a similar belief. “We cannot diagnose the problem if we can’t stratify the data,” she concluded.