Best Practices for Addressing the Health Needs of the LGBTQ+ Community in Oncology Care

Presented by Bláz Bush, MEd; Paula Chambers Raney; Shail Maingi, MD; Mandi L. Pratt-Chapman, PhD; and Scout, PhD; and moderated by Clifford Goodman, PhD

ABSTRACT

Patients with cancer in the LGBTQ+ community experience worse health outcomes when compared with their non-LGBTQ+ peers because of a variety of factors, including stigma, underrepresentation in research, lack of support, and implicit bias on the part of clinicians. For generations, many LGBTQ+ people have feared disclosing their identity to providers, leading to gaps in care and even higher mortality. As more people are identifying as members of the LGBTQ+ community, it’s crucial for providers to recognize them appropriately in healthcare, take steps such as acknowledging chosen names and pronouns, and provide care free from judgment. In today’s political climate, members of this community are facing increasing scrutiny, challenges, and barriers to accessing safe and affirming care. Providers can do their part to improve health outcomes among LGBTQ+ people by making their practices known as safe and affirming spaces, working to increase inclusivity in oncology care and improving data collection.

Who Comprises the LGBTQ+ Community?
LGBTQ+ is an abbreviation for lesbian, gay, bisexual, transgender, queer, and more, which encompasses genderqueer, nonbinary, questioning, queer, intersex, and asexual, among others. According to Bláz Bush, MEd, Executive Director for the LGBTQ+ Health Program, Stanford Medicine, who identifies as queer/genderqueer, the community is focused on inclusivity, so the term LGBTQ+ is used as an umbrella to provide representation for an incredibly diverse and underrepresented group.

“So many of us don’t see ourselves in society, and especially in healthcare,” Bláz said. “Anybody who doesn’t feel like they are represented well in our society at large, and in our social construction around gender and sexual orientation, are part of this community.”

Scout, PhD, Executive Director, National LGBT Cancer Network, who identifies as trans, nonbinary, and queer, acknowledged that the proliferation of letters is complicated, even for those in the community. However, Bláz maintains that every added letter increases the feeling of social support felt among those in the community, particularly among the youth, who tend to feel more isolated.

“The more we create these categories, the more people begin to understand and connect with others online and in person,” Dr. Scout said. “They no longer feel like they’re one gazelle alone on the Serengeti, which makes us feel very much like we’re prey. Instead, we have a huge group of people around us, who are similar to us.”

Increased Cancer Risk in the LGBTQ+ Community
According to Shail Maingi, MD, a community oncologist and palliative care physician, Dana-Farber Cancer Institute, who identifies as a “Pennsylvania-born Punjabi-American lesbian,” several social factors and gaps in healthcare point to the increased cancer risk seen in the LGBTQ+ community. However, evidence-based sexual orientation and gender identity (SOGI) data are lacking because generations of LGBTQ+ people are staying “in the closet” as a result of stigma, safety concerns, fears about job security, and a host of other reasons for not disclosing their identities.

Now, however, society is changing. According to the United States Census data, 15% of people aged <35 years and 7% of the total population now identify as part of the LGBTQ+ community.

“As people are coming out more, we’re finding that this invisibility has been harmful,” Dr. Maingi said. Minority stress can contribute to increased rates of smoking, alcohol intake, and substance use, as well as increased obesity. Laws prohibiting gay marriage have historically led to gaps in insurance coverage in this population and limits in healthcare access. Distrust of the healthcare system and the experience of discrimination can lead to avoidance of healthcare settings altogether, and assumptions about sexual behavior within the healthcare system can lead to missed opportunities for appropriate cancer screenings.

According to Mandi L. Pratt-Chapman, PhD, Associate Director for Community Outreach, Engagement,
and Equity for the George Washington Cancer Center in Washington, DC, who identifies as queer. 3 main factors can be blamed for the cancer disparities seen in this population: lack of safety, lack of social support, and inertia.

She noted that stress and maladaptive coping strategies are particularly high in the bisexual community because of biases coming from both the LGBTQ+ community and the heterosexual/cisgender community. However, social support has been shown to mitigate that stress. “When people have supportive families, partners, friends, physicians, and healthcare teams, some of these disparities are mitigated,” Dr. Pratt-Chapman commented. “We need to be aware of that in terms of interventions and tapping into resiliency.”

Bláz emphasized the impact of the current political climate on members of the community. “There’s such a threat across the country right now. As of today, a total of 21 states have proposed anti-trans laws, and some laws prohibit us from talking about LGBTQ+ lives in schools.”

These healthcare disparities can have a snowball effect throughout life, Bláz added, and shared his own story of growing up queer in rural Texas. He didn’t feel he had a safe place to discuss his sexuality, so he grew up terrified of contracting HIV but too fearful of stigma to be tested in his hometown. When he later moved to New York, Bláz worked with clients who, like himself, didn’t have access to safe and confidential HIV testing until they went to college. However, a critical difference is that in many of these cases the delay in access to HIV tests resulted in a dual diagnosis of HIV and AIDS, leading to a catastrophic cascade of events in many of their lives and increasing their risk of developing cancer.

However, Bláz added, even in places that do provide gender-affirming care for members of this population, the system eventually becomes disjointed for people who receive cancer diagnoses and must leave a safe primary care environment. This healthcare system failure can lead to even higher cancer mortality. Bláz shared an example of what typically occurs if a young trans person who was diagnosed with cancer at the Pediatric and Adolescent Gender Clinic at Stanford Medicine had to move to an adult cancer center to receive treatment. Eventually, gender-inclusive approaches are lost, their pronouns are disregarded, and they eventually stop engaging in care across the board.

A provider’s inability to respond to how a patient identifies or describes their identity can lead to these patients being “pushed off” in another direction or even to a total shutdown in care, agreed moderator Clifford Goodman, PhD, an independent consultant in healthcare technology and policy.

According to Dr. Scout, although trend analysis and SOGI data collection are challenging in this population, one statistic is certain: the number of people identifying as LGBTQ+ is increasing. “I’m optimistic that part of the reason for this is people feeling safer about disclosing [their identity],” he said. “There might have been a latent level of identification in the population because they didn’t feel that safety before.”

From a practical standpoint, the magnitude of this diverse population is increasing, and providers will undoubtedly have more and more patients who identify as members of this community, agreed Dr. Goodman.

“If people are going to disclose to us—and that is what we want—we have an obligation to use that information to elevate care,” said Dr. Maingi. “We’re not just collecting information and putting it into a file; we’re asking people to be vulnerable. We’re asking people to do this in states that are actively making it difficult to disclose. So, if we’re able to get that information, we should use it, acknowledge it, and incorporate it into the visit.”

Paula Chambers Raney, Hope Coordinator for the Fight Colorectal Cancer Organization and a survivor of stage I colorectal cancer, agreed that bias on the part of healthcare providers can be incredibly dangerous. “As a lesbian whose cancer was found in the emergency room, I believe that implicit bias almost killed me,” she said. She believes it took so long to receive her diagnosis because she wasn’t taken seriously by care providers, even after presenting with signs and symptoms of colorectal cancer. One doctor even explicitly refused to treat her because she was “gay and going to Hell.”

“I didn’t know that that wasn’t okay, and when I started sharing my story, I found other people had similar experiences,” she said. “When an individual’s dignity and humanity are not acknowledged, it just makes a person who’s already afraid of hearing the ‘C word’ not want to go back and get the necessary tests.”

Ms. Raney said this struggle is particularly acute among Black trans women, because of being prone to both racial and gender biases. Many of them simply avoid seeking care altogether because they don’t feel they will be seen or taken seriously. “When we’re talking about cancer care, time is of the essence,” she explained. “This just snowballs and delays treatment; Black trans women need to be heard.”

What Can Providers Do?
According to Bláz, one of the easiest things providers can do is to use a person’s correct name and pronouns. “Using the right pronouns and using the right names really does save lives,” Bláz said.

Bláz encourages providers to practice these interactions by introducing themselves using their own name and pronouns. This can help a patient feel safe to disclose their own. Using “they/them” as singular pronouns can be challenging for providers who aren’t used to it, so Bláz urges everyone to approach it as if they’re learning pronouns in a new language. It simply takes practice, and
providing an LGBTQ+-focused curriculum for established providers as well as for those still receiving their education will be a pivotal part of making this commonplace.

In addition, Bláz added that oncology providers should be educated on the implications of gender-affirming surgery for trans patients. For example, conducting a prostate cancer screen on a trans woman may require reaching out to the patient’s gender-affirming surgeon to learn about techniques and access points for assessing the prostate.

Dr. Scout noted that more information is available. For example, an 8-part cancer-focused training series is available free online from the National LGBT Cancer Network (https://cancer-network.org/welcoming-spaces/), and NCCN also provides a toolkit with resources (https://www.nccn.org/patient-advocacy-resources).

Dr. Pratt-Chapman emphasized the importance of simply trying to do better. “It’s okay to be uncomfortable in practicing these things, but it makes a difference, and people are usually extraordinarily forgiving,” she said. “I think the point is to try.” That said, the panel also emphasized the importance of impact: good intentions are not sufficient when the impact of a provider’s actions is loss to follow-up care.

**Outreach and Eliminating Care Avoidance**

Dr. Maingi wants providers to understand that they can help prevent members of the LGBTQ+ community from avoiding care. Community outreach can make a significant impact by making an institution known in the community as a provider of culturally competent care. This can be done through such avenues as the Human Rights Campaign, the National LGBT Cancer Network, and LGBTQ+ provider directories. “I don’t want people thinking this isn’t our problem as clinicians, to walk away from this conversation thinking, ‘we can’t take care of LGBTQ+ communities if they don’t come to us,’” she said.

**Offering Trauma-Informed Care**

Experiencing systemic discrimination can be traumatic for many, so offering trauma-informed care to those in need should be another central component of providing equitable care, added Dr. Maingi. She offered an example of a lesbian patient who did not want anesthesis for her surgery because of traumatic memories of being unconscious, and another example of a trans man who did not want treatment for triple-negative breast cancer that would lead to facial hair loss, because of fears of not being recognized. These types of situations can be challenging and do require patience, she admitted, but it’s important to work with patients to find solutions rather than dismissing them.

“People will come to you if you let them know that you’re safe to come to,” Dr. Maingi said.

**Obtaining Research Data on the LGBTQ+ Community**

Reiterating the challenges around SOGI data collection in the LGBTQ+ community, Dr. Scout emphasized the importance of providers asking pertinent questions of their patients about sexual orientation and gender identity. This information informs things like cancer registries, research, and interventions. “Identifying, quantifying, and fixing health disparities start with health records,” he said. “So, when you’re not asking these questions, you’re helping to perpetuate those disparities.”

Dr. Pratt-Chapman noted that her research shows that leadership support, structured storage of data in the electronic health record, and understanding the relevance of data to clinical practice are factors that have been found to be associated with institutional settings that collect these data versus those that do not. Bláz added that many electronic health records now include an organ inventory, which can be helpful for providers treating LGBTQ+ patients, particularly those in the trans and intersex/differences in sex development (DSD) populations.

Dr. Maingi pointed out that the NCCN is currently working to de-gender its guidelines (ie, “people of child-bearing years” vs “women of childbearing years”). In the meantime, taking steps to provide implicit bias training for providers, implementing safe space support groups, and employing more LGBTQ+ people in healthcare are all steps in the right direction.

Dr. Goodman asked the panel about the impact of certain current events, noting recent legislative and judicial developments in various states. Panelists concurred that these are increasing risks to the health and safety of the LGBTQ+ community.

“LGBTQ+ people are under attack right now. The people on this panel are putting themselves in harm’s way because we think it’s that important to ask you to please help us,” stated Dr. Scout. “So, please do not be silent.”

**Disclosures:** Dr. Maingi has disclosed serving as a consultant for PRIME Oncology, and owning equity interest/stock options in Merck & Co., Inc. Dr. Pratt-Chapman has disclosed serving as a consultant for Merck & Co., Inc., and Novartis Pharmaceuticals Corporation; and receiving honoraria from Pfizer Inc., and Takeda Pharmaceuticals North America, Inc. Dr. Scout has disclosed receiving grant/research support from Bristol-Myers Squibb Company, Genentech, Inc., Gilead Sciences, Inc., GlaxoSmithKline, and Syros Pharmaceuticals; and serving as a consultant for EMB Serono. The remaining presenting disclosures are confidential.

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