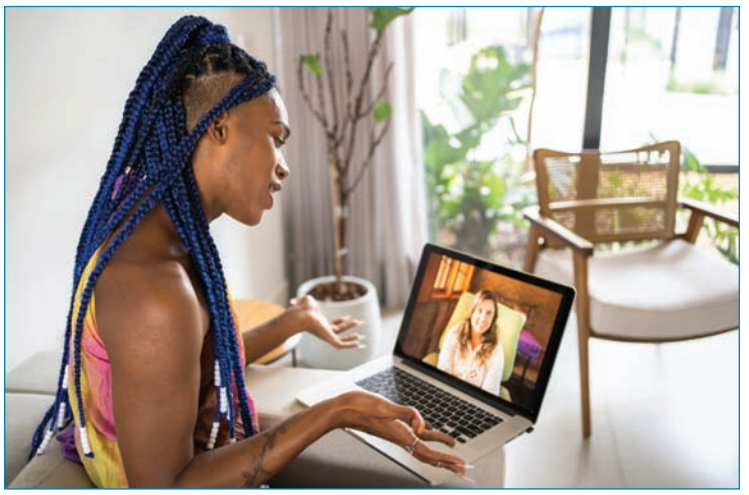
Improving Cancer Outcomes Through Increased LGBTQ+ Awareness

BY LINDSEY NOLEN

Just as a patient's particular cancer will influence their treatment, a patient's care plan must factor in their gender identity and gender expression. According to the LGBTQIA+ Health Education Center glossary of terms, a person's gender identity is defined by a person's inner sense of being a girl/woman, boy/man, beyond, or having no gender; all people have a gender identity. On the other hand, it is gender expression that represents how one presents themselves through behavior, mannerisms, speech patterns, dress, hairstyles, etc.

By fully understanding each of these fundamental LGBTQ+ terms, oncologists are able to more effectively reduce harm and improve cancer outcomes across this population of patients. To help explain why LGBTQ+ awareness is important amongst practitioners, and how these practitioners can improve upon their ability to deliver effective care to this population, Cedars-Sinai hosted an LGBTQ+ Cancer Symposium in June to expand on ways to promote LGBTQ+ inclusivity across health care and the cancer journey.



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One of the first presentations given at the symposium, titled "Overcoming Barriers and Medical Mistrust," helped begin a discussion about the importance of sexual and gender minority (SGM) health. Author Kenneth Mayer, MD, Medical Research Director and Co-Chair of The Fenway Institute, as well as Professor of Medicine at Harvard Medical School, shared that these patients often receive suboptimal care, as they are reticent to disclose their identity because of fears of stigma. He noted that many health care providers today remain unaware of the diversity that exists across SGM patients and how this diversity impacts varying oncological conditions.

For these reasons, he stressed that culturally competent care must be prioritized. Without inclusive care, Mayer explained that SGM patients may perceive themselves to be in non-affirming environments, which can internalize stigma that may thereby decrease their willingness to seek care, engagement in care, and medication adherence, as well as increase their ongoing behavioral risks (such as depression).

As these risks specifically relate to cancer treatment, Ash Alpert, MD, MFA, a fellow in Hematology and Medical Oncology at the Wilmot Cancer Institute of the University of Rochester Medical Center, shared through her presentation, "Centering Patient Priorities and Identities to Reduce Harm and Improve Outcomes for Transgender and Gender Diverse People with Cancer," that verbiage used within modern literature continues to create barriers to adequate care.

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She relayed that, in the NCCN ovarian cancer guidelines, the word "women" appears 192 times. Yet, she shared this information alongside a photo of Robert Eads, a transgender man who was denied care for and died from ovarian cancer, and whose life was the subject of a documentary named *Southern Comfort*.

"You can imagine that oncologists who are [familiar] with this sort of language, who are reading the word 'women' 192 times in the guidelines about ovarian cancer, may feel somewhat confused or uncomfortable or uncertain when a man walks into their office and has ovarian cancer," Alpert said.

From clinical trial inclusion to the exclusivity of oncology facilities (i.e., changing rooms, gowns, etc.), many providers do not realize that they are enforcing the residence of gender expectations for transgender people with cancer in their practice. Another way in which they do not understand that they are causing harm is through their general language. Alpert shared that this notion was emphasized to her through one of her qualitative studies where transgender people talked about their experiences after physicians found out they were transgender.

"One Black transgender woman said, 'It wasn't until after I told the doctor that I was on hormones for transition that I began [being addressed as he],'" Alpert shared. "Additionally the language that oncologists use in their documentation or notes may also erode their relationships with patients. In that same qualitative study, we investigated the experiences of transgender people before reading their electronic health records."

She shared that all of the patients who had access to their medical records noticed that providers had used the wrong name, pronouns, or gender marker when describing them. They even noticed this with the clinicians whom they had good relationships with, and who had used the correct names, pronouns, and gender markers when treating them in the clinic. Through these findings, Alpert stressed that oncologists' actions may in fact worsen rapport.

> "Through [my 25] years, I've learned to stay open and figure out ways to make people feel comfortable. It's really just creating that space, and I think everyone has their own way of creating that space of safety."
>
> *—Jan-Kees van der Gaag, MSW, LCSW, at Cedars-Sinai*

Such data inaccuracies can also lead to poorer care in general. For example, lab values are often based on gender/sex markers, and the gender listed in patients' charts is related to registration and other logistical factors. If the values are swayed by sex and gender norms used to develop standards for care, then the care provided will not be the most effective means of treatment.

"What this ends up meaning for patients is that often they have persistently flagged, abnormal values when their labs are actually just fine. This can be quite concerning for patients and clinicians as well,"

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Alpert said. "One participant in one of our studies said, 'When I get labs done, they have me as a female for my lab levels, and so they're always a little bit off and it freaks me out, and I'm like, is this normal?'"

Also concerning is that some chemotherapeutic dosing is based on creatinine clearance, which is based on a sex/gender marker. Alpert said it is currently unclear how to extrapolate this dosing to transgender people, particularly those who have had surgery or who are on hormone therapy.

"There are some small steps that we can take to disentangle some of these variables and concepts and provide more thoughtful nuanced and inclusive care for all of our patients," Alpert conveyed. "One of them is by changing guidelines, and ASCO recently started to do this and has begun to develop guidelines that are gender inclusive."

She indicated that eligibility criteria for studies should also be amended to ensure that everyone is welcome across health care settings. Words like "male" and "female" can easily be changed to the word "people." She said this is important because, if people are excluded from studies based on prior hormone therapy or cancer, their experiences cannot become better understood for future cancer treatment purposes.

Alpert theorizes other "big changes" that could help providers progress toward greater LGBTQ+ inclusivity and, therefore, increased oncological outcomes, including:

- normal lab ranges and drug dosing based on other objective measures;
- clinical trial data collected on hormone levels and gender rather than a conflated sex/gender variable; and
- laws prohibiting insurance refusals on the basis of a sex/gender marker.

Addressing more LGBTQ+ inclusivity topics, Cedars Sinai welcomed an SGM oncologist and social work panel including Christopher T. LoPiccolo, NP, and Jan-Kees (JK) van der Gaag, MSW, LCSW. Together, they expanded on the theme that oncologists must prioritize LGBTQ+ gender identity inclusion and awareness across cancer treatment settings. Their conversation went on to explain why progression must start from the moment a clinician is met with an LGBTQ+ patient.

"Through [my 25] years, I've learned to stay open and figure out ways to make people feel comfortable," van der Gaag said. "It's really just creating that space, and I think everyone has their own way of creating that space of safety."

"We're a team and we're there to help, and I think sometimes [cancer patients] think that they're [in our practice just] for chemotherapy, but it's so much more than that," added LoPiccolo. [We're there for] psychosocial support, mental health support, side effect support—it's holistic. I tell all of my patients, 'The more that you're able to share, the more you're comfortable to share, the more I can get you to what you need.'"

On the topic of communication, van der Gaag explained that many patients come into cancer care with a preestablished set of values. He believes that to understand these values, communication with LGBTQ+ patients with cancer must be fluid. He believes the provider must continuously ask questions and remain curious to better understand the unique experiences and perspectives of each patient.

"I think what's so tricky in the medical system is that we want to put [everyone and everything] in a checkbox, and then once we have the checkbox we want to keep it there. Cancer has shown again and again it that doesn't work that way. People are constantly evolving and pushing themselves and growing," van der Gaag said.

Thanks to these contributing presenters and others, the information presented at the Cedars-Sinai LGBTQ+ Cancer Symposium successfully demonstrated the need to better understand the LGBTQ+ patient perspective on oncological care. More important than ever before, quantitative data is beginning to help medical professionals understand LGBTQ+ patients and their particular cancer outcomes.

Due to this data, more information is already available, including a 2020 study of cancer prevalence in transgender people was published by Boehmer et al in the journal *Cancer* (2020; https://doi.org/10.1002/cncr.32784). The authors of the report estimated that 62,530 of the nearly 17 million cancer survivors in the U.S. are reported to be transgender. This was broken down into an estimated 30,420 transgender women, 21,970 transgender men, and 10,140 gender nonconforming individuals.

Further, the grant study "More Information About Cancer in LGBTQ+ People May Help Improve Prevention, Diagnosis, and Treatment," coordinated by Brittany M. Charlton, ScD, added that people who identify as LGBTQ+ may have a higher risk of getting cancer than those who identify as heterosexual or cisgender. Potential cancer disparities in cervical, breast, lung, and other types of cancer are largely due to discrimination and other factors.

Similar to Alpert's thinking, Charlton's results suggest that tailored health policies, public health programs, and clinical practices are needed to "raise awareness of and access to cancer prevention information and screenings based on nuanced risk factors according to sexual orientation, gender orientation, race/ethnicity, and other sources of social inequity." Ultimately, the symposium and related research point to the fact that awareness and inclusion are the keys to progression and increased LGBTQ+ cancer outcomes. OT

Lindsey Nolen is a contributing writer.