Cancer and the LGBTQ+ Community [VIDEOS]

From structural barriers and binary patient forms to gendered diseases, “queer cancer” can be fraught with bias and bad assumptions.

August 14, 2023 By Fred Hutch News Service and Diane Mapes

Spouses are ignored or assumed to be supportive “buddies.” Patients are deadnamed, referred to by a name they no longer use or relate to. And then there’s the delayed diagnoses, something Molly Wilvich experienced back in 2013 trying to find out what was causing their weird one-sided throat pain.

An emergency room doc thought it was strep. It wasn’t. The ear, nose and throat specialist said it was a deviated septum and recommended surgery. Wilvich demurred, finally landing at a cancer treatment center. There, a doctor refused to accept what Wilvich suspected: they had an HPV-driven cancer.

“The doc said, ‘It can’t be an HPV cancer — those only affect men,’” said Wilvich, a 44-year-old bisexual design manager who was assigned female at birth and identifies now as nonbinary.

All told, it took six doctors, multiple appointments and many months to get an accurate diagnosis — stage 4a throat cancer — a delay Wilvich attributes to bias. While HPV-driven throat cancers are more common in white male heterosexuals age 50 and older, anyone who has oral sex with a person with HPV is at risk of becoming infected themselves. Once infected, the virus has the potential to cause pre-cancerous changes to cells as well as cancer itself.

“There’s no such thing as girl cancer or boy cancer — it’s just cancer,” Wilvich said. “I had to go several rounds with that doctor until he agreed to a biopsy. I told him, ‘This isn’t a cancer that just affects men. It’s a cancer that mostly affects people who have sex with women. I have sex with women.’”

From delayed diagnoses to missing choices on medical forms to simply not being seen, heard, acknowledged or offered much-needed preventive screening — cancer while queer can be frustrating, heartbreaking and at times, much harder than necessary. (The word “queer” has become a sort of umbrella term for non-heterosexual individuals and identities including lesbian, gay, bisexual, queer/questioning, Two-Spirit, intersex, asexual and more.)

“People have been turned away from care, made to feel not welcome and been discriminated against — either overtly or through microaggressions,” said Matty Triplette, MD, MPH, a health services researcher and physician who serves as medical director of the Lung Cancer Early Detection and Prevention Clinic at Fred Hutchinson Cancer Center. “This may have been more common in the past, but we’ve repeatedly heard about experiences with bias from LGBTQ+ patients with cancer.”

More Discrimination, Less Data

Although around 7% of Americans are lesbian, gay or bisexual (and another 5% of adults under 30 are trans or nonbinary), there’s not much research on LGBTQ+ patients with cancer. Australia’s Out with Cancer group recently conducted a large online survey of 430 LGBTQ patients with cancer in Australia and other English-speaking countries. Among their findings, published in Frontiers of Oncology:

- More than 40% reported high or very high distress levels, 3-6 times higher than in non-LGBTQ cancer studies.
- 82% of respondents experienced discrimination in their life in general.
- 33% experienced discrimination during their cancer care.
- Trans and gender diverse people had higher rates of distress and lower quality of life.

These and other findings led the group to call for “inclusive and affirmative cancer care for LGBTQ patients,” a similar response to that of the American Society of Clinical Oncology’s 2017 “Strategies for Reducing Cancer Health Disparities Among Sexual and Gender Minority Populations.”

LGBTQ+ people with cancer aren’t just facing discrimination, distress and delays, however. Other research shows they may also face higher risk of cancer recurrence.

A study in the Journal of Clinical Oncology in 2022 showed sexual and gender minority patients with breast cancer experienced delays to diagnosis and treatment, and also had a higher chance of cancer recurrence — around 31% as compared to 14% for non LGBTQ+ folks.

Lack of Good Data

Discovering what's at the heart of these health disparities and poor outcomes is crucial, especially as the population ages and the number of cancer patients — of all stripes — continues to rise.

But there's a dearth of data on LGBTQ+ patients with cancer. The main reason? A lack of self-reported sexual orientation and gender identity, or SOGI (pronounced "So-Gee") data.

Although mandated by the Affordable Care Act, only a few cancer centers collect this data, so it can't be systematically incorporated into national cancer registries like the National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program. That means researchers can't determine overall cancer risk and outcomes for these populations.

Sometimes, SOGI data are just not requested: medical forms don't have the proper checkboxes or care providers don't ask for it. Other times, it's not shared by patients because sharing it feels unsafe — and with good reason.

Claire Turner, a 52-year-old cultural consultant and patient advocate from Manchester, U.K., was originally diagnosed with lobular carcinoma in situ at 44, then lobular breast cancer when she was 47. Then she went through a local recurrence at 49.

"I've found coming out in any cancer situation the most terrifying," she said. "I think it's because we are already extremely vulnerable and traumatized and the concern of a bad response is too much."

Another patient, Winter Downs of Seattle, put it this way: "With cancer, you feel nakeder than you've ever felt before."

Out with Cancer dug into this issue further in one study, collecting and analyzing responses from providers, patients and caregivers, then placing providers into three pots: inclusive/reflective; egalitarian and anti-inclusive.

While the LGBTQ+ patients and caregivers they talked to felt "safe and respected" and willing to disclose SOGI data with the inclusive/reflective providers, this did not hold true for the other two groups. Anti-inclusive providers caused patients distress and "feelings of negative judgment," but even egalitarian providers who said they treat patients the same but did not see the "relevance" of SOGI information caused "feelings of invisibility and dissatisfaction" and anxiety about disclosing information.

"Derogatory views and descriptions of LGBTQ+ patients and cis-normative practices need to be challenged," the study authors concluded. Further, they called for visible indicators of LGBTQ+ inclusivity as well as more targeted resources and information.

Tracking Cancer Risk and Disparities

As director of Fred Hutch's Tobacco-Related Health Disparities Research Group, public health scientist Jaimee Heffner, PhD, has been working with LGBTQ+ adults for several years, coming up with interventions to help them quit using tobacco.

"Rates of tobacco use are 1.5 to 2 times higher in the LGBTQ+ community overall, and it differs to some extent by which part of the community we're talking about," she said. "But in some cases, there aren't enough data to do meaningful analysis to fully understand tobacco use within specific groups. That tends to be the case for gender minority groups, like transgender people."

Fellow researcher Triplette, recently named a Cancer Moonshot Scholar by the White House, said the increased smoking rate can be attributed in part to targeted marketing campaigns by tobacco companies.

"They were marketing to the LGBTQ+ community before it was fashionable," he said. "Despite selling an incredibly dangerous product, they were speaking the community's language: creating targeted ads, creating welcoming spaces, using affirming, inclusive language."

As a result of that — and the ongoing stress of living queer in a predominantly straight, cisgender world — many LGBTQ+ people smoke, he said. Want to quit? Learn about this new program!

"'It's stress relief from living in a society that rejects you' is something we hear commonly," Triplette said. "This is one of several complex reasons why the LGBTQ+ community smokes at twice the rate as other subgroups."

"Homophobia" and transphobia are among those reasons, as well as violence, both domestic and political, that continues to rise. LGBTQ+ people are nine times more likely to be victims of violent hate crimes than non-LGBTQ+ people. And the American Civil Liberties Union is currently tracking nearly 500 proposed bills attacking LGBTQ+ rights here in the United States.

Alcohol use, another cancer risk factor, is also more prevalent in a number of different LGBTQ+ groups, Heffner said. As is obesity. Recent research published in JAMA Oncology on cancer risk, prevention and care in transgender and gender-diverse people also showed higher rates of infection with HPV and HIV and a higher incidence of HIV- and HPV-associated cancers.

But even with higher cancer risk, screening rates for some of these folx may be lower.

"There can be a general distrust of the health care system," Heffner said. "But part of it is socioeconomic: LGBTQ+ folks have lower rates of health insurance and health care coverage."

The two researchers recently launched a pilot study to create a standardized process of collecting SOGI data and pronouns for all patients in order to better serve this community through the entire cancer continuum. The study is in partnership with the National Cancer Institute, or NCI; the National LGBT Cancer Network and Fred Hutch's Health Equity Program.

Misgendering, Making Assumptions

“We’ll never know about disparities in terms of outcomes and quality of care until we collect the data,” Heffner said. “It’s not just a research issue. It’s about providing good quality care. If you’re going to have a credible conversation as a clinician about somebody’s sexual health, for example, you can’t just make assumptions.”

Even something as simple as knowing someone’s pronouns immediately provides more compassionate, culturally attuned care.

“Understanding what terminology patients use when referring to themselves and their bodies and following their lead is part of providing respectful care,” she said. “Some people might prefer the word chest to breast, for instance.”

Heffner speaks from a place of authority. Diagnosed and treated for early-stage breast cancer last year, she experienced several missteps during her care. No one asked her about her sexual orientation, for instance. Or her pronouns.

“The first interaction I remember was going online to fill out a form and having to pick either male or female as a gender,” she said. “That’s not very welcoming for people who don’t use binary terms.”

Other incidents stuck with her as well: being misgendered in a waiting room; having a provider completely ignore her wife during a visit; lugging a pink folder around to all her appointments.

In the documentary Trans Dudes with Lady Cancer, breast cancer survivor Yee Won Chong and ovarian cancer survivor Brooks Nelson, transmasculine best friends diagnosed within weeks of each other, touch on a number of issues trans patients experience during cancer including transphobia, misgendering and deadnaming.

Even insurance coverage and cancer prevention screenings can be impacted by heteronormative bias, with some insurance codes now correlated with gender (think “well woman” exams).

Making Institutions More Welcoming

“Going through treatment and surgeries for cancer is already a pretty stressful experience, so cultural competency among health care providers is really important,” Chong said in an interview, offering the following tips for cancer providers.

- Don’t make assumptions about your patients’ sexual orientation or gender identity.

- Don’t be afraid to touch a trans patient’s body.

- “Degenderize” anatomy whenever possible.

- Just accept that there will be awkwardness.

How do you make institutions more welcoming to the LGBTQ+ community?

“It’s always a good practice for providers to ask the patient, ‘Who’s here with you today?’” Heffner said. “And to just understand someone’s gender identity and pronouns. And look at medical forms, which are often the first interaction people have with a health care organization.”

In other words, a cancer center’s website or intake form can act as a welcome mat — or a slammed door. Ditto for the men/women labels on restroom doors and gendered clinic names.

“There are minimal things that can make a huge difference to how people feel about navigating a space,” said Triplette. “When a staff person shares their pronouns first, that can make it more comfortable. Many LGBTQ+ people will walk into a medical space and expect the worst — that they’ll be discriminated against, that they’ll have to explain themselves and face resistance. These are real experiences people have had, and they may avoid care to not have them again.”

LGBTQ+ patients with cancer mainly just want to feel seen and accepted, the researchers said.

“That was the thing that meant the most to the patients we talked to,” Triplette said. “They want to feel that they’re going to a clinic or provider that affirms their identity.”

Having loved ones treated as family members is a part of that.

“During breast cancer treatment, one nurse declared, ‘It’s lovely when our friends come with us, isn’t it?’” Turner said of her experience. “She immediately assumed Shell was a friend and not my partner. I had to think about coming out again. I was also terrified they wouldn’t let her come see me if something went wrong. She wasn’t ‘family,’ despite having been together for nearly 10 years.”

Decoupling Gender and Cancer

Downs, a 42-year-old Seattle project manager who identifies as nonbinary, said less focus on “gendered cancers” would also make things better for LGBTQ+ patients.

Diagnosed with ductal breast cancer in 2014, Downs found the pink headscarves and prioritization on “assuring breast cancer patients they’re still women” extremely off-putting. Ditto for the focus on rebuilding breasts.

“They assumed I was having full breast reconstruction after the surgery,” they said. “Flat closure was an option, but they were surprised I wanted that and couldn’t tell me what it would look like. It

was frustrating."

Downs' surgeon assured them a double mastectomy would basically be the same as "top surgery," a gender-affirming surgery often pursued by trans-masculine individuals who want chest masculinization. It wasn't. Mastectomies remove all breast tissue, including nipples and nerves endings.

And while this and other aspects of care proved frustrating for Downs, the cancer diagnosis did provide the impetus for them to come out.

"It's what tipped me over to decide to share that I'm nonbinary," they said. "It made me realize I didn't want to go about my life living a pretense anymore. I wanted to be open and loud about it."

What would have made the experience better?

"Doctors could spend more time imagining patients whose lives are different from their own," Downs said. "They could do better by asking questions and doing more personal tailoring. I never encountered outright hostility or judgment, but again and again, I had conversations where I'd realize the doctor's assumptions about my life were incongruent with reality."

Challenges and Opportunities

Tailored care is especially important for LGBTQ+ patients with breast or prostate cancer who may need to suppress hormones as part of their treatment.

Downs was put on anti-estrogen therapy by their oncologist at the same time they were taking the hormone testosterone to transition. The oncologist wasn't concerned about contraindications in their case, but in other instances, patients and oncologists may clash if gender aligning hormone treatments interfere with cancer treatments.

Fred Hutch medical oncologist Jessica Hawley, MD, MS, who treats patients with bladder and prostate cancer, said she's definitely tailored treatment to align with LGBTQ+ patients' wishes.

"I had one gay patient with prostate cancer back in New York who did not want to start his anti-hormone treatment until it was absolutely necessary," she said. "He wanted to maintain his quality of life — anti-hormones can cause hot flashes and erectile dysfunction. We ended up watching him for a number of years before he had to go on the treatment."

While Hawley hasn't treated any trans patients, she said she does worry about trans women who have medically transitioned. Prostates are not removed as part of transition surgery.

"I wonder if they are getting their PSAs checked or if prostate cancer prevention is even on their radar," she said. "You're supposed to start when you turn 50, depending on risk and family history. But I don't know if that's happening."

Trans men may also need to keep up with HPV testing and Pap smears and possibly mammograms. Documentary maker Chong offered this simple bit of advice for transgender patients: “If you have the part, get it checked.”

LGBTQ+ patients may also have profound sexual side effects after cancer treatment, everything from erectile dysfunction, penile shrinkage and loss of ejaculate to vaginal dryness, loss of sensation, orgasmic problems and more.

“Sexual function and identity problems are common, distressing and diverse in LGBTQ+ cancer survivors,” said Jennifer Reese, PhD, FSBM, a cancer prevention researcher at Fox Chase Cancer Center who recently gave a keynote at Fred Hutch’s 2023 Diversity, Equity & Inclusion Summit. “And patients can differ in their priorities and health. That’s why it’s important to have open dialog.”

Unfortunately, just as with straight cisgender patients, many providers are loath to discuss the sexual aftermath of cancer treatment.

Hawley said there are workarounds for those with erectile dysfunction such as Viagra, intramuscular injections and vacuum devices. Men with sexual side effects can also find help at the UW Medicine Men’s Clinic or a similar offering elsewhere.

Overall, she acknowledged how difficult these drugs can be for many cancer patients.

“These sexual side effects really highlight the need to keep working on potential therapies that are not hormonally based,” Hawley said.

Another important opportunity: making sure enough LGBTQ+ patients with cancer are enrolled into clinical trials. Bias and discrimination have proven to be a barrier there, too.

Heffner, both researcher and cancer patient, said even with these challenges, she believes there’s still room for hope and opportunity.

“More of the National Institutes of Health’s funding is now focused on LGBTQ+ populations,” she said. “It is absolutely good news that more funds are being devoted and focused on cancer care and preventive care for the LGBQT+ community.”

Heffner and Triplette, along with many others at Fred Hutch are more determined than ever to both see and serve this growing, yet underserved, community.

“We have an obligation to treat the patients in front of us with respect, and they deserve that,” Triplette said. “It’s not an option to have a judgment about their lives.”

SIDEBARS:

Local & National Resources and Support for LGBTQ+ People

- Cancer Support Community/Gilda's Club: Support for LGBTQ+ cancer survivors
- Entre Hermanos: Services for the Seattle Latino LGBTQ+ community
- Fenway Health: LGBTQ+ health care, research and advocacy
- Gay City: Seattle's LGBQ+ Center
- GLMA, Gay & Lesbian Medical Assn: World's largest association of LGBTQ+ health professionals
- Howard Brown Health: One of the largest LGBTQ+ health organizations in the U.S.
- Lambert House: Seattle's community space for LGBTQ+ youth ages 10-22
- LGBTQ+ friendly providers: Compiled by Ingersoll Gender Center, Seattle
- National LGBT Cancer Network: Support and resources for LGBT cancer patients
- Trans-Health.com: Resources for the transgender community
- Utopia Washington: Resources for the queer and trans Pacific Islander (QTPI) community
- UW Men's Health Clinic
- UW Sexual Health Clinic at Harborview

Research on Cancer in the LGBTQ+ Community

AACR Research Report: Unique Issues Facing Sexual and Gender Minorities in Cancer

ASCO Progress Report: Advancing Health Equity for LGBTQ People with Cancer

Journal of Clinical Oncology: Debunking Sex and Disentangling Gender from Oncology

Out with Cancer studies: Cancer Prevention, Treatment and Survivorship in the LGBTQIA Community

Additional Resources for LGBTQ+ Patients With Cancer

FLAT: Reclaiming My Body from Breast Cancer, memoir

Clinical Care Options, podcast

What Every Gay Man Needs to Know About Prostate Cancer, book

Trans Dudes with Lady Cancer, short documentary

Can the cancer experience be more queer inclusive? Video series from Shine Cancer Support

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