Understanding barriers to LGBTQ+ cancer clinical trial participation: A qualitative inquiry.

Elif Andac-Jones, Maria Belen Gonzalo, G. Thomas Wilson, Rachel Saks, Nicholas James Power; Cancer Support Community, Washington, DC

Background: It is well documented that LGBTQ+ cancer patients face severe challenges in accessing care and resources. Barriers are persistent despite recent advancements. Cancer clinical trial (CCT) participation rates for LGBTQ+ communities reflect this disparity. Understanding the reasons behind low participation rates and evaluating how LGBTQ+ specific experiences differ from the general population can help develop resources and programs that address the disparities in CCT participation, advancing LGBTQ+ health equity. Methods: In October 2022, CSC facilitated two virtual focus groups with 12 adults diagnosed with cancer and self-identifying as LGBTQ+. Participants were recruited from CSC’s Cancer Experience Registry (CER), representing wide gender and sexual orientation spectrums, a variety of cancer diagnosis and treatment trajectories, were 26-83 years of age, and a majority were college educated. A pre-screener survey collected sociodemographics to diversify the participant profile. Focus group data included participants’ background, their experiences living with cancer as members of LGBTQ+ communities, and knowledge, attitudes, and experiences with CCTs. Transcripts were analyzed using deductive codes of sociodemographic information and inductive codes based on emergent themes. Results: LGBTQ+ patients reported: 1—Perceived institutional discrimination by healthcare providers in addressing their needs resulting in trust issues among patients; and 2—Relational and informational barriers block LGBTQ+ participation in CCTs. 19/21 screening survey respondents and 11/12 focus group participants had heard of CCTs, though none had participated. Each expressed a strong desire to help others and contribute to cancer research. However, patients doubted the medical ethics and personal benefits of CCTs, and most believed there are selective biases in recruitment. Conclusions: LGBTQ+ patients feel discriminated against when advocating for their health, identity, and rights, and struggle to trust their medical providers. Experiences of mistrust and discrimination inform LGBTQ+ patients’ perspective on and participation in CCTs. Findings suggest a need for 1—well-developed informational materials addressing the needs of LGBTQ+ communities; 2—better education and engagement of CCT teams on how to address those needs. Research Sponsor: None.