Reflections on Community Engagement

Spotlight on Queer & Trans Hereditary Cancer Communities in the U.S.

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Background

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ORIGINAL ARTICLE

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Experiences of hereditary cancer care among transgender and gender diverse people: "It's gender. It's cancer risk…it's everything"

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Abstract

Transgender and gender diverse (TGD) individuals are a significant yet underrepresented population within genetic counseling research and broader LGBTQI+ health studies. This underrepresentation perpetuates a cycle of exclusion from the production of medical knowledge, impacting the quality and equity of care received by TGD individuals. This issue is particularly poignant in cancer genetic counseling, where TGD individuals with elevated cancer risk receive risk assessment, counseling, and referral to support based on risk figures and standards of care developed for cisgender individuals. The experiences of TGD individuals navigating inherited cancer syndromes remain largely undocumented in medical literature, posing challenges to the provision of inclusive care by genetics providers. To bridge this knowledge gap, we conducted a cross-sectional qualitative study. Nineteen semi-structured interviews were held with gender diverse adults having hereditary cancer syndromes, family histories of such syndromes, or personal histories of chest cancer. Our study employed thematic analysis using combined inductive and deductive methods to illuminate how hereditary cancer care intersects with participants' gender identities, gender expression, and gender-affirming care experiences. Participants reflected on care experiences that felt affirming or triggered gender dysphoria. Participants also discussed the interplay between risk-reducing mastectomy and top surgery, exploring co-emergent dynamics between cancer risk management and gender expression. Significantly, participants identified actionable strategies for healthcare providers to enhance support for gender diverse patients, including the mindful use of gendered language, collaborative decision-making, and conveying allyship. These findings offer valuable insights into tailoring genetic counseling to meet the unique needs of TGD individuals, advancing the path toward inclusive and appropriate care for LGBTQI+ individuals with hereditary cancer syndromes.

KEYWORDS
discrimination, gender identity, genetic counseling, hereditary cancer care, lived experience, risk management

Themes

Theme 1 | Discrimination and Dysphoria in Hereditary Cancer Care

Theme 2 | Intertwining Journeys: Gender Identity and Genetic Diagnosis

a. *Gendered Crossroads and Horizons in Cancer Risk Management*
b. *Challenging Barriers, Facing Uncertainty*

Theme 3 | Aspirations for Hereditary Cancer Care

Participant Recommendations for Providers

- Communicate allyship
- Be attentive to gendered language
- Partner around difficult decisions
- Validate patient preferences
- Work to grasp the complex emotional significance of living with cancer risk

Reflections on Engagement

- Worked with pre-existing groups (FORCE, The Breasties, Basser Center for BRCA)
- Also, worked to build trust through dynamic and iterative relational process (transparency, congruency, and holding space)
- Shared results and media over time
- Maintaining commitment to clinician education
- **Need for**: larger-scale, more diverse, longer-term work

Thank you!

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