Trans and Gender Diverse Experiences of Hereditary Cancer Care:

Insights from Interviews

Sarah Roth, ScM

ISCC-PEG Scholar

PhD candidate, Johns Hopkins University

Thursday, October 26, 2023

sarahroth@jhu.edu

ISCC-PEG Scholar Project (2021-2023)

Objective: To gain an understanding of the lived experiences, care trajectories, and unmet needs of trans and gender diverse people navigating care with hereditary cancer risk

Methods: Participant-observation and interviews (n=19), analysis, and writing for publication

ISCC-PEG Mentorship: Danielle McKenna, MS, CGC and Audrey Squire, MS, CGC, with support from ISCC-PEG LGBTQI+ project group, Leila Jamal, ScM, PhD, CGC, and Kellan Baker, PhD

Sex

assigned at birth based on assessment of external genitalia, chromosomes, and/or gonads

Gender

one's personal awareness of being a man, woman, non-binary person, and/or another gender

Transgender

describes a person whose gender identity differs from their sex assigned at birth

National LGBTQIA+ Health Education Center (2020)

Background

- Transgender and gender diverse (TGD) individuals are a significant population, yet underrepresented in genetic counseling work & LGBTQ+ health research
- This creates a cycle of exclusion from the production of medical knowledge, impacting care
- In cancer care, TGD folks receive risk assessment, counseling, and care based on risk figures and standards developed for cisgender individuals
- TGD experiences navigating care are largely undocumented in medical literature, which poses challenges to the provision of inclusive care
- To bridge this gap, we interviewed a cohort of TGD individuals living with hereditary cancer risk (N=19)

Participant Characteristics

Gender Identity	Sexual Orientation	Age	Genetic Dx	Race/Ethnicity	U.S. Region
Nonbinary or Genderqueer (N=12)	Queer (N=9)	18-24 (N=4)	BRCA1 or BRCA2 (N=13)	White (N=17)	New England (N=4)
Transgender Man or Transmasculine (N=7)	Bisexual or Pansexual (N=7)	25-39 (N=10)	TP53 (N=1)	Black or African American (N=1)	Mid-Atlantic (N=1)
	Ace or Asexual Spectrum (N=3)	40-60 (N=3)	ATM (N=1)	Latine or Latin American (N=1)	Midwest or Mountain States (N=6)
		Over 60 (N=2)	MSH2 (N=2)		Southeast (N=1)
			L2TR1 & HOXB13 (N=1)		Pacific Coast (N=7)

Themes

1	Discrimination and Dysphoria in Hereditary Cancer Care
2	Intertwining Journeys: Gender Identity and Genetic Diagnosis
	a. *Gendered Crossroads and Horizons in Cancer Risk Management*
	b. *Challenging Barriers, Facing Uncertainty*
3	Aspirations for Hereditary Cancer Care

Theme 1 | Discrimination and Dysphoria in Hereditary Cancer Care

"I'm sure you are going to hear this from basically every transmasculine person you talk to in this study… 'Women's Imaging,' 'Center for Women's Care,' 'Women with Lynch Syndrome.' Like, it doesn't end. **It's everywhere**."

- Frankie (they/he), nonbinary/transmasculine, *MSH2* and *ATM*

"I think **the worst thing is the waiting rooms**. Especially in the Catholic places, they call you by your first name, legally, and it's all very feminine. There's just mostly what appears to be cis women in the room. And as I've been dressing more and more [masculine], it feels like I'm a very big outlier there. Being in that waiting room... <laughs> they only have pink gowns."

- Ben (he/him), transgender man, *BRCA2*

Theme 2 | Intertwining Journeys: Gender Identity and Genetic Diagnosis

Theme 2a

Gendered Crossroads and Horizons in Cancer Risk Management

"In a weird way, the kinds of gender-related care that I would have wanted are **tied up in the kinds of care I'm getting**. I don't know if I would have ever had top surgery—probably not, because I'm terrified of surgery—but it would have been on my list in an ideal world."

- Fern (they/he), nonbinary/trans, *BRCA1*

Theme 2b

Challenging Barriers, Facing Uncertainty

Theme 3 | Aspirations for Hereditary Cancer Care

"When I meet a new clinician and they say 'Oh, your intake form identifies you as nonbinary. I just want to let you know that I understand that' ···I feel like **my identity is included in the room, rather than just my biology**."

- Jason (they/them), nonbinary, *BRCA2*

Recommendations

- 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 as a “previvor”

Practice Implications

Building Trust

- Listen compassionately
- Share pronouns and ask for theirs
- Convey allyship with a pin/flag
- Ask for input on pedigree
- Partner around dysphoria
- Use gender-neutral language to describe the body (and follow their lead)

In the context of anti-trans legislation, where you work will shape how people show up

Exploring Gender Identity in the Clinic

- Ask open-ended questions
- Follow the client’s lead on language, especially labels
- Explore their vision for what gender affirmation or gender creativity looks like
- That said, understand that the clinic may not be a safe space

Help Folks Connect with Community

- LGBTQI+ specific affinity spaces:
  - **FORCE LGBTQI+ Support Group** (Zoom) | FORCE website
  - **LGBTQ+ Breasties** (Zoom) | www.breasties.org/virtual-events
  - **Transgender Cancer Network** | Facebook Group
- National LGBT Cancer Network

Thank you!

Mentors & Collaborators

Audrey Squire, MS, CGC

Danielle McKenna, MS, CGC

ISCC-PEG LGBTQI+ Project Group

FORCE, The Breasties, The Basser Center for *BRCA*

JHU/NIH Thesis Committee

Dr. Leila Jamal, ScM, PhD, CGC

Dr. Jill Owczarzak, PhD, MA

Dr. Kellan Baker, PhD, MPH

Study Participants 💖

Email: sarahroth@jhu.edu

Twitter/X: @saraheroth