
**“Multiple weights off my chest”:
Gender Diverse Experiences of
Hereditary Cancer Care**

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“S***, now I guess I must
really be a woman.”

– Eve Kosofsky Sedgwick



Presentation Outline



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Background

02

Methods

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Findings

04

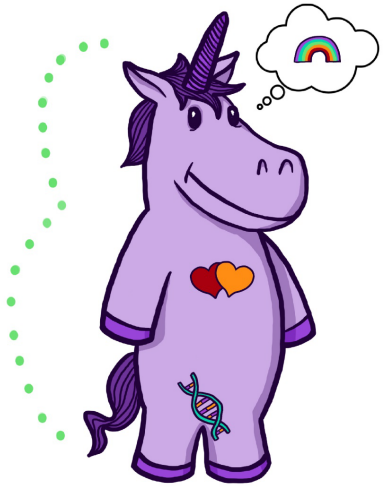
Implications
and Next Steps





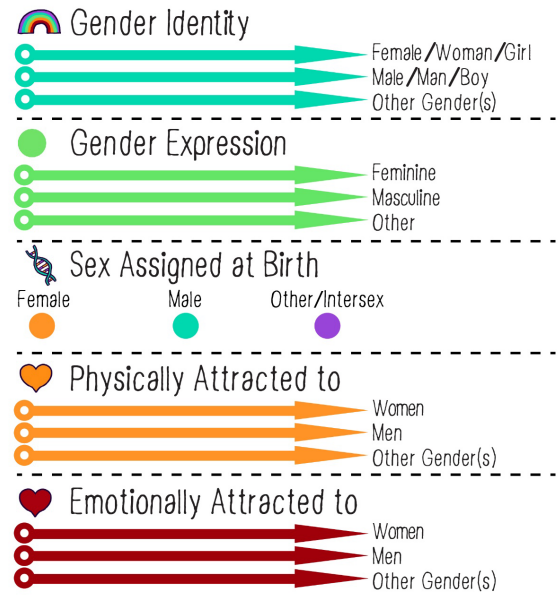
The Gender Unicorn

Graphic by:
TSER
Trans Student Educational Resources



To learn more, go to:
www.transstudent.org/gender

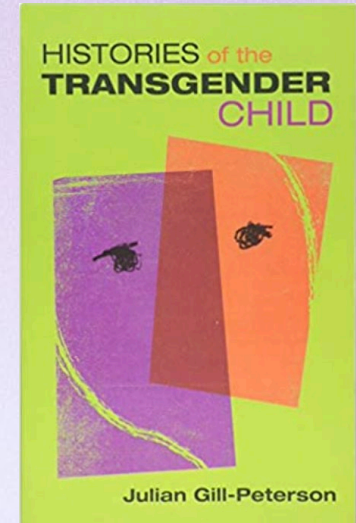
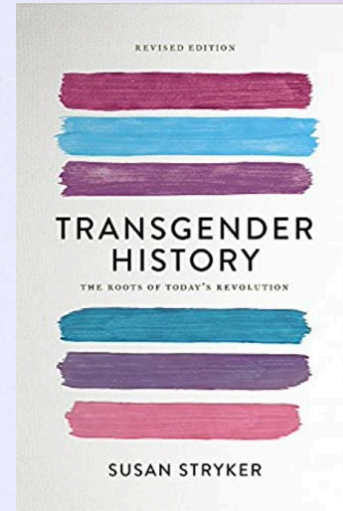
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Gender Diversity in the U.S.

- An estimated 1.6% of the population, and a higher percentage of youth, identify as gender diverse
- Gender affirmation can occur in multiple dimensions
- Gender diverse folks face marginalization and stigma, which affects healthcare access
- Though the term “transgender” only came into widespread use in the 1990s, gender diversity has a deep social, political, and medical history





Previous Research on Gender Diverse Experiences in Genetic Counseling

- Research has focused on provider's perspectives
- Only a few studies include gender diverse voices
- That said, allied research tells us that gender diverse folks face discrimination and widespread disparities in health outcomes
- In cancer genetic counseling, gender diverse folks receive risk assessment, counseling, and care based on risk figures and standards for presumed cisgender individuals





Study Objective

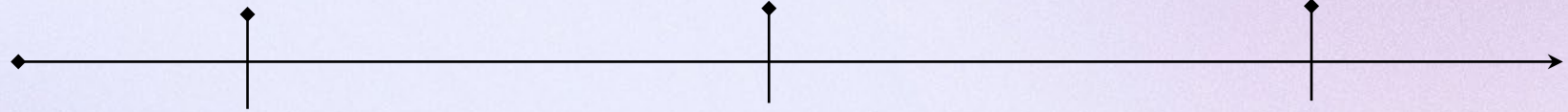


To gain an understanding of the *lived experiences, care trajectories,* and *unmet needs* of trans and gender diverse people with *hereditary cancer syndromes or previous cancer diagnoses*





Methods



Exploratory Work

Jan. 2022 – May 2022

Participant-observation in virtual
peer support community

Piloted interview guide

Interviews

May 2022 – Oct. 2022

Semi-structured interviews (n=19)

60-120 mins per interview

Coding & Analysis

May 2022 – Dec. 2022

Developed codebook

Iterative coding and analysis

Writing for publication



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)	<i>BRCA1</i> or <i>BRCA2</i> (N=13)	White (N=17)	New England (N=4)
Transgender Man or Transmasculine (N=7)	Bisexual or Pansexual (N=7)	25-39 (N=10)	<i>TP53</i> (N=1)	Black or African American (N=1)	Mid-Atlantic (N=1)
	Ace or Asexual Spectrum (N=3)	40-60 (N=3)	<i>ATM</i> (N=1)	Latine or Latin American (N=1)	Midwest or Mountain States (N=6)
		Over 60 (N=2)	<i>MSH2</i> (N=2)		Southeast (N=1)
			<i>L2TR1</i> & <i>HOXB13</i> (N=1)		Pacific Coast (N=7)





Overarching Themes



Theme 1

Experiences of discrimination and dysphoria in hereditary cancer care

Theme 2

Mutual implications of genetic diagnosis and gender journey

Theme 3

Participant guidance for care providers



Discrimination and Dysphoria

I asked about going flat and at this point [the plastic surgeon] started behaving really strangely, couldn't put my finger on it. Eventually she said, "You know, I feel I should tell you **I don't serve trans people.**"

Zoe (she/they), nonbinary, *BRCA1*

I'm sure you are going to hear this from basically every transmasculine person ... "**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*





Mutual Implications of Genetic Diagnosis and Gender Care Journey

The biggest thing is that it **allowed me to get gender-affirming care**... I would not have been able to afford it all without [the genetic diagnosis].

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

I know the surgeries aren't the same, but symbolically, [mastectomy] holds the same feeling for me [as top surgery]. It's also, like, **multiple weights off my chest**, because it's gender. It's cancer risk. It's, you know, self-image. It's everything.

Jay (she/they), nonbinary, *BRCA1*





Mutual Implications of Genetic Diagnosis and Gender Care Journey

*“I’m not sure if my egg would have cracked if not for the BRCA diagnosis. In a weird way, I’m grateful...**I’ve thought about it a lot as a turning point**—like this moment where the possible futures I envisioned for myself collapsed but also other ones began to unfurl.”*

Fern (he/they), transmasculine, BRCA1





Mutual Implications of Genetic Diagnosis and Gender Care Journey

I feel like I'm **stuck in the middle** of euphoria, of having my body look like it's supposed to. And, also, like, the trauma of having to do it for a very traumatic reason.

Jax (they/them), nonbinary, *BRCA1*







Participant Recommendations for Clinicians

- Work to avoid making cis-hetero-normative assumptions about patients and their preferences
- Be attentive to gendered language, and use gender-neutral medical language when possible
- Partner around difficult care decisions
- Validate and normalize patient preferences





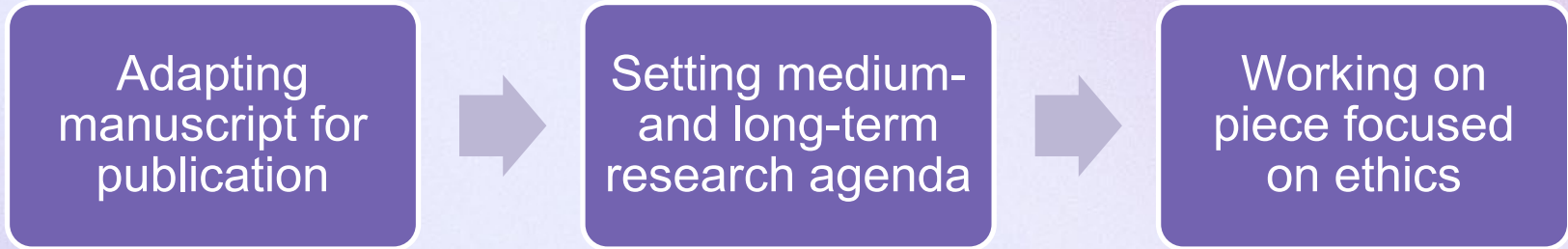
Practice Implications

- According to a gender-affirming care approach, the role of clinicians is to ***“listen to families, understand what patients are expressing about gender, and facilitate safe gender exploration”*** (Call et al., 2021)
- Providers can better equip themselves to respond to gender diverse folks’ social and emotional care needs





Next Steps





Thank you!

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Thanks

Does anyone have any questions?

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