



Transgender and gender-diverse (TGD) individuals' perspectives on research seeking genetic variants associated with TGD identities: a qualitative study

Antoine Rajkovic¹ · Allison L. Cirino¹ · Tala Berro² · Diane R. Koeller³ · Kimberly Zayhowski⁴

Received: 13 July 2021 / Accepted: 20 September 2021 / Published online: 12 October 2021
© The Author(s), under exclusive licence to Springer-Verlag GmbH Germany, part of Springer Nature 2021

Abstract

Recent genetic research has explored how genetic variants may contribute to gender dysphoria and transgender and gender-diverse (TGD) identities. When investigating communities that have been marginalized, it is important for researchers to incorporate perspectives of the communities the research is targeting. Therefore, investigators should incorporate the TGD community's opinions into this research to mitigate potential ethical issues, given the history of pathologization of TGD identities and utilization of genetics for eugenics. The aim of this study was to understand the perspectives of TGD individuals about trans-associated genetic research (TAGR). Eighteen semi-structured interviews were conducted with members of the TGD community to explore how TGD individuals view TAGR. Through inductive content analysis, five major themes were emergent: (1) TAGR could affect self-perception of identity; (2) TAGR could affect external views of TGD people; (3) TAGR could affect access to gender-affirming services; (4) TAGR could contribute to the pathologization and elimination of TGD identities; and (5) researchers should consult TGD community members and consider ethical concerns before conducting research. Participants highlighted concerns about TAGR being used as a tool for discrimination. Those who identified potential advantages of TAGR gave warning that TAGR would be unlikely to solely have positive effects. It is important for genetic researchers to prioritize the perspectives and concerns of TGD people highlighted in this study. Research about the TGD community needs to include TGD individuals as core members of the research team. Moreover, due to the serious ethical issues outlined in this study, TAGR should be reconsidered altogether.

Keywords Transgender · Gender identity · Diversity · Genetic research · Discrimination

Background

Transgender and gender-diverse (TGD) people have a gender identity that differs from the sex they were assigned at birth, whereas cisgender people have a gender identity that aligns with their sex assigned at birth (see Table 1 for glossary of

terms used in this paper). Because gender is socially constructed, gender varies between societies and can change over time. It is estimated that there are around 1.4 million transgender people in the USA (Flores et al. 2016). This number is expected to grow with increasing social acceptance and awareness of TGD identities. It is important to note that transgender people have a significantly shorter life expectancy due to systemic issues such as lack of healthcare access, unemployment, homelessness, and susceptibility to violence (Cicero et al. 2020; Feldman et al. 2016; Kachen and Pharr 2020). Moreover, historical events that disproportionately affected the transgender community, such as the high volume of deaths in the gay and transgender communities related to the HIV/AIDS epidemic, have decreased the number of transgender people from affected generations (Feldman et al. 2016; Rosenfeld et al. 2012).

Pathologization is generally defined as a process where a non-medical characteristic or identity becomes defined and

✉ Kimberly Zayhowski
kzayhows@bu.edu

¹ Genetic Counseling Program, MGH Institute of Health Professions, Boston, MA, USA

² Division of Genetics, Brigham and Women's Hospital, Boston, MA, USA

³ Division of Cancer Genetics and Prevention, Dana-Farber Cancer Institute, Boston, MA, USA

⁴ Department of Medical Oncology, Boston Medical Center, Boston, MA, USA

Table 1 Glossary of relevant terms (adapted from Vaupel-Klein and Walsh (2021))

Cis/cisgender (adj.)	Describes people whose sex assigned at birth aligns with their gender identity
Gender diverse (adj.)	Umbrella term describing gender identities that demonstrate a diversity of expression beyond the binary framework of cisgender male and cisgender female
Gender dysphoria (noun)	Distress resulting from discord between a person's gender identity and their physical body, and/or others' perceptions of their gender. Not all gender-diverse people experience gender dysphoria
Gender expression (noun)	The ways in which someone communicates their gender identity to others, such as through their pronouns, name, clothing, appearance, tone of voice, posture, and general behavior
Gender identity/gender (noun)	A personal awareness of being a man, woman, non-binary person, or another gender. Gender is distinct from sex. Gender differs between cultures, as it is socially constructed
LGBTQIA + (acronym)	Acronym for lesbian, gay, bisexual, transgender, queer, intersex, asexual, plus the many other identities encompassing gender and sexuality
Non-binary (adj.)	Describes people whose gender identity falls outside the binary of male or female. Their gender identity may be somewhere between male and female, may be both, or may be something else
Trans/transgender (adj.)	Describes people whose sex assigned at birth differs from their gender identity
Transition (verb)	The process in which a gender-diverse person adopts their physical characteristics and/or gender expression to align with their gender identity, rather than the sex assigned at birth. This may include gender affirmation therapy such as hormones or surgery
Transmedicalism/transmedicalist (noun)	Broadly defined as the belief that being transgender is contingent upon experiencing gender dysphoria or undergoing medical treatment in transitioning. The term typically refers to transgender people who hold these beliefs. May be colloquially referred to as "truscum" by members of the TGD community

treated as a medical condition (Conrad 1992; Illich 1976). Pathologizing TGD identities has caused them to be perceived as "sexual deviations," "gender identity disorders," or "mental disorders" (Bockting et al. 2010; Cohen-Kettenis and Pfäfflin 2010; Dewey and Gesbeck 2017; Prunas 2019; Winter et al. 2016; Zucker 2013). The pathologization of TGD identities implies that TGD identities can be "cured" and adds a barrier where a diagnosis may be necessary in order to access care. This hinders TGD people's ability to access transitioning resources, thereby restricting or removing TGD people's freedom to gender expression (Walsh and Einstein 2020; White Hughto et al. 2015). Members of the TGD community experience increased discrimination in healthcare settings compared to cisgender individuals (Ferlatte et al. 2020; Romanelli and Lindsey 2020; White Hughto et al. 2017). Thus, TGD people utilize healthcare services less often due to experiencing stigma and feeling unsafe about disclosing their gender identity (Giblon and Bauer 2017; Merkel 2017; Poteat et al. 2013; Puckett et al. 2018; Veale et al. 2015). Additionally, pathologization can be harmful to TGD people's identity development and mental health as it creates minority stress (Meyer 2003) where stigma, prejudice, and discrimination are an added stress for TGD individuals in addition to the general stressors that all people face in their lives.

Several genetic studies have explored biological and genetic causes of sexual identities and gender-diverse identities (Bentz et al. 2008; Foreman et al. 2019; Ganna et al. 2019; Hamer 2011; Hamer et al. 1993; Kreukels et al. 2018). The initial study seeking genetic associations

with homosexuality by Hamer et al. (1993) has been heavily criticized as scientifically legitimizing a tool for discrimination against LGBTQIA + people (Petersen 1999; Schüklenk et al. 1997). A recent study conducted by Theisen et al. used exome sequencing to investigate genetic variants that could contribute to gender dysphoria and found a small number of variants associated with the development of sexually dimorphic brain development (Theisen et al., 2019). This study was conducted prior to any research on the TGD community's attitudes about this kind of genetic research. Theisen et al.'s paper suggested that genetics could help better understand and treat gender dysphoria in TGD people. One such example is the potential use of pharmacogenomics to understand the impact of hormone therapy particularly as medicine moves towards individualized treatments (Moyer et al. 2019).

Framing genetics as the cause of sexual and gender diversity carries inherent homophobia and transphobia because it requires LGBTQIA + and TGD communities to prove their identities are innate in order to obtain social acceptance, even though gender is socially constructed (Petersen 1999; Schüklenk et al. 1997; Somerville 1994). Genetics in this framework could become the newest tool in a bioessentialist framework to pathologize TGD identities. Bioessentialism, the theory that suggests sex assignments are straightforward, objective, and purely biological differences (Frohard-Dourlent et al. 2020), has long been criticized as framing sex as binary while neglecting the complex intricacies of the spectrum of sex (Fausto-Sterling 2000, 2012). Bioessentialism is harmful to members

of the TGD community as it continues to marginalize and pathologize them.

Many LGBTQIA+ people have been forced to undergo “treatments” attempting to change their sexual orientation, and others have been pressured to undergo “treatments” to avoid discrimination and social stigma (Hamer 2011; Schüklenk et al. 1997). Genetics and eugenics have both contributed to trans-erasure and TGD pathologization worldwide, most notably through the forced sterilization of LGBTQIA+ people, TGD people specifically, as well as individuals with disabilities (seen in Nazi Germany, the USA, Finland, Sweden, and Japan, amongst others) (Inch 2016; Lowik 2018; Repo 2019; Ripley 2019; Röhl 1996). Given the complicated history of genetics and eugenics, future research could venture into ethically complicated areas.

Conducting research about TGD individuals without including their perspectives or considering the research’s potential ethical, legal, social, and political impacts poses a moral challenge (Marshall et al. 2019). Therefore, the inclusion of TGD perspectives is crucial when conducting trans-focused research (Vincent 2018). Studies have explored the TGD community’s attitudes about trans-inclusive genetic counseling services (Barnes et al. 2019; Tuite et al. 2020). One mixed-methods study (Thomas et al. 2020) assessing opinions on genetic research of sexual and gender minorities and mental health strongly recommends that genetic research projects related to TGD people have community advisory councils with stakeholders from a variety of gender and sexual identities. These studies presented recommendations from TGD individuals for researchers and clinicians, indicating that participants felt that it is highly important for their perspectives to be considered. Such findings reinforce the importance of using a community-based participatory research (CBPR) model to incorporate the opinions and perspective of community members when designing research studies that focus on a particular community (Satcher 2005; Viswanathan et al. 2004).

There is limited research specifically assessing the perspectives of the TGD community on transgender-associated genetic research (TAGR), defined in this paper as genetic testing and research seeking to identify genetic associations with TGD identities. Given the history of medical pathologization and discrimination, it is critical to better understand the TGD community’s perspectives about TAGR. This qualitative study explores the TGD community’s perception of TAGR in order to educate genetics researchers about its potential implications.

Methods

Semi-structured video interviews were conducted with TGD individuals with any level of familiarity with genetics to better understand their perceptions of genetic research seeking

genetic variants that could be associated with TGD identities. This study and all procedures were reviewed by the Mass General Brigham Institutional Review Board (Protocol #2020P003562), and were approved as an exempt protocol in December 2020.

Participants

A demographics survey (Supplemental Material I) was created using the online survey tool REDCap v10.0.30 (REDCap 2020) to identify interested participants and determine eligibility. In January 2021, social media advertisements were posted to various transgender- and non-binary-focused Facebook and Reddit groups.

Through targeted sampling (Watters and Biernacki 1989) and snowball sampling (Baltar and Brunet 2012; Naderifar et al. 2017), we recruited people who met the following criteria: (1) 18 years of age or older, (2) self-identified as any gender identity that is not cisgender (i.e., transgender, genderqueer, gender-diverse, non-binary, agender, etc.), (3) able to speak and read in English, and (4) have access to a device with internet for the interview. Participants are defined as those who completed both the survey and the interview.

Instrumentation

The survey was created in the REDCap platform to confirm eligibility for the study and to collect demographic information, including respondents’ pronouns, gender identity and sexual orientation, race/ethnicity, level of education, general knowledge about biology and genetics, and source of recruitment (forum/group in which they learned about the study).

A semi-structured interview guide (Supplemental Material II) was developed by the first author (AR), and subsequently reviewed and edited by the co-authors, three of whom (KZ, TB, DK) have experience working with TGD individuals and conducting transgender studies, and all of whom have experience with qualitative research methodology. Most of the authors are members of the LGBTQIA+ community, and one author is a member of the TGD community. Interview questions fell under the following categories: (a) general familiarity and understanding of genetics and genetic research, (b) thoughts and feelings about genetic research specifically related to transgender identities, (c) possible personal and community effects and implications of TAGR, (d) benefits and harms of research seeking genetic associations to TGD identities, and (e) recommendations for researchers and future studies. Core questions were asked in every interview and unscripted probing and rephrased questions were asked for clarification purposes. Additional topics were discussed in each individual interview as participants mentioned topics of interest. The interview guide

was piloted with two TGD individuals. No revisions were made to the interview guide after the pilot.

Procedures

The demographics screening survey presented interested people with a study information sheet that explained the study goals and procedures. Individuals could only progress to the demographic questions if they indicated that they met all inclusion criteria and consented to the survey. Respondents were only eligible for an interview if they submitted a completed REDCap survey and had answered all required questions.

All interviews were conducted by a single researcher (AR), a genetic counseling graduate student, in January and February 2021. Interviews were recorded using Microsoft Teams™ video conferencing software. Over a period of 6 weeks, individuals who completed the survey were invited for the interview. Participant invitations were sent in an order which prioritized a diverse representation of ages, races and ethnicities, genders, and levels of education. Invitations were sent on a weekly basis, and if a previous invitation went without response, additional prospects would be emailed. The first 18 individuals to respond to the email invitations were interviewed. No additional interviews were conducted as decline in new themes was observed and patterns of redundancy were identified as recordings were reviewed. This indicated that data saturation was being reached (Saunders et al. 2018). Upon completing the interview, participants were awarded a \$20 electronic gift card as compensation. The de-identified interview audio recordings were transcribed verbatim by AR or third-party transcription service Temi (2021) and manually reviewed by AR for accuracy.

Data analysis

Dedoose version 8.3.47b, a qualitative research tool, was used to manually code the de-identified transcripts. Qualitative content analysis was used to categorize participants' responses and to identify recurring themes within the transcripts (Bengtsson 2016). This approach is used to describe the meaning derived from interview data and extract categories from it for analysis. An inductive approach was utilized due to the lack of existing data on this novel research topic. More specifically, manifest content analysis was used to generate codes in addition to interviewer notes from reviewing all interview transcripts. Two members of the research team (AR and KZ) coded initial transcripts to increase the reliability of the study and to reduce coder bias. Each created initial codebooks. Through an iterative process, the researchers reviewed, revised, and combined codebooks. Once a codebook was finalized, codes were applied to all

interviews. The second coder performed an interrater reliability test on transcripts coded by the first coder in order to examine interrater agreement as compared to agreement that would be expected by chance (Cohen 1960). The kappa score for this study was 0.81, indicating excellent interrater agreement (Cohen 1960; Fleiss 1971). The researchers then manually compared applied codes and resolved discrepancies through discussion. Themes were derived from the codes based on topics of codes and frequencies of application. Microsoft Excel was used to summarize participants' demographics. Quotes selected for this article, including the minor edits for clarity (removing filler words such as "like" and "kind of," adding clarifying language in brackets), were emailed to participants for approval, to ensure that participants felt the quotes accurately represented the participants' intentions. Participants were given the opportunity to decline quotes from being published. No quotes were removed in this process.

Results

Recruitment results

Of 91 surveys recorded in REDCap, 51 were complete and eligible for an interview. A total of 44 people were contacted from January to February 2021 by their preferred mode of contact to invite them to a 60-min interview. Participants were emailed in an order that prioritized diverse representation. The first 18 people to schedule were interviewed. Interviews ranged from 32 to 67 min (mean: 49 min). Participant demographics are summarized in Table 2. Participants were recruited from four different Reddit groups ($n = 15$, 83%) and three different Facebook groups ($n = 3$, 17%).

Thematic analysis

Five major themes were emergent from the exploratory interviews. Theme 1 encompasses both negative and positive effects TAGR could have on self-perception of identity. Theme 2 encompasses negative and positive effects TAGR could have on external views of TGD people. Theme 3 discusses how TAGR could both exacerbate existing barriers to gender-affirming care, as well as serve as a tool to increase access to gender-affirming care. Theme 4 broaches how TAGR could contribute to the pathologization and elimination of TGD identities. Finally, Theme 5 discusses how researchers should consult community members and consider ethical concerns before conducting research. Additional interview quotes can be found in Table 3 to further support these themes.

Table 2 Demographic information for interviewed participants

Age (years)	Number of participants (<i>n</i> = 18)
18–24	5 (28.0%)
25–34	9 (50.0%)
35–44	2 (11.0%)
45–54	0
55–64	2 (11.0%)
Gender ^a	
Transgender	8 (44.0%)
Non-binary	8 (44.0%)
Man	5 (28.0%)
Genderqueer	4 (22.0%)
Woman	3 (17.0%)
Not listed	2 (11.0%)
Questioning	1 (5.5%)
Sex assigned at birth	
Female	13 (72.0%)
Male	5 (28.0%)
Sexual orientation ^a	
Queer	11 (61.0%)
Bisexual	6 (33.0%)
Asexual	4 (22.0%)
Gay	2 (11.0%)
Pansexual	2 (11.0%)
Lesbian	1 (5.5%)
Straight	1 (5.5%)
Questioning	1 (5.5%)
Ethnicity	
White	14 (78.0%)
Black/African American	1 (5.5%)
East Asian	2 (11.0%)
Indigenous	1 (5.5%)
Hispanic/Latinx	
No	17 (94.5%)
Yes, Mexican American	1 (5.5%)
Highest level of education	
Some college	3 (16.7%)
Bachelor's degree	12 (66.7%)
Graduate/professional degree	3 (16.7%)
Genetics education ^b	
High school	10 (56.0%)
College (non-major)	5 (28.0%)
College (major-related)	1 (5.0%)
Professional/career-related	2 (11.0%)
Country of residence	
USA	15 (83.0%)
Non-USA	3 (17.0%)
Canada	2 (11.5%)
Singapore	1 (5.5%)

^aBecause participants were allowed to select more than one answer, percentages do not add up to 100%

^bParticipants were asked to select how they received their baseline knowledge of biology and genetics

Theme 1: TAGR could affect self-perception of identity

Participants reported that TAGR could affect how they perceived their own identity, both in negative and positive ways.

Negative effects All participants warned that TAGR could negatively affect one's self-perception, especially in creating doubt about their sense of identity or feeling invalidated. Participants worried that this information could contradict their journey of self-exploration, self-acceptance, and transitioning.

I can definitely see it causing some problems if you feel... that's your authentic self and then you don't have the [genetic] marker. - Participant 17

If I didn't have [the genetic variant], would that invalidate the journey that I've been on? - Participant 13

Some participants mentioned that when someone is transitioning, this genetic information could be seen as unnecessary and/or destabilizing.

If there were a solid testing mechanism, I don't think I would ever take it because... if it's a bad test [that] fails to account [for] something, that seed of doubt that I've been living a lie... I have nothing to gain from it. - Participant 2

Positive effects All participants discussed that TAGR could potentially positively affect self-perception of their identity, particularly if it was validating or contributing to their process of self-acceptance. Participants noted that the timing of learning this information in their life or transition would affect its impact. Many participants explained that for people uncertain of their gender identity, this genetic research could provide them with additional information that may help them figure out their gender.

And I feel like... if [TAGR] existed earlier on in my transition, [it] probably... would've helped in making the process of accepting who I was happen more quickly or... maybe come to terms with [my gender] more easily. - Participant 12

Several participants added that some TGD individuals associate their gender identity to the experience of gender dysphoria and that genetic research may support their view of their identity as a medical condition or hormone sensitivity. One participant added that TAGR could further reinforce his personal narrative about his gender identity and how he explains it to others.

I tell people... 'I am a guy and... I have an endocrine condition... so I do see a doctor quite regularly.'... For me, experiencing dysphoria, it was... purely physical...

Table 3 Additional exemplary quotations from interviews

Theme	Subtopic	Illustrative quotations
Trans-associated genetic research (TAGR) could affect self-perception of identity	Negative effects	<p>“For people who may not express this gene but still identify as gender non-conforming, then it could be very gatekeeping and exclude them from a community that they feel should include them for rightful reasons.”—Participant 1</p> <p>“It would sow division between people that are scientifically ‘checked off’ versus those who either choose not to, versus those who get a negative result.”—Participant 2</p> <p>“If you’re even seeking out this testing, you’re probably trans, regardless of the outcomes of it. So, it could... possibly shorten the time that people spend questioning [their identities].”—Participant 10</p> <p>“If somebody were to say like, ‘Yeah, [Participant 5], here’s the reason why [you are transgender].’ Sure, there’d be some validation there [from this testing].”—Participant 5</p> <p>“I feel like if there was some genetic thing to [me transitioning], instead of me fighting with like inner demons for years... I feel like in that case, it would be a sigh of relief... [of] less struggle or [of], ‘Let’s do something about it then,’ rather than freak out about it for years and feel uncomfortable.”—Participant 17</p>
	Positive effects	<p>“I could see other people using it to dismiss or invalidate someone... I could see it more used as like a parent or a partner or... a service provider saying ‘I’m sorry... There’s no substantiation.’”—Participant 5</p> <p>“If it became another thing like when you tick in male, female, and then, ‘Do you have the genetic [finding] for being trans or nonbinary?’ Then that’s when I think that... would be stressful.”—Participant 1</p>
TAGR could affect external views of TGD people	Negative effects	<p>“[Genetic testing] might be conducive to some gatekeeping [like] ‘Well, if you haven’t had genetic testing done, then I don’t know if you can be here.’”—Participant 18</p> <p>“Once we know that there’s something ‘wrong’ with us, that we can be seen by others as ‘less than’ a whole person, or a defective person... you’ll have to deal with negative attitudes from people [with] negative thoughts about [TGD] people for some reason. So that’s always my fear, that this kind of knowledge will bring that situation to fruition and might make it more uncomfortable for some of those in that community to do [TAGR].”—Participant 6</p> <p>“[For] someone who is closeted, unaware that they’re trans, and they’re from a very abusive family situation or in a country [where] trans people don’t have rights. That could be incredibly dangerous.”—Participant 16</p> <p>“This would almost normalize being transgender, right? Like being able to prove that this genetic factor in somebody’s life, that... would normalize it.”—Participant 16</p> <p>“If my parents had the knowledge ahead of time that I was going to be struggling with gender identity... they might have found a way to let me treat it the way that it should have been treated sooner rather than later.”—Participant 6</p> <p>“If it’s used in a positive note of better understanding and learning about [trans people] and providing resources... even saying ‘Oh, it’s not a choice.’”—Participant 17</p>
	Positive effects	

Table 3 (continued)

Theme	Subtopic	Illustrative quotations
TAGR could affect access to gender-affirming services	Exacerbating existing barriers to medical care	<p>"I imagine that the trans community as a whole would be up in arms if they were required to go get genetically tested in order to gain access to hormones or surgery or gender therapy." —Participant 7</p> <p>"I also think [genetic testing] could mean some things for the gatekeeping that already exists for people who are transitioning. I mean, they need to jump through a lot of hoops to make that happen. Already, it exists that they have to have a diagnosis of gender dysphoria and have multiple mental health professionals attest to the validity of that diagnosis and whether they are of sound mind to make surgical and medical decisions." —Participant 10</p> <p>"Would I pay for genetic testing versus a surgery that is required?" —Participant 5</p>
	A tool to increase access	<p>"If you have these findings, then healthcare providers might know a bit more about how to treat trans patients, even in areas that are not related to their transition." —Participant 15</p> <p>"I take a whole medicine cabinet of hormones. And all those hormones work... on people [in] different ways and in combination, ... people have different medications on top of hormones. So, understanding how these things interact with... with trans bodies... are all vitally important." —Participant 4</p> <p>"Maybe being able to remove other barriers... like, 'Oh, then you don't need to get multiple letters [from healthcare providers for approval].'" —Participant 12</p> <p>"It could potentially be a lot easier [access] gender confirmation surgery and hormones, because now there's a medical basis for [our identities]. So, you won't have to jump through loopholes with insurance." —Participant 1</p> <p>"A lot of people who are queer feel pride in [being queer]: 'I was born this way... This is not a choice I am making. This is who I am.'" —Participant 10</p> <p>"I'm definitely wary of how results could potentially be used to... deny the validity of trans peoples' existences, or even pathologize [them] as well. I'm concerned about pathologization." —Participant 8</p> <p>"Have you ever heard of transmedicalism?... There are some trans people [who] have a very specific idea of what being trans is, defined by specific experiences and experiencing classical gender dysphoria. Most of them conceptualize being trans as like a birth defect or a medical condition... Those people would be very strongly in favor of genetic research." —Participant 11</p>
TAGR could contribute to the pathologization and elimination of TGD identities	Pathologizing TGD identities	<p>"I wouldn't want it to go the other way where it's a way to pinpoint people or to... try to remove a group of people." —Participant 17</p> <p>"My first concern is that by identifying that... if it's something that would show up before somebody plans on following through with the pregnancy, is there a chance they would terminate because of sexual orientation or gender identity?" —Participant 9</p> <p>"I would hope that people aren't like... 'Oh, let me just edit my baby before it's born so that it's not gay or trans.'" —Participant 14</p> <p>"[Who] are the people... conducting the research?... Are they genuinely searching for... genetic or biological information about trans people? Or is it more so... are they trying to... somehow identify exactly what makes someone trans or gender nonconforming... so [they] prevent that from happening?" —Participant 11</p> <p>"It seems not good to just take a whole swathe of people out of the gene pool just because you don't like it." —Participant 18</p> <p>"Anything with the, 'Let's try to explain it through science,' worries me because, well, what's the point? Are you trying to get rid of them?" —Participant 14</p>
	The harmful history of genetics as a tool for eugenics	<p>"I wouldn't want it to go the other way where it's a way to pinpoint people or to... try to remove a group of people." —Participant 17</p> <p>"My first concern is that by identifying that... if it's something that would show up before somebody plans on following through with the pregnancy, is there a chance they would terminate because of sexual orientation or gender identity?" —Participant 9</p> <p>"I would hope that people aren't like... 'Oh, let me just edit my baby before it's born so that it's not gay or trans.'" —Participant 14</p> <p>"[Who] are the people... conducting the research?... Are they genuinely searching for... genetic or biological information about trans people? Or is it more so... are they trying to... somehow identify exactly what makes someone trans or gender nonconforming... so [they] prevent that from happening?" —Participant 11</p> <p>"It seems not good to just take a whole swathe of people out of the gene pool just because you don't like it." —Participant 18</p> <p>"Anything with the, 'Let's try to explain it through science,' worries me because, well, what's the point? Are you trying to get rid of them?" —Participant 14</p>

Table 3 (continued)

Theme	Subtopic	Illustrative quotations
Researchers should consult community members and consider ethical concerns before conducting research	TGD involvement in all levels of research	<p>“This assumption that somebody who’s an ally can always think in our ‘best’ interest is not always accurate... Allies will still sometimes make mistakes, and it’s not their intention... it’s the fact that they don’t have that experience.”—Participant 5</p> <p>“There are certainly trans genetic researchers in this world... They should be in there. There should be some degree of consultant work, where... trans folks come in to ensure... the scope is directionally correct. I would also encourage them to have a diverse group of geneticists and beyond just trans representation, I don’t want a group of just white people [with] no sense of marginalization in their life to be the only ones doing research.”—Participant 16</p> <p>“I feel like a lot of people would feel a... similar sense of ‘Nothing about us without us... As long as there are trans people involved in it and it’s done in a sensitive and respectful way... I would think most people would be... for it.”—Participant 12</p> <p>“You definitely want to have someone who identifies as genderqueer on your research team, whether as a researcher, as a consultant, as community outreach. If you can get some local organizations on board, [it] could help [with] direct community interfacing.”—Participant 1</p> <p>“I think in general, there’s not enough research about trans people. So, I’m supportive of that in general, but I think the underlying concern of who is conducting the research, what is their intent, and how to ensure impartialness.”—Participant 11</p> <p>“A lot of data and research completely neglects trans people and doesn’t... include us, even though it’s supposed to be... representative.”—Participant 12</p>
	Considering the ethical, legal, and social implications of research	<p>“[Is TAGR needed in the TGD community?] If [TAGR] was validating and confirming, absolutely. If it was invalidating, hell no. Which is absolutely at odds with the concept of research. In an ideal world, you ask a question to get the answer, not to confirm or deny a bias. The consequences of those answers are sometimes out of one’s control and [we’re] unable to predict them.”—Participant 7</p> <p>“There’s so little regulation surrounding the research into genetic... editing... as evidenced by CRISPR-related issues that have happened in the public sphere in the last couple of years... Not everybody has the same ethical code... [The] issue with any iffy genetic research is that there [are] so few actual laws surrounding what you can or can’t do right now.”—Participant 13</p> <p>“Why not... determine what [are] the possible outcomes of the survey... or of the [TAGR] genetic testing, and then ensure that the proper trip wires are in place... What do you need to do to ensure that those results don’t end with the worst possible outcomes?”—Participant 16</p> <p>“I will admit to hav[ing] never [thought] about genetic research as [a] need for the trans community. When I think about needs, I think about funding, I think about a structured support community care system.”—Participant 8</p> <p>“I hope that science does realize that... scientists are categorizing a vulnerable group of people with this work and it needs to be done with a lot of care. And maybe it shouldn’t be done at all. I’m going to be frank.”—Participant 10</p>

I can treat it. It is purely medication... So, because I personally perceive it as a medical issue, [I could tell people] ‘Hey, look, it’s a medical issue, and genetics backs it up.’ - Participant 3

Theme 2: TAGR could affect external views of TGD people

All participants discussed that this type of genetic research could affect how TGD people are viewed by those in the broader LGBTQIA+ community and by cisgender people.

Negative effects Participants primarily mentioned how TAGR could negatively affect people’s perspectives of TGD people. This was described as using TAGR to dismiss someone’s identity if it could not be linked to genetic findings.

[There are] a lot of arguments online over, ‘Do you need dysphoria for you to be trans?’ And so, I would hope that [TAGR] wouldn’t become a, ‘Are you ‘genetically’ trans or not?’ thing. - Participant 14

A few participants elaborated on this, stating that this genetic information may be used by non-TGD people as a way to control TGD people’s lives.

People have strong emotions who are not even part of those communities and who may want to dictate what happens. So, it could really become a method of... controlling people in their access to anything really. - Participant 5

Many participants mentioned that genetic associations to gender identity, if identified, may be used by non-TGD people to further divide the TGD community into subgroups based on genetic test results.

Community-wise... if we found one gene that supported one specific group [being trans] ... that would entirely fracture the community because there would be [only] one scientifically legitimate side... That’s a big problem with fractured communities. It’s an intent to weaken... There’s a chance that [the] other unconfirmed group will just fall out of existence purely because science said one group is legitimate without having proof for the other. - Participant 2

Some participants further theorized that genetic testing could continue to support the positions of those who hold transmedicalist beliefs (see Table 1 for definition), referred to as *truscum* by the participant and some in the wider community.

There are already so many people who gate-keep being trans. So, if you don’t have dysphoria, then you’re not a real trans person is what... ‘truscum’

[people believe]. Is this just like a genetic way... to prove those people right [or] wrong? When it comes to somebody’s identity, do you really need to prove anything? - Participant 16

Positive effects While the focus remained on negative effects of outsider perceptions of TGD people, participants also mentioned three general positive impacts. Firstly, participants felt TAGR could help develop a better understanding of TGD people and trans-genetics.

The larger body of research there is, the more that could potentially help... scientists and the public at large better understand the nature of being trans. - Participant 11

Secondly, several participants felt that by increasing cisgender people’s understanding and knowledge of TGD people, TAGR may also make cisgender people more willing to listen to and believe TGD people when speaking about their identities, experiences, and needs.

When I first came out... I had to do a lot of justifying and validating [my identity] being the truth. I did not get my parents on board until we met with several medical providers who all attested to the same thing... I was really dependent on what scientific research was saying in order for my family to validate me and accept me and allow me to transition. - Participant 9

Lastly, some participants felt that TAGR could create more acceptance for transgender people and contribute to normalizing them, with the hopes that it could allow TGD to not always have to advocate for themselves.

I feel like having some legitimacy from a scientific standpoint could help trans people feel like they don’t have to do all the work. Because trans people are responsible to educate the world around them and to stand up for themselves and advocate. And wouldn’t it be great if trans people could sit? And people could have a discussion around, ‘How do we solve this issue around access to services?’... and [the burden] not be on the backs of trans people. - Participant 5

Theme 3: TAGR could affect access to gender-affirming services

When asked about the potential benefits and harms of TAGR, both on a personal and community level, many participants primarily expressed that this kind of research could both create new barriers in accessing gender-affirming services, as well as increase access to gender-affirming and transitioning care.

Exacerbating existing barriers to medical care The concerns mentioned by the participants were that genetic research could create a threshold of determining who qualifies for gender-affirming care and possibly be used by insurance providers to deny coverage for care.

The one thing that I can see... be[ing] a problem is cis doctors implementing genetic testing as a ‘gate-keep-y’ way to keep from transition. ‘You have to get this genetics test, you don’t have the gene, we can’t give you the meds.’ - Participant 4

I could see insurance companies emphatically deciding that if it were cost effective, they would only cover treatment for people who have this ‘pre-existing genetic condition.’ - Participant 10

A few participants discussed how general barriers to healthcare can play a role in accessing care.

Genetic testing is expensive. [A] lot of trans people, because their famil[ies are] not supportive [of them]... are low income. And so, if we use this genetic testing as a way to justify if someone is trans or not, then if [TGD people] can’t afford the genetic testing, then we’re preventing themselves from being themselves. - Participant 15

A tool to increase access Most participants expressed that accessing gender-affirming care can be difficult and complicated, with many barriers along the way. Those who saw this genetic research positively felt that it could help remove existing barriers or justify gender-affirming care for TGD people experiencing difficulty accessing services such as surgeries, hormone replacement therapy, or puberty blockers. Several participants who discussed this also felt that by removing these barriers, it would allow for earlier access to these types of services.

If I had known [genetic testing for gender identity] was a thing, I could have got access to [gender-affirming treatments] when I was younger. - Participant 3

Specifically, several participants mentioned that this genetic research could serve as evidence for doctors to feel more comfortable in treating transgender patients.

If there was some way of substantiating [transgender identities] through data or evidence... that would allow doctors to be more comfortable and say... ‘I feel comfortable prescribing the right treatments.’ - Participant 5

Some participants explained that gender-affirming and transitioning care are complex, individualized processes. Because of this, participants felt that genetic research could

contribute to evidence-based care for trans people and to increasing the success rates of treatments and surgeries.

I’ve been on hormones for ten years [and] it wasn’t until the past year and a half that my levels have finally been stable... If there was a way to have not gone through that and to [have] found the course that works for me from the start, it would’ve saved me a lot of agony, a lot of health problems. - Participant 9

Lastly, several participants mentioned this genetic research could reduce the numerous barriers transgender adolescents face when accessing care and serve as evidence to support treatments like hormone replacement therapy or puberty blockers.

The hesitation I see the most with parents, and the same that I saw with my own parents, is, ‘What if you change your mind... your brain is still developing. You’re a teenager... I don’t want to take the leap and put you on hormone blockers because that affects your body. And what if this doesn’t end up being how you feel?’ Whereas if there were a gene and then that could have been identified, maybe I could have started my transition even younger, because [the test result] would have said, ‘No, this is definitely how it is. He’s not going to change his mind. This is who he is. And there is actually a prescribed course of treatment for this.’ - Participant 9

Theme 4: TAGR could contribute to the pathologization and elimination of TGD identities

All participants expressed concerns about how TAGR could harm and pathologize the TGD community. Many mentioned that this genetic research would create an additional mechanism of oppression, on top of the already present discrimination. Participants’ concerns about harms stemming from this genetic research could be sub-categorized into two different groups: (a) this genetic research could further pathologize TGD identities as “mental disorders,” and (b) this genetic research could be utilized as a tool for eugenics.

Pathologizing TGD identities Most participants expressed that trans and non-binary identities have been pathologized in the past and this genetic research could contribute to this oppression.

As far as public understanding [of] this narrative of, ‘This person is a boy trapped in a girl’s body,’ instead of honoring the natural variability of human gender identity. [It is] framing the narrative for cis people that something was wrong in this person and [cisgender people are] fixing it. - Participant 10

I'm concerned because of the very real backgrounds, historical and present, of how... the field of science... often gets evoked in the name of defending a gender binary, like a bio-essentialist view in the world... People love to cite studies that somehow support their claim that... all billions of bodies existing in the world can really be simplified into just two categories based on genitalia. - Participant 8

Participants expressed a strong sense of pride about their TGD identities, which they felt should not be pathologized as a “disorder” to be cured, or as something undesirable that they would want to change about themselves.

There was this survey... given to trans people and they were asked: ‘If you could become cis and not be trans, would you do it?’ And most of them said they didn't want to be cis... If they became cis, that would be a completely different identity and experience and they can't identify with it. - Participant 6

The harmful history of genetics as a tool for eugenics A couple of participants described this genetic research as medical eugenics, drawing similarities to how genetic testing has impacted other communities. The quotes listed in this section and corresponding section of the table come from participants whose highest level of formal genetics education ranges from high school level courses to professional level/career-related genetics education.

There's often news publications about isolating the gene ‘responsible’ for... a range of disabilities. There's overlap between trans justice and disability justice considering how pathologization works. I could easily see... future parents, doctors, certain hospitals wanting to offer the option of isolating that gene and effectively... nullify it to ensure their child is not trans. - Participant 8

I've heard...some pushback from the Deaf community [surrounding genetic testing for deafness] saying: ‘Medicalizing that issue makes it seem like there's something wrong with that.’ And so, for some Deaf people, preserving their deafness is absolutely essential. And I could see some trans people feeling like, ‘This is who I am. This does not need correction.’ - Participant 5

A few participants went to further lengths, citing that the pathologization and medical genocide that may result from TAGR could potentially be even worse in places less tolerant of TGD people.

What could less accepting countries do with that information?... It could just open a box of different kinds of discrimination. - Participant 10

Many participants brought up the role of genetics in eugenics against TGD people with the goal of eliminating TGD people.

The more aware we are of any genes related to not just gender, but any marginalized aspect of someone's self, the more it opens up avenues for people to select away from those genes. - Participant 13

Participants felt that TAGR could also contribute to the elimination of TGD people by using assisted reproductive technology (ART) and in vitro fertilization (IVF) to test an embryo for any genetic variants associated with TGD identities and decide whether to implant it or attempt to change it. When elaborating on ART and IVF, participants described that the existence of a genetically identifiable trait could cause someone to abort a pregnancy or to want to change the outcome of a pregnancy by not selecting embryos with trans-associated genetic variants.

Say we do find some specific genetic sequence... If [people] find out that a fetus they're carrying has that genetic sequence, they could terminate the pregnancy [and] select away from that. If they're doing any kind of genetic testing on fertilized embryos, it is... a slippery slope... veering on eugenics. - Participant 13

Theme 5: Researchers should consult community members and consider ethical concerns before conducting research

TGD involvement in all levels of research When asked about their recommendations for researchers, every participant discussed involving the TGD community at all levels of the research process. Many participants described interviewing or consulting with TGD individuals as a way to determine how they feel about this kind of research and how it should be done.

Too often, trans people are left out of [the] conversation with development [of research material]. Cis scientists and doctors... can look at things in [their own] perspective and not understand the different trans perspectives, [they] can miss something that a trans person would notice. - Participant 4

This is true for every research [study] ever about trans and non-binary people... Trans people need to be involved in some major capacity, whether... that's the lead team of researchers, if [not], consultants should be brought in. And I think that there should be a community advisory board [that is] as diverse as possible. - Participant 9

Considering the ethical, legal, and social implications of research Overall, participants offered different concerns

about conducting this type of research, from the impacts it could have on trans people's lives to the ways in which it could be used in supportive or harmful manners.

At some point, a researcher's curiosity and desire for knowledge has very deep, ethical implications for the lives of so many people... That researcher or that team of researchers... might never meet or interact with all of those lives, but... they have a high level of impact. And I think that that's... a very difficult, moral choice that each person has to make individually about involving themselves in this work or not. - Participant 7

Some participants stated that TGD individuals have differing priorities when it comes to care and overall health.

If I were running the government and I had... money to allocate, this wouldn't be what I chose to fund, because there are already so many other current pressing issues like social issues, legal rights... housing discrimination - Participant 2

Many participants expressed that it may not be possible to predict or control the ways in which this genetic research could be used, and that research should not be done solely out of curiosity.

If you're doing a study to control [TGD people] or because it's some interesting guinea pig [experiment]... , then I don't see the point if it's not going to help trans people... live better lives. - Participant 14

All participants felt it is important to identify the TGD community's needs and desires when conducting research that impacts them.

Discussion

This study is one of the first studies exploring the perspectives of TGD individuals about genetic testing and research seeking genetic associations to their gender identities. Individual interviews with members of the TGD community identified areas of optimism about ways that such research could improve self-perception and others' perception of their gender, and therefore could potentially increase acceptance and access to gender-affirming care. However, this optimism was tempered by a number of concerns for potential misuse of this information now and in the future, and participants largely focused on avenues by which trans-associated genetic research could be used for discrimination.

Areas that TAGR could contribute to the discrimination of the TGD community

All participants described three main ways in which TAGR could lead to negative outcomes for the TGD community: (1) furthering divisiveness regarding what it means to be TGD, (2) creating new barriers or exacerbating existing barriers to gender-affirming care, and (3) TAGR being used as a new tool for eugenics. They also commented on their concern about the inability to predict how research could be used in the future.

Most participants expressed concern that TAGR could worsen divisiveness both internally in the TGD community and externally from cisgender perspectives. Participants felt that both transmedicalists and cisgender people could use TAGR to subdivide TGD people into groups of those who have genetic findings and those who do not. Subdividing communities that have been marginalized can harm group efforts in accessing financial, legal, and societal resources. Similar to how the model minority myth has been divisive amongst racial minorities by creating detrimental assumptions, TAGR could potentially create a model gender minority by legitimizing inaccurate and damaging rhetoric and creating undue tensions between subgroups (Kiang et al. 2017). Participants drew comparisons to divisive transmedicalist perspectives and the assumption that a TGD person must access gender-affirming care to be transgender (Bettcher 2014). This could create more TGD-targeted discrimination and pathologization of TGD identities by further pushing a narrative of medicalization rather than recognizing the validity of the spectrum of gender-diverse identities. Several participants expressed not needing external validation from genetic testing for their self-discovery process and that attributing TGD to a genetic finding is reductive of their experiences.

Nearly all participants noted that current existing barriers to medical care could be further exacerbated by TAGR. If providers and/or payors used TAGR to decide who can access medical care, particularly transitioning and gender-affirming care, this could further perpetuate existing inequities in healthcare (Roberts and Fantz 2014; Safer et al. 2016). Notably, participants were concerned that healthcare providers could control their access to genetic testing. Some participants living in the USA felt worried that insurance companies could utilize TAGR as a prerequisite test to determine both access to and coverage of gender-affirming care and procedures. Studies have shown that health insurance coverage for medically necessary services for TGD people is both cost-effective and has an overall low economic impact on US society and on payors (Padula et al. 2016). However, currently, many health insurance payors do not cover gender-affirming care (Dowshen et al. 2019), and some TGD people avoid accessing care due to insurance-based denials of

care coverage (Bakko and Kattari 2020; Kcomt et al. 2020). These barriers can be further complicated by the intersectionality of individuals having multiple minoritized identities, such as the experiences of discrimination and stigma that Black TGD youth and adults encounter when accessing care (Goldenberg et al. 2019; Sevelius 2013). Thus, TAGR has the potential to add an additional barrier to gender-affirming care.

Genetics has been used as a tool for eugenics to target certain populations as “undesirable” and change or eliminate them. The history of genetics is deeply rooted in eugenics, discrimination, and oppression (Ekberg 2007; Rembis 2009), which has also extended to attempts at eliminating TGD people and identities, both literally and conceptually through bioessentialist frameworks. Participants expressed that TAGR could worsen existing discrimination against TGD people (Ferlatte et al. 2020; Inch 2016; Romanelli and Lindsey 2020; White Hughto et al. 2017; Zeluf et al. 2018) and be used as a eugenics tool to further eliminate TGD identities. A few participants drew comparisons between the disability justice critique of genetics selecting against disabilities, which is well documented in existing literature (Hall 2013; Miller and Levine 2013). Some participants described how the elimination of TGD people could occur through assisted reproductive technology (such as IVF and genetic testing of embryos), use of gene therapy to “turn off” trans-associated genetic findings, or selectively terminating pregnancies with genetic findings associated to TGD identities. These technologies and procedures have previously been criticized as perpetrating “medical eugenics” and selecting against people with disabilities (Hall 2013; Karpin 2007; Mahowald 2007; Pergament 2013; Wasserman and Asch 2006), and our participants felt that TAGR could result in a similar negative selection against TGD people. With past uses of genetics and scientific research to inflict harm on the LGBTQIA+ and TGD communities, all participants were emphatic that TAGR should not be used for eugenics, and that since predicting use of TAGR is unavoidable, then researchers should not conduct TAGR.

Areas that TAGR could positively affect TGD lives

A common point that participants discussed was the possibility of TAGR having beneficial outcomes for the TGD communities. However, they largely felt that these potential positive outcomes would represent a best-case scenario, and some felt it was impossible for TAGR to lead to any positives without associated negative consequences. The most common positive outcomes described fell into two main categories: (1) self-validation and normalization of TGD identities and (2) increasing access to transitioning and gender-affirming care. Of note, many noted

beneficial outcomes are improvements that could be made without any research on or use of TAGR.

TAGR was described by some participants as having the potential to help TGD people in their self-acceptance process by reducing or removing self-doubt about their gender, which may be particularly important for TGD youth. Studies have shown that normalization of TGD identities in healthcare helps TGD people reach self-actualization (Condat et al. 2018). Examples of normalization and validation in healthcare are TGD people having access to mental health care, assisted reproductive technologies and inclusive pathways to parenthood, and gender-affirming care (Ashley and Ells 2018; Condat et al. 2018; Dubov and Fraenkel 2018; Ruderman et al. 2021; Vanderburgh 2009). Moreover, seeing one’s identity represented in media and culture has positive effects for the TGD community (Miller 2018). If TAGR helps improve validation and normalization of TGD identities, it also has the potential to assist TGD people reach self-actualization. TAGR could contribute to de-pathologizing TGD identities if used to show that TGD identities exist on a spectrum of gender expression along with cisgender identities, allowing for a continued effort in normalization of TGD (Castro-Peraza et al. 2019; Sues Schwend 2020).

Current barriers to accessing gender-affirming care were mentioned in several interviews. Some described TAGR as a tool that could increase access to gender-affirming care if used to remove barriers to care or justify coverage of gender-affirming services to insurance payors. Genetics has already impacted gender-affirming surgery decisions for TGD patients with pathogenic cancer-predisposing variants, such as influencing whether to opt for a bilateral risk-reducing mastectomy instead of a gender-affirming mastectomy, often called “top surgery” (Berro et al. 2019; Selvaggi 2020; Vaupel-Klein and Walsh 2021; Zayhowski et al. 2019). Additionally, due to the lack of knowledge of some primary care providers regarding transgender medicine and limited but growing clinical guidelines, TGD individuals are at a disadvantage when accessing both primary and transition-related healthcare (Edmiston et al. 2016; Shuster 2016). Genetics has contributed significantly to developing precision individualized medicine in the field of pharmacogenomics (Relling and Evans 2015). A few participants felt TAGR could help if used to understand the impact of genetics on hormone replacement therapy. TAGR could increase TGD visibility if used to alleviate existing financial, knowledge, provider, and health systems barriers (El-Hadi et al. 2018; Safer et al. 2016; Tomson 2018; White Hughto et al. 2015), and could contribute to more trans-centered research and evidence-based care for those TGD individuals in which TAGR confirms their identity.

Recommendations for researchers

It is necessary to consider ethical, legal, and social implications that TAGR could have on the TGD community prior to initiating TAGR and similar research. To do this, researchers must identify the needs and concerns of the TGD community. All participants alluded to CBPR, describing the need for trans and gender-diverse contributions in TAGR at all levels: participants, researchers, scientists, and members of community advisory boards or institutional review boards. Scientific research has been used to oppress several marginalized communities, damaging trust between community members and researchers. Examples like the Tuskegee Syphilis Study and the use of Henrietta Lacks (HeLa) cell lines without her permission highlight ethical problems arising from research done without consulting those involved and affected (Alsan and Wanamaker 2018; Katz et al. 2006; Skloot 2017). Using a CBPR approach would allow for establishing and maintaining partnerships with communities historically marginalized and antagonized by science (Katz-Wise et al. 2019; Northridge et al. 2007; Satcher 2005; Thomas et al. 2020; Viswanathan et al. 2004). Publication of results should offer clear and concise takeaway points for the broader public (Thomas et al. 2020). This is particularly crucial because it is impossible to predict and mitigate all ways in which research will be used to leverage various harmful ideologies. Many participants questioned the utility of TAGR and believed that because of the ethical challenges, TAGR should not be conducted. It is important that researchers consider ethical implications of research, and only conduct research when the research goals are shared by the TGD community.

Limitations

There are several limitations to this study. This qualitative study had a sample size of 18 participants. Because these results are drawn from 18 participants' responses, results cannot be deemed representative of the TGD community. Although only 18 interviews were conducted, thematic saturation was reached through recurring themes repeatedly appearing in later interviews with a rapid decline in new emerging themes (Guest et al. 2020; Lowe et al. 2018; Saunders et al. 2018). Qualitative interviews are inherently biased due to the subjectivity of interviewer and interviewee's perspectives, as well as due to the phrasing of the interview questions (Creswell 2007). We mitigated this by conducting side-by-side coding to review and modify the initial codebook as needed. The study advertisement was made available to several relevant social media groups, composed of hundreds of thousands of members in total. However, not all group members necessarily met inclusion criteria. Moreover, participants were self-selected.

Those who responded to the survey and participated in the research are likely to have stronger opinions about this study's research topic (Collier and Mahoney, 1996; Norris 1997; Robinson 2014). This may have caused a selection bias for individuals who feel discriminated by or have had a negative experience with genetic research. However, in the interview, participants were asked what their experiences with genetics are, if any, and most participants indicated little or no experience with genetics research and genetic testing. Those who did reflected neutral experiences. Finally, the majority of participants were White. We did not gather information about socioeconomic status. The ways in which intersecting identities interact could impact opinions towards TAGR. Future research like this study should be done with a larger sample size with varying demographics of participants to incorporate how participants' intersecting identities, as well as level of genetics education, impact their views on TAGR.

Conclusions

This study presents initial data on the opinions of TGD individuals on emerging types of TAGR. This paper outlines potential harms and benefits that could materialize from TAGR such as increased discrimination, pathologization, and usage of TAGR as a tool for eugenics, as well as increased acceptance for and normalization of gender diversity. Participants in this study made it clear that researchers must examine the ethics of their research endeavors and the possible consequences on the target participants' community before proceeding. Scientists should not be conducting research, such as TAGR, solely out of curiosity—research efforts must prioritize the opinions and needs of the TGD community. The possible harms of eugenics and discrimination stemming from TAGR likely outweigh any benefit. As one participant summarized:

[TAGR] could be very validating or very prohibitive for trans people... I can understand the inherent curiosity to try to get answers. I just don't know that there's enough benefit from potentially what could be discovered to outweigh the cost of having that information. - Participant 13

Supplementary Information The online version contains supplementary material available at <https://doi.org/10.1007/s12687-021-00554-z>.

Acknowledgements This study was completed in partial fulfillment of the requirements of the first author's Master of Science degree in Genetic Counseling from MGH Institute of Health Professions. The authors would like to extend a thank you to the participants that took part in this study.

Author contribution All authors contributed to the study conception and design. Material preparation and data collection were performed by Antoine Rajkovic. Data analysis was performed by Antoine Rajkovic and Kimberly Zayhowski. The first draft of the manuscript was written by Antoine Rajkovic and Kimberly Zayhowski, with critical feedback from Allison Cirino and Tala Berro. All authors commented on previous versions of the manuscript. All authors read and approved the final manuscript. Kimberly Zayhowski supervised the overall project.

Funding Funding for this project was provided by the Genetic Counseling Program at MGH Institute of Health Professions.

Data availability Research data is not shared due to the remote risk of re-identifying a participant.

Declarations

Statement of ethics All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Verbal informed consent was obtained from all patients for being included in the study.

Ethics approval This study and all procedures were reviewed by the Mass General Brigham Institutional Review Board (Protocol #2020P003562), and were approved as an exempt protocol in December 2020.

Conflict of interest The authors declare no competing interests.

Informed consent Informed consent was obtained from all individual participants included in the study.

Animal studies No non-human animal studies were carried out by the authors for this article.

References

- Alsan M, Wanamaker M (2018) Tuskegee and the health of black men. *Q J Econ* 133(1):407–455. <https://doi.org/10.1093/qje/qjx029>
- Ashley F, Ells C (2018) In favor of covering ethically important cosmetic surgeries: facial feminization surgery for transgender people. *Am J Bioeth* 18(12):23–25. <https://doi.org/10.1080/15265161.2018.1531162>
- Bakko M, Kattari SK (2020) Transgender-related insurance denials as barriers to transgender healthcare: differences in experience by insurance type. *J Gen Intern Med* 35(6):1693–1700. <https://doi.org/10.1007/s11606-020-05724-2>
- Baltar F, Brunet I (2012) Social research 2.0: virtual snowball sampling method using Facebook. *Internet Res*, 22(1), 57–74. <https://doi.org/10.1108/10662241211199960>
- Barnes H, Morris E, Austin J (2019) Trans-inclusive genetic counseling services: recommendations from members of the transgender and non-binary community. *J Genet Counsel*, <https://doi.org/10.1002/jgc4.1187>
- Bengtsson M (2016) How to plan and perform a qualitative study using content analysis. *NursingPlus Open* 2:8–14. <https://doi.org/10.1016/j.npls.2016.01.001>
- Bentz E-K, Hefler LA, Kaufmann U, Huber JC, Kolbus A, Tempfer CB (2008) A polymorphism of the CYP17 gene related to sex steroid metabolism is associated with female-to-male but not male-to-female transsexualism. *Fertil Steril* 90(1):56–59. <https://doi.org/10.1016/j.fertnstert.2007.05.056>
- Berro T, Zayhowski K, Field T, Channaoui N, Sotelo J (2019) Genetic counselors' comfort and knowledge of cancer risk assessment for transgender patients. *J Genet Counsel*, <https://doi.org/10.1002/jgc4.1172>
- Bettcher TM (2014) Trapped in the wrong theory: rethinking trans oppression and resistance. *Signs: J Women Cult Soc*, 39(2), 383–406. <https://doi.org/10.1086/673088>
- Bockting W, Fraser L, Knudson G, Whittle S, Botzer M, Brown G, De Cuypere G, Green J, Rachlin K, Winter S, Wylie KR (2010). WPATH de-pathologisation statement. https://amo_hub_content.s3.amazonaws.com/Association140/files/depsychopathologisation%205-26-10%20on%20letterhead.pdf
- Castro-Peraza ME, García-Acosta JM, Delgado N, Perdomo-Hernández AM, Sosa-Alvarez MI, Llabrés-Solé R, Lorenzo-Rocha ND (2019) Gender identity: the human right of depathologization. *Int J Environ Res Public Health*, 16(6). <https://doi.org/10.3390/ijerph16060978>
- Cicero EC, Reisner SL, Merwin EI, Humphreys JC, Silva SG (2020) The health status of transgender and gender nonbinary adults in the United States. *PLoS ONE* 15(2):e0228765. <https://doi.org/10.1371/journal.pone.0228765>
- Cohen J (1960) A coefficient of agreement for nominal scales. *Educ Psychol Measur* 20(1):37–46. <https://doi.org/10.1177/001316446002000104>
- Cohen-Kettenis PT, Pfäfflin F (2010) The DSM diagnostic criteria for gender identity disorder in adolescents and adults. *Arch Sex Behav* 39(2):499–513. <https://doi.org/10.1007/s10508-009-9562-y>
- Collier D, Mahoney J (1996) Insights and pitfalls: selection bias in qualitative research. *World Politics* 49(1):56–91
- Condat A, Mendes N, Drouineaud V, Gründler N, Lagrange C, Chiland C, Wolf J-P, Ansermet F, Cohen D (2018) Biotechnologies that empower transgender persons to self-actualize as individuals, partners, spouses, and parents are defining new ways to conceive a child: psychological considerations and ethical issues. *Philos Ethics Humanit Med* 13(1):1. <https://doi.org/10.1186/s13010-018-0054-3>
- Conrad P (1992) Medicalization and social control. *Ann Rev Sociol* 18(1):209–232. <https://doi.org/10.1146/annurev.so.18.080192.001233>
- Creswell JW (2007) Qualitative inquiry and research design: choosing among five approaches, 2nd ed (pp. xvii, 395). Sage Publications, Inc
- Dewey JM, Gesbeck MM (2017) (Dys) Functional diagnosing: mental health diagnosis, medicalization, and the making of transgender patients. *Humanit Soc* 41(1):37–72. <https://doi.org/10.1177/0160597615604651>
- Dowshen NL, Christensen J, Gruschow SM (2019) Health insurance coverage of recommended gender-affirming health care services for transgender youth: shopping online for coverage information. *Transgender Health* 4(1):131–135. <https://doi.org/10.1089/trgh.2018.0055>
- Dubov A, Fraenkel L (2018) Facial feminization surgery: the ethics of gatekeeping in transgender health. *Am J Bioeth* 18(12):3–9. <https://doi.org/10.1080/15265161.2018.1531159>
- Edmiston EK, Donald CA, Sattler AR, Peebles JK, Ehrenfeld JM, Eckstrand KL (2016) Opportunities and gaps in primary care preventative health services for transgender patients: a systemic review. *Transgender Health* 1(1):216–230. <https://doi.org/10.1089/trgh.2016.0019>
- Ekberg M (2007) The old eugenics and the new genetics compared. *Social History of Medicine* 20(3):581–593. <https://doi.org/10.1093/shm/hkm075>

- El-Hadi H, Stone J, Temple-Oberle C, Harrop AR (2018) Gender-affirming surgery for transgender individuals: perceived satisfaction and barriers to care. *Plastic Surgery* 26(4):263–268. <https://doi.org/10.1177/2292550318767437>
- Fausto-Sterling A (2000) Sexing the body: gender politics and the construction of sexuality. Basic Books
- Fausto-Sterling A (2012) Sex/gender: biology in a social world. Routledge
- Feldman J, Brown GR, Deutsch MB, Hembree W, Meyer W, Meyer-Bahlburg HFL, Tangpricha V, T'Sjoen G, Safer JD (2016) Priorities for transgender medical and healthcare research. *Curr Opin Endocr Diabet Obes*, 23(2), 180–187. <https://doi.org/10.1097/MED.0000000000000231>
- Knight, R. (2020). Identifying health differences between transgender and cisgender gay, bisexual and other men who have sex with men using a community-based approach. *J Sex Res*, 1–9. <https://doi.org/10.1080/00224499.2020.1740148>
- Fleiss JL (1971) Measuring nominal scale agreement among many raters. *Psychol Bull* 76(5):378–382. <https://doi.org/10.1037/h0031619>
- Flores A, Herman J, Gates G, Brown TNT (2016) How many adults identify as transgender in the United States? UCLA School of Law Williams Institute. <https://williamsinstitute.law.ucla.edu/publications/trans-adults-united-states/>
- Foreman M, Hare L, York K, Balakrishnan K, Sánchez FJ, Harte F, Erasmus J, Vilain E, Harley VR (2019) Genetic link between gender dysphoria and sex hormone signaling. *J Clin Endocrinol Metab* 104(2):390–396. <https://doi.org/10.1210/jc.2018-01105>
- Frohard-Dourlent H, Saewyc E, Veale J, Peter T, MacAulay M (2020) Conceptualizing gender: lessons from the Canadian Trans Youth Health Survey. *Signs: J Women Cult Soc*, 46(1), 151–176. <https://doi.org/10.1086/709302>
- Ganna A, Verweij KJH, Nivard MG, Maier R, Wedow R, Busch AS, Abdellaoui A, Guo S, Sathirapongsasuti JF, 23and Me Research Team, Lichtenstein P, Lundström S, Långström N, Auton A, Harris KM, Beecham GW, Martin ER, Sanders AR, Perry, JRB, ... Zietsch BP (2019) Large-scale GWAS reveals insights into the genetic architecture of same-sex sexual behavior. *Science*, 365(6456), eaat7693. <https://doi.org/10.1126/science.aat7693>
- Giblon R, Bauer GR (2017) Health care availability, quality, and unmet need: a comparison of transgender and cisgender residents of Ontario Canada. *BMC Health Services Research* 17(1):283. <https://doi.org/10.1186/s12913-017-2226-z>
- Goldenberg T, Jadwin-Cakmak L, Popoff E, Reisner SL, Campbell BA, Harper GW (2019) Stigma, gender affirmation, and primary healthcare use among Black transgender youth. *J Adolesc Health* 65(4):483–490. <https://doi.org/10.1016/j.jadohealth.2019.04.029>
- Guest G, Namey E, Chen M (2020) A simple method to assess and report thematic saturation in qualitative research Andrew Lowe, Anthony C. Norris, A. Jane Farris, Duncan R. Babbage. *PLOS ONE*, 15(5), e0232076. <https://doi.org/10.1371/journal.pone.0232076>
- Hall MC (2013) Reconciling the disability critique and reproductive liberty: the case of negative genetic selection. *Int J Feminist Approach Bioethics* 6(1):121–143. <https://doi.org/10.2979/intjfemappbio.6.1.121>
- Hamer DH (2011) Science of desire: the gay gene and the biology of behavior. Simon and Schuster
- Hamer DH, Hu S, Magnuson VL, Hu N, Pattatucci AM (1993) A linkage between DNA markers on the X chromosome and male sexual orientation. *Science (New York, N.Y.)*, 261(5119), 321–327. <https://doi.org/10.1126/science.8332896>
- Illich I (1976) Medical nemesis: the expropriation of health. Pantheon Books
- Inch E (2016) Changing minds: the psycho-pathologization of trans people. *Int J Ment Health* 45(3):193–204. <https://doi.org/10.1080/00207411.2016.1204822>
- Kachen A, Pharr JR (2020) Health care access and utilization by transgender populations: a United States transgender survey study. *Transgender Health* 5(3):141–148. <https://doi.org/10.1089/trgh.2020.0017>
- Karpin I (2007) Choosing disability: preimplantation genetic diagnosis and negative enhancement. *J Law Med* 15(1):89–102
- Katz RV, Kegeles SS, Kressin NR, Green BL, Wang MQ, James SA, Russell SL, Claudio C (2006) The Tuskegee Legacy Project: willingness of minorities to participate in biomedical research. *J Health Care Poor Underserved* 17(4):698–715. <https://doi.org/10.1353/hpu.2006.0126>
- Katz-Wise SL, Pullen Sansfaçon A, Bogart LM, Rosal MC, Ehrensaff D, Goldman RE, Bryn Austin S (2019) Lessons from a community-based participatory research study with transgender and gender nonconforming youth and their families. *Action Research* 17(2):186–207. <https://doi.org/10.1177/1476750318818875>
- Kcomt L, Gorey KM, Barrett BJ, McCabe SE (2020) Healthcare avoidance due to anticipated discrimination among transgender people: a call to create trans-affirmative environments. *SSM - Population Health* 11:100608. <https://doi.org/10.1016/j.ssmph.2020.100608>
- Kiang L, Huynh VW, Cheah CSL, Wang Y, Yoshikawa H (2017) Moving beyond the model minority. *Asian Am J Psychol* 8(1):1–6. <https://doi.org/10.1037/aap0000070>
- Kreukels BPC, Beach L, Chan Y-M, Derks EM, Esteva I, Ehrenfeld J, Heijer MD, Posthuma D, Raynor L, Tishelman A, Davis LK (2018) The biological contributions to gender identity and gender diversity: bringing data to the table. *Behav Genet* 48(2):95–108. <https://doi.org/10.1007/s10519-018-9889-z>
- Lowe A, Norris AC, Farris AJ, Babbage DR (2018) Quantifying thematic saturation in qualitative data analysis. *Field Methods* 30(3):191–207. <https://doi.org/10.1177/1525822X17749386>
- Lowik AJ (2018) Reproducing eugenics, reproducing while trans: the state sterilization of trans people. *J GLBT Fam Stud* 14(5):425–445. <https://doi.org/10.1080/1550428X.2017.1393361>
- Mahowald MB (2007) Prenatal testing for selection against disabilities. *Camb Q Healthc Ethics* 16(4):457–462. <https://doi.org/10.1017/S0963180107070594>
- Marshall Z, Welch V, Minichiello A, Swab M, Brunger F, Kaposy C (2019) Documenting research with transgender, nonbinary, and other gender diverse (trans) individuals and communities: introducing the global trans research evidence map. *Transgender Health* 4(1):68–80. <https://doi.org/10.1089/trgh.2018.0020>
- Merkel J (2017) Access to healthcare and lack thereof for transgender people. *Theory in Action* 10(4):41–47. <https://doi.org/10.3798/tia.1937-0237.1724>
- Meyer IH (2003) Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: conceptual issues and research evidence. *Psychol Bull* 129(5):674–697. <https://doi.org/10.1037/0033-2909.129.5.674>
- Miller M (2018) Transgender YouTubers and the power of coming out: existentialism, gender performance, and self-actualization. Electronic Thesis and Dissertation Repository. <https://ir.lib.uwo.ca/etd/5742>
- Miller PS, Levine RL (2013) Avoiding genetic genocide: understanding good intentions and eugenics in the complex dialogue between the medical and disability communities. *Genet Med* 15(2):95–102. <https://doi.org/10.1038/gim.2012.102>
- Moyer AM, Matey ET, Miller VM (2019) Individualized medicine: sex, hormones, genetics, and adverse drug reactions. *Pharmacol Res Perspect* 7(6):e00541. <https://doi.org/10.1002/prp2.541>
- Naderifar M, Goli H, Ghaljaie F (2017) Snowball sampling: a purposeful method of sampling in qualitative research. *Strides in*

- Development of Medical Education, 14(3). <https://doi.org/10.5812/sdme.67670>
- Norris N (1997) Error, bias and validity in qualitative research. *Educational Action Research* 5(1):172–176. <https://doi.org/10.1080/09650799700200020>
- Northridge ME, McGrath BP, Krueger SQ (2007) Using community-based participatory research to understand and eliminate social disparities in health for lesbian, gay, bisexual, and transgender populations. In I. H. Meyer & M. E. Northridge (Eds.), *The health of sexual minorities: public health perspectives on lesbian, gay, bisexual and transgender populations* (pp. 455–470). Springer US. https://doi.org/10.1007/978-0-387-31334-4_18
- Padula WV, Heru S, Campbell JD (2016) Societal implications of health insurance coverage for medically necessary services in the U.S. transgender population: a cost-effectiveness analysis. *J General Int Med*, 31(4), 394–401. <https://doi.org/10.1007/s11606-015-3529-6>
- Pergament, D. (2013). What does choice really mean? Prenatal testing, disability, and special education without illusions. *Health Matrix (Cleveland, Ohio)*, 23(1), 55–117.
- Petersen A (1999) The portrayal of research into genetic-based differences of sex and sexual orientation: a study of “popular” science journals, 1980 to 1997. *J Commun Inq* 23(2):163–182. <https://doi.org/10.1177/0196859999023002005>
- Poteat T, German D, Kerrigan D (2013) Managing uncertainty: a grounded theory of stigma in transgender health care encounters. *Soc Sci Med* 1982(84):22–29. <https://doi.org/10.1016/j.socscimed.2013.02.019>
- Prunas A (2019) The pathologization of trans-sexuality: historical roots and implications for sex counselling with transgender clients. *Sexologies* 28(3):e54–e60. <https://doi.org/10.1016/j.sexol.2019.06.002>
- Puckett JA, Cleary P, Rossman K, Newcomb ME, Mustanski B (2018) Barriers to gender-affirming care for transgender and gender nonconforming individuals. *Sexual Res Social Pol J NSRC: SR & SP* 15(1):48–59. <https://doi.org/10.1007/s13178-017-0295-8>
- REDCap. (2020). <https://www.project-redcap.org/>
- Relling MV, Evans WE (2015) Pharmacogenomics in the clinic. *Nature* 526(7573):343–350. <https://doi.org/10.1038/nature15817>
- Rembis MA (2009) (Re)Defining disability in the ‘genetic age’: behavioral genetics, ‘new’ eugenics and the future of impairment. *Disability & Society* 24(5):585–597. <https://doi.org/10.1080/09687590903010941>
- Repo J (2019) Governing juridical sex: gender recognition and the biopolitics of trans sterilization in Finland. *Polit Gend* 15(1):83–106. <https://doi.org/10.1017/S1743923X1800034X>
- Ripley N (2019) Forced sterilization of trans people in Japan. *Human Rights Brief Spring 2019 Regional Coverage*. <https://digitalcommons.wcl.american.edu/hrbregionalcoverage-spring2019/3>
- Roberts TK, Fantz CR (2014) Barriers to quality health care for the transgender population. *Clin Biochem* 47(10):983–987. <https://doi.org/10.1016/j.clinbiochem.2014.02.009>
- Robinson OC (2014) Sampling in interview-based qualitative research: a theoretical and practical guide. *Qual Res Psychol* 11(1):25–41. <https://doi.org/10.1080/14780887.2013.801543>
- Röll W (1996) Homosexual inmates in the Buchenwald Concentration Camp. *J Homosex* 31(4):1–28. https://doi.org/10.1300/J082v31n04_01
- Romanelli M, Lindsey MA (2020) Patterns of healthcare discrimination among transgender help-seekers. *Am J Prev Med* 58(4):e123–e131. <https://doi.org/10.1016/j.amepre.2019.11.002>
- Rosenfeld D, Bartlam B, Smith RD (2012) Out of the closet and into the trenches: gay male Baby Boomers, aging, and HIV/AIDS. *Gerontologist* 52(2):255–264
- Ruderman M, Berro T, Torrey Sosa L, Zayhowski K (2021) Genetic counselors’ experiences with transgender individuals in prenatal and preconception settings. *J Genetic Counsel*, jgc4.1394. <https://doi.org/10.1002/jgc4.1394>
- Safer JD, Coleman E, Feldman J, Garofalo R, Hembree W, Radix A, Sevelius J (2016) Barriers to health care for transgender individuals. *Curr Opin Endocrinol Diabetes Obes* 23(2):168–171. <https://doi.org/10.1097/MED.0000000000000227>
- Satcher D (2005) *Methods in community-based participatory research for health*. John Wiley & Sons
- Saunders B, Sim J, Kingstone T, Baker S, Waterfield J, Bartlam B, Burroughs H, Jinks C (2018) Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quant* 52(4):1893–1907. <https://doi.org/10.1007/s11135-017-0574-8>
- Schüklenk U, Stein E, Kerin J, Byne W (1997) The ethics of genetic research on sexual orientation. *Hastings Cent Rep* 27(4):6. <https://doi.org/10.2307/3528773>
- Selvaggi G (2020) Mastectomy in trans men. In A. Cordova, A. Innocenti, F. Toia, & M. Tripoli (Eds.), *Plastic and cosmetic surgery of the male breast* (pp. 161–170). Springer International Publishing. https://doi.org/10.1007/978-3-030-25502-2_17
- Sevelius JM (2013) Gender affirmation: a framework for conceptualizing risk behavior among transgender women of color. *Sex Roles* 68(11):675–689. <https://doi.org/10.1007/s11199-012-0216-5>
- Shuster SM (2016) Uncertain expertise and the limitations of clinical guidelines in transgender healthcare. *J Health Soc Behav* 57(3):319–332. <https://doi.org/10.1177/00221465166660343>
- Skloot R (2017) *The immortal life of Henrietta Lacks*. Crown Publishing Group, a division of Random House, Incorporated.
- Somerville S (1994) Scientific racism and the emergence of the homosexual body. *J Hist Sex* 5(2):243–266
- Suess Schwend A (2020) Trans health care from a depathologization and human rights perspective. *Public Health Rev* 41(1):3. <https://doi.org/10.1186/s40985-020-0118-y>
- Temi. (2021). Temi. <https://www.temi.com/>
- Theisen JG, Sundaram V, Filchak MS, Chorich LP, Sullivan ME, Knight J, Kim H-G, Layman LC (2019) The use of whole exome sequencing in a cohort of transgender individuals to identify rare genetic variants. *Sci Rep* 9(1):20099. <https://doi.org/10.1038/s41598-019-53500-y>
- Thomas TR, Hofmann D, McKenna BG, Van Der Misen AIR, Stokes MA, Daniolos P, Michaelson JJ (2020) Community attitudes on genetic research of gender identity, sexual orientation, and mental health. *PLoS ONE* 15(7):e0235608. <https://doi.org/10.1371/journal.pone.0235608>
- Tomson A. (2018). Gender-affirming care in the context of medical ethics – gatekeeping v. Informed consent. *South Afr J Bioethics Law*, 11(1), 24–28.
- Tuite A, Dalla Piazza M, Brandi K, Pletcher BA (2020) Beyond circles and squares: a commentary on updating pedigree nomenclature to better represent patient diversity. *J Genetic Counsel*, jgc4.1234. <https://doi.org/10.1002/jgc4.1234>
- Vanderburgh R (2009) Appropriate therapeutic care for families with pre-pubescent transgender/gender-dissonant children. *Child Adolesc Soc Work J* 26(2):135–154. <https://doi.org/10.1007/s10560-008-0158-5>
- Vaupel-Klein AM, Walsh RJ (2021) Considerations in genetic counseling of transgender patients: cultural competencies and altered disease risk profiles. *J Genet Couns* 30(1):98–109. <https://doi.org/10.1002/jgc4.1372>
- Veale J, Saewyc E, Frohard-Dourlent H, Dobson S, Clark B, the Canadian Trans Youth Health Survey Research Group (2015) *Being safe, being me: results of the Canadian Trans Youth Health Survey*. University of British Columbia. <http://www.saravyc.ubc.ca/2018/05/06/trans-youth-health-survey/>
- Vincent BW (2018) Studying trans: recommendations for ethical recruitment and collaboration with transgender participants

- in academic research. *Psychology & Sexuality* 9(2):102–116. <https://doi.org/10.1080/19419899.2018.1434558>
- Viswanathan M, Ammerman A, Eng E, Garlehner G, Lohr KN, Griffith D, Rhodes S, Samuel-Hodge C, Maty S, Lux L, Webb L, Sutton SF, Swinson T, Jackman A, Whitener L (2004) Community-based participatory research: assessing the evidence: summary. In AHRQ Evidence Report Summaries. Agency for Healthcare Research and Quality (US). <https://www.ncbi.nlm.nih.gov/sites/books/NBK11852/>
- Walsh R, Einstein G (2020) Transgender embodiment: a feminist, situated neuroscience perspective. *J Int Netw Sexual Ethics Pol*, 8(SI), 9–10
- Wasserman D, Asch A (2006) The uncertain rationale for prenatal disability screening. *AMA J Ethics* 8(1):53–56. <https://doi.org/10.1001/virtualmentor.2006.8.1.oped2-0601>
- Watters JK, Biernacki P (1989) Targeted sampling: options for the study of hidden populations. *Soc Probl* 36(4):416–430. <https://doi.org/10.2307/800824>
- White Hughto JM, Reisner SL, Pachankis JE (2015) Transgender stigma and health: a critical review of stigma determinants, mechanisms, and interventions. *Soc Sci Med* 198(147):222–231. <https://doi.org/10.1016/j.socscimed.2015.11.010>
- White Hughto JM, Rose AJ, Pachankis JE, Reisner SL (2017) Barriers to gender transition-related healthcare: identifying underserved transgender adults in Massachusetts. *Transgender Health* 2(1):107–118. <https://doi.org/10.1089/trgh.2017.0014>
- Winter S, De Cuyper G, Green J, Kane R, Knudson G (2016) The proposed ICD-11 gender incongruence of childhood diagnosis: a World Professional Association for Transgender Health Membership Survey. *Arch Sex Behav* 45(7):1605–1614. <https://doi.org/10.1007/s10508-016-0811-6>
- Zayhowski K, Park J, Boehmer U, Gabriel C, Berro T, Campion M (2019) Cancer genetic counselors' experiences with transgender patients: a qualitative study. *J Genetic Counsel*, jgc4.1092. <https://doi.org/10.1002/jgc4.1092>
- Zeluf G, Dhejne C, Orre C, Mannheimer LN, Deogan C, Höijer J, Winzer R, Thorson AE (2018) Targeted victimization and suicidality among trans people: a web-based survey. *LGBT Health* 5(3):180–190. <https://doi.org/10.1089/lgbt.2017.0011>
- Zucker KJ (2013, May 13) Gender identity disorder. *Child Psychopathol; Psychol Press*. <https://doi.org/10.4324/9780203763414-13>

Publisher's note Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.