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“I Am Tired All the Time from Existing”: Understanding Nonbinary Student and Staff Experiences of Higher Education in the UK as Social Harm

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Transgender inclusion is an increasingly prominent part of “equality, diversity, and inclusion” agendas in higher education. However, there has been little attention to the specific experiences of nonbinary students and staff. This article seeks to redress this and draws on data from an online survey conducted in 2019 of UK nonbinary higher education staff and students. The survey data highlight the importance participants attach to having their gender known and respected in their higher education institution, but also contained pervasive reports of erasure, invisibility, and ridicule in their work and/or study lives. We analyze these experiences through the lens of social harm in order to focus on the institutional norms, structures and practices that shape nonbinary experiences of higher education, and to counteract narratives of vulnerability/victimhood. Our analysis demonstrates the interconnections between mechanisms of harm in higher education, effects of harm as manifested in reports of exhaustion, distress, and fear, and the strategies nonbinary people engage in to mitigate or resist harm.

KEYWORDS nonbinary gender; social harm; higher education; transgender; erasure
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In their efforts to address gender diversity, UK higher education institutions have thus far largely centered around two nodes: "transgender" and "inclusion." Indeed, transgender inclusion is increasingly prominent in "equality, diversity, and inclusion" agendas in higher education, in part due to their requirement to comply with the 2010 Equality Act. This has resulted in universities and colleges adopting policies and guidance on, for example, transitioning at work and supporting transgender students. The aim of this article is to open up and expand this discussion in two key ways, firstly by focusing specifically on the experiences of nonbinary staff and students in higher education, and secondly by drawing on theories of social harm to understand those experiences.

While nonbinary gender is not a new phenomenon (Lester 2017; Vincent 2020), during the last 10–15 years nonbinary people have become more visible as part of wider trans and queer communities in the UK. Furthermore, government data has shown that younger people are more likely to identify as nonbinary than those over 35 (Government Equalities Office 2018; ONS 2023). Thus, there is a higher prevalence of nonbinary people amongst typical university-aged students than in the general population. We use "nonbinary" as an inevitably inadequate term to describe all those whose gender is outside the exclusive categories of man or woman. Nonbinary people are a particularly heterogenous group in terms of how they describe their gender(s). Indeed, the survey this article is based on contained 93 different formulations of self-defined nonbinary gender (see Benato et al. 2023). There are also wide variations in terms of whether they use the term "trans" to describe themselves, what pronouns or titles they use, or whether or not they undertake any kinds of social or medical transition. We are aware that many of the experiences of nonbinary people in higher education will overlap with experiences of other trans people, whose experiences are also not homogenous, and that they intersect along lines of race, class, disability, migrant status, sexuality, and gender expression in ways that undermine the idea of a singular nonbinary experience. The data we draw on in this article is from an online survey conducted in 2019 of 367 nonbinary higher education staff and students in the UK. This was the first UK survey to focus exclusively on nonbinary participants.

In this article we bring a framework of social harm to understand the experiences of nonbinary staff and students reported in the survey. The social harm approach, also known as zemiology, has contributed to the analysis of a wide variety of issues including state corporate harms (Tombs 2019), the harms of border controls (Iliadou 2019), the harms of austerity (Pemberton 2015), anti-trans harms (Boukli and Copson 2019; Boukli and Renz 2018), as well as the harms imposed by gender norms and heteronormativity (Bibbings 2004; Pantazis 2004). A social harm conceptual, analytical, and empirical lens sheds light on social injury and takes us "beyond the confines of criminal law and the cultures of crime" and "away from targeting certain populations through regulation and discipline" (Boukli and Kotze 2018, 4). Social harm exceeds the interpersonal or individualist level and highlights the structures that perpetuate harm. Our survey captured a range of individual stories from participants; each story is meaningful as it offers a map of the harm inflicted to this person. We want to bear witness to those stories, but we do not want this to be addressed at an individual level. Rather, we aim to demonstrate how they reflect larger dynamics and collective issues. We are interested in how structures perpetuate harm, so while our data recount individual stories and experiences, as a whole the data map out and locate collective struggles and narratives of harm.

In the argument that follows we first set out our methodological approach and theoretical framework, before moving on to discuss the qualitative data from the survey and analysis of the interconnections between mechanisms of harm in higher education, effects of harm as manifested in reports of exhaustion, distress, and fear, and the strategies nonbinary people engage in to mitigate or resist harm.

METHODOLOGICAL APPROACH AND THEORETICAL FRAMEWORK

Our data come from a UK-wide online survey conducted in 2019 as part of the Nonbinary in Higher Education: Lived Experiences, Imagined Futures project. This exclusive focus on nonbinary people arose in part from our own experiences as nonbinary academics in UK higher education and the need we saw to separate nonbinary experiences from the wider "trans" or LGBTQI+ ones that are more often the subject of research and inclusion policies or guidance (Lawrence and Mckendry 2019; Nicolazzo 2017; Regan 2023). We began the project with a survey to allow us to gather data more broadly on how nonbinary staff and students were negotiating their work and studies. We recruited participants through social media and community networks over a six-week period. Eligible participants included students or recent (within 5 years) graduates, PhD students, and staff who teach. Teaching was broadly understood to include academics, as well as staff such as librarians and learning developers. We limited the staff participants to those who teach in some form because our research is focused on learning and teaching spaces within the university. The survey was open to anyone who identified their gender as "nonbinary," which we described as any of the range of gender identities that fall outside the man/woman binary, and participants were able to define their gender within that parameter.

Our survey contained quantitative and qualitative elements with 75 closed and open-ended questions (Benato et al. 2019). All questions in the survey, except for consent, were optional to answer. This article focuses on the sections of the survey which aimed to understand the importance of nonbinary gender for participants in the context of higher education, for example the desire to be known and recognized as nonbinary, as well as the nuances of their experiences of erasure and validation. The design of these questions was informed by existing literature that highlights the erasure of nonbinary people. For instance, Vincent (2020), Zimman and Hall (2009, 169), and Zimman (2017, 89 and 97) all argue that the experiences of constantly being erased through misgendering and misrepresentation, as well as being denied healthcare and legal validation, are contributing factors to both psychological and physical harms, as well as socially harmful conditions such as poverty. We therefore designed survey questions to explore how the erasure of possibilities beyond binary gender affected participants' experiences in higher education.

Despite actively encouraging discussion of affirming experiences, a preliminary analysis of the survey results indicated a preponderance of qualitative data recounting negative and difficult experiences across the survey participants. As nonbinary researchers, we were not surprised at the depth and number of painful experiences participants recounted. It was nonetheless deeply challenging to sit with the stories and responses they shared. We sought to find ways to understand them individually and collectively. Our preliminary readings of the responses led us toward social harm as a theoretical and methodological tool for understanding participants' narratives and experiences.

Social harm opens a discursive space to articulate a multiplicity of harms that lie outside the conventional discourses of crime and the criminal justice system. These are injurious acts and omissions that occur both on interpersonal and structural levels. Processes of social harm generation have not yet been explored in relation to higher education. Yet, in social harm literature, scholars have highlighted that in all aspects of social life, such as education, workplaces, and healthcare, societies "can have a host of injurious consequences" (Pemberton 2015, 145). With particular reference to education, formal education systems and informal opportunities for development and learning are often understood to be supporting the ability to lead lives of "one's own choosing," based on key cognitive skills, such as communication and critical evaluation as well as a range of practical and intellectual skills (Pemberton 2015, 29). Further, educational experiences and qualifications are, particularly when negative, often linked to unemployment and material insecurity (Pemberton 2015, 126; Wikeley et al. 2009). The right to education, as set out in Article 2 (Protocol 1) of the Human Rights Act 1998, may be infringed when certain people are systematically excluded from higher education. It therefore follows that the systematic exclusion from higher education and from opportunities to develop can be perceived as harms. In this sense, social harm constitutes a nuanced conceptual tool to understand some of our survey results, excavating a multiplicity of harms that occur at interpersonal and institutional levels in higher education institutions.

In recent years, scholars have recognized that trans, nonbinary, and queer people are often understood as victims and the problems they face located within the individuals themselves instead of focusing on wider societal cisgenderism, systemic transphobia, and the harmful attitudes of others (Armitage 2020, 15; Budge et al. 2020; Nicholas 2020, 3). In line with this, utilizing a social harm approach moves away from presenting nonbinary communities as inherently vulnerable and the experiences of participants as individual problems. It instead focuses on the wider societal and structural issues that are present in institutional settings. Drawing on theories of social harm also allows us to consider the array of harms described by our nonbinary participants and to begin conceptualize the range of diverse socially harmful (or injurious) behaviors that are inflicted by social processes (Pemberton 2015).

In the existing literature, attempts have been made to mark out a typology of harms (Hillyard and Tombs 2004; Paoli and Greenfield 2018; Pemberton 2015). Hillyard and Tombs (2004, 19–21) for example, distinguish between physical harms, financial/economic harms, emotional, and psychological harms, and something that has been described as "cultural safety" (Alvesalo 1999 as quoted in Hillyard and Tombs 2004, 20). In our analysis, we used social harm as a conceptual tool for understanding our data as well as a method for surfacing and naming social exclusion and the mechanics of marginalization. The typologies and taxonomies of social harm informed the approach we took in the analysis of our data, providing an initial model through which to grasp the possible structural conditions underpinning individuals' narratives of navigating higher education.

In this article we focus solely on qualitative data analysis, with quantitative data provided to give context for our participants (for further discussion of the survey's quantitative findings, please see Benato et al. 2023 and Benato et al. 2024). Our analysis of the qualitative data followed a three-stage thematic analysis based on Braun and Clarke (2006). First, we identified the various contours of harm evidenced by participants. We were led by explicit references to violence, assault, damage, marginalization, humiliation, ridicule, anxiety, hostility, stigma, and exhaustion. Second, we grouped these references using the following typologies of social harm; physical, economic, emotional, psychological, cultural, and academic/pedagogic harms, based on and expanding the types referenced by Hillyard and Tombs (2004) discussed above. This initial analysis gave us an understanding of the range of social harms experienced by our participants, but not necessarily how they were produced nor how they interconnected. With this in mind we, re-sorted the data into three categories we named: mechanisms of harm, effects of harm and strategies for dealing with harm. In delineating the mechanisms and effects of harm, we identified abuse and ridicule, refusal and denial, and erasure as the key mechanisms through which harm was caused, while exhaustion, distress and anxiety, and fear were the key effects of that harm. Strategies for dealing with harm included regulating visibility, leaving higher education and undertaking additional labor.

Thematic analysis allowed us to understand the nuances of participants' experiences and to understand how the mechanisms, effects of and responses to social harm interlock. For example, erasure is both a mechanism and an effect of harm, while the harm-reduction strategies employed by participants often caused further harm in the form of exhaustion, distress, or erasure. Nonetheless, we have attempted to present them thematically in the analysis that follows.

FINDINGS AND ANALYSIS

The survey attracted 367 participants, which we refer to as belonging to one of three groups: "students" (including all levels of current student and recent [within 5 years] graduates; *n* = 277), "PhD students" (PhD students who also undertake teaching work; *n* = 30), and "staff" (academic staff and other staff who teach; *n* = 60). Participants were invited to describe their gender identity. We received 356 responses providing 93 unique terms and phrases (see Benato et al. 2023). Eleven percent of participants were from minoritized racial or ethnic backgrounds, while 44.3% (*n* = 160) declared a disability or disabilities. Participants came from across academic disciplines: Academic Skills 0.9% (*n* = 3); Business 1.2% (*n* = 4); STEM subjects 24.2% (*n* = 79); Social Sciences and Law 28.4% (*n* = 93); and Arts and Humanities 45.3% (*n* = 148).

To understand the significance of participants' nonbinary genders to their experiences of higher education we included a series of questions using Likert scales. Three are relevant here. First, we asked participants to rank how important it was that people at their university knew their gender and treated them accordingly. We received 362 responses to this question with 43.9% (*n* = 159) indicating it was very important; 34.5% (*n* = 125) somewhat important; 12.4% (*n* = 45) neither important nor unimportant; 6.6% (*n* = 24) not particularly important; and 2.5% (*n* = 9) not at all important. Second, we asked participants if there had been moments when their gender felt particularly validated, seen or accepted at university. We received a total of 357 responses: yes, frequently 7.8% (*n* = 28); yes, occasionally 35% (*n* = 125); yes, rarely 31.4% (*n* = 112); and no, never 25.8% (*n* = 92). Third, we asked participants if there had been moments when their gender felt erased at university. We received a total of 355 responses: yes, frequently 51.3% (*n* = 182); yes, occasionally 28.2% (*n* = 100); yes, rarely 9.6% (*n* = 34); and no, never 11% (*n* = 39).

The comparatively high incidence of positive responses, 78.4% (*n* = 284) reporting that it is “very” or “somewhat” important that people know participants’ genders and treat them accordingly, should be considered alongside the high numbers of participants feeling that their gender was erased and the low number that felt validated or seen. This reflects the significance that having a set of discourses and practices that enable nonbinary lives to be visible, meaningful, and culturally intelligible in higher education held for participants. As will become clear from our analysis of the data, participants’ lived experiences demonstrate that universities fall short of providing a space in which their nonbinary genders were recognized and could flourish.

Mechanisms of Harm

In this first section we outline the practices and norms through which harm was produced in the lives of the participants, which we have identified as “mechanisms” of harm. We found three key mechanisms: overt instances of abuse and ridicule, conscious refusals, and denials to acknowledge or accommodate nonbinary genders/identities, and erasure. The erasure of nonbinary gender(s) alludes to the lack of cultural intelligibility of gender outside binary conceptions, as reflected in language (pronouns, titles), physical space (gendered toilets and changing rooms), and absence of legal recognition in the UK beyond anti-discrimination measures (see HM Courts and Tribunals Service 2020).

Abuse and Ridicule

When asked about their experiences in higher education our participants shared many different instances of abuse and ridicule that were related to both institutional structures and encounters with individual members of staff and students. For example, they referred to mocking and joking regarding nonbinary and trans people.

> I’ve heard other students making comments or jokes about nonbinary people and trans people as a whole, which makes me feel incredibly uncomfortable and sometimes unsafe. (Undergraduate student)
>
> It is really hard, lecturers often make fun of nonbinary identities and students laugh along, and forms and stuff never include us. (Postgraduate student)

> People often make transphobic comments to me about my appearance … People erase trans people, laugh at the only 2 (only 2!) all gender toilets and diversity training. (Part-time, fixed-term staff)

Even when "jokes" were not directed specifically at the participants they had the effect of producing discomfort and fear. Abuse and ridicule represent an overt, and often overtly transphobic, mechanism of inflicting harm.

Refusal and Denial

We now turn to more insidious mechanisms, which we have called refusal and denial. These mechanisms include misgendering, deadnaming, and the refusal (sometimes persistent) to use inclusive language, and the more passive or "forgetful" non-use of correct pronouns and names.

Significantly, participants reported that misgendering takes place regardless of institutional architecture; institutions with good policy frameworks and practices were not immune. Misgendering and deadnaming (referring to someone by a name they no longer use) also occur regardless of the actions that participants took or others took on their behalf. For example, participants told us:

> One tutor in particular repeatedly and deliberately misgendered me, even after I corrected him repeatedly in person, and by email, and asked the faculty administrator to send round an email to faculty staff reminding everyone. (Undergraduate student)

> It is a part of my identity that is dependent on other people referring to me correctly. When colleagues or other students don't do so, it leaves me in a situation of having to guess whether they're doing it out of ignorance or out of maliciousness, and whether or not I should correct them. This conflict or grief takes away from energy I could be spending on my teaching or studies. (PhD student)

Some participants reported that they were left wondering whether these practices of refusal were intentional and whether any action they could take would have an impact. The data contained frequent reports of this process of conflict, refusal, and grief requiring energy to process and navigate. Ultimately it redirects energy and work away from learning, teaching and research to navigating and confronting practices of refusal and denial. These experiences were compounded when participants reported intersectional challenges, often finding themselves having to choose one aspect of themselves over another. For example:

> Because I already find it hard to be at the research spaces used by other students/staff members due to my auditory processing disorder and executive functioning problems, I have with many people given up on trying to correct their language when I am misgendered and so coming "out" as trans/nonbinary, however I do it, is often temporary. (PhD student)

Refusal and denial also extend to directly contesting the existence of nonbinary people. For instance, one of our participants shared that they were, "regularly deadnamed and misgendered by staff and peers; one lecturer stated during teaching that 'some people feel that they are nonbinary but I don't know how much I believe that'" (Postgraduate student). It is important to note that denying nonbinary people exist is a different tactic to refusing to use someone's pronouns or name. Given the power dynamics in a classroom setting, this refusal to "believe" that students may be nonbinary can be particularly detrimental and can be cloaked as academic debate or as policing disciplinary knowledge. In a context of learning this plays out in traditional power dynamics and hierarchies of knowledge, so that our student participants were left in a position of having both their self-knowledge and their academic knowledge refused. Disciplinary and academic knowledges are also misconstrued to engage in refusal and denial. One staff member recalled, "being challenged that 'it's all a social construct' (with reference to Judith Butler) by a previous head of department" (full-time, fixed-term staff). The reference to Butler here works not only as an attempt to dismiss this participant's own identity, but a whole field of gender theory which is presumed to support and legitimate such identities. In almost all the examples above refusal and denial happens along institutional power lines whether they be between students and staff or between members of staff. As one participant powerfully articulates "acceptance of my identity shouldn't be conditional on me withstanding interrogation: a nonbinary identity isn't a philosophical stand-point, it's just existing" (undergraduate student).

Erasure

As a term, erasure helped us design our survey, so it is unsurprising that it is a key theme in the data. We specifically asked participants about their experiences of erasure because it is already a central motif in academic and activist discussions of nonbinary gender and identity (see Bear Bergman and Barker 2017; shuster and Lamont 2020; Vincent 2020). We asked participants "Have there been moments when your gender felt erased at University?" As previously noted, their responses reflected the dissonance between their desire for visibility and their actual experience. Only 11% (n = 39) reported that their gender never felt erased at university, while only 7.8% (n = 28) reported that their gender frequently was validated, seen or accepted at university. This reveals a significant disparity between the 78.4% (n = 284) who indicated that it is important that people at the university know their gender and treat them accordingly and those whose experience was of erasure or rare validation. While we asked these specific questions because we knew they would resonate with participants and yield nuanced data about the multiple forms erasure takes, participants independently reference erasure in response to many of the questions in the survey.

Administrative Erasure

Administrative erasure is distinguished from denial as discussed above to refer to instances such as a lack of options for nonbinary genders on forms and paperwork. This was reported as happening in multiple aspects of university life for students and staff including, finance systems, HR records, university profiles, enrolment, class registers, and graduation certificates. Participants reported their administrative erasure in terms of not being able to indicate their gender, pronouns, or a chosen/preferred name on their student or staff record, which impacted them not only at initial application/registration but in ways that followed their journeys through institutions. This administrative erasure leads to consistent misnaming and misgendering. One participant explained very clearly how this process of administrative erasure functions:

> Various aspects of the university's administrative architecture (particularly forms and online portals relating to finances etc) remain rooted in a language of binary sex, leaving little room to have my gender identity registered by the institution. (PhD student)

Physical Erasure

A complex example of erasure emerged around the provision of gender-neutral toilets. Our survey asked participants "Does your institution have specific gender-neutral toilets? (i.e. we mean toilets specifically designated as gender neutral, not disability or accessible toilets that have been appropriated for multiple uses)." All 367 participants answered this question with 63% saying yes, 31% saying no and 6% said they did not know.

For some participants access issues were about the physical location of toilet facilities in relation to their classrooms or offices, for example:

> There are buildings on campus which have no gender neutral toilets and so I consistently have to go out of my way to use a gender neutral toilet. (Undergraduate student)

For participants who also had a physical disability this often intersected with the availability of gender-neutral toilets around accessibility:

> I typically use accessible/disabled toilets because of this disability which often aren't gendered but in the building where my office is these toilets are within gendered bathroom suites. So I would have to walk further to another building to use a gender neutral accessible toilet which unfortunately my body won't allow for. (PhD student)

Finally, the absence of gender-neutral toilets causes a kind of symbolic erasure that has a very tangible and felt impact for participants each time they need to access a toilet.

> Although there are gender neutral toilets in the university, there are none in the building where I work. Every time I use the "male" toilet I feel erased because anyone seeing me go in can say to themselves "oh, he's really a man because he has accepted the label on the door." (Full-time, permanent staff)

The importance of gender-neutral toilets for the majority of participants cannot be overstated. Participants' responses demonstrate the level of physical and emotional labor they are required to undertake to access appropriate facilities in their places of work and study (see also Benato et al. 2024).

Intersectional Erasure

Erasure takes different forms if a person has intersecting or multiple marginalized identities, where one identity is presumed to exclude another or where because of a culture of scarcity people are compelled to prioritize aspects of their identities in order to access services. The following participant demonstrates how this ties into larger dynamics of racism and coloniality.

> Queer stuff at uni is presented as a very white thing. Tutors couldn't even imagine that positive queer stuff happens in the global south. Feminism was taught in an almost white savior way, as if it needed to be brought to "other" countries and communities. I remember we had a

> good class in intersectionality that was completely hijacked by students who wanted to "debate" trans people. When I then worked at the same uni and was the only queer POC [person of color] I was treated like I didn't know anything about being queer cos I was from a backwards place. (Postgraduate student)

Other participants, including those with disabilities, reported issues arising from institutional cultures' inability to recognize and support multifaceted needs. For example,

> As a disabled person whose disability is 'invisible' as it is a mental health issue, I have been told by students and lecturers and other staff that it would be better for my mental health if I was not trans or if I chose a binary gender. (Undergraduate student)

> Class (I am from a very low-income family) because of the amount of formal events at my university that require expensive outfits that are much more difficult to find for someone whose body isn't the expected shape. I would normally buy all my clothes in charity shops but it isn't possible for formal outfits because my body doesn't match the gendered clothes that I have to wear. (Undergraduate student)

Significantly, while participants shared their individual experiences and feelings of erasure, what these collectively demonstrate is a wider system of erasure – or a system that maintains and reproduces erasure – in which universities become sites where the issues become visible or experienced in new ways. Overall university culture for participants not only did not make space for nonbinary people but it actively erased them and their experiences. As one participant shared: "I feel very, very invisible" (PhD student).

Effects of Harm

In this section we outline three effects of harm that relate to the mechanisms previously discussed and these are exhaustion, distress/anxiety, and fear. In doing so we do not mean to imply that the mechanisms "cause" these effects in a linear fashion, rather the mechanisms and effects are related in a more inter-connected and cyclical relationship. The effects of harm we have identified are also in many ways generic and experienced widely by other minoritized groups pointing to broader structural and institutional issues, not just the individuals or communities within them. Nevertheless, there was a pervasive emphasis in the data on emotional and psychological harms brought about by issues that are directly related to participants' nonbinary genders.

Exhaustion

In response to the cumulative effort of having to explain themselves, their pronouns, or their needs to colleagues, tutors or university administration, or being on the receiving end of (micro)aggressions, participants frequently reported feelings of exhaustion brought about by the "constant," "routine," and "everyday" ways in which their gender is ignored. Participants noted the detrimental impact this had on their ability to study and/or work. Student participants noted that:

> It is exhausting to keep up with my studies which I already struggle with and continually have to validate and justify my own identity. (Undergraduate student)
>
> I am tired all the time from existing which makes putting work into my degree draining. (Undergraduate student)

These comments also allude to the labor that is required by nonbinary people to exist in higher education spaces, something one participant explicitly referred to:

> It's tiring you know? As a nonbinary person I am always out (or I am misgendered and misread) and there's a huge amount of work that comes with being often the only visibly out nonbinary person…within a cohort of students and staff. (PhD student)

Distress and Anxiety

As well as causing exhaustion, it was evident from our survey that many participants experienced more specific forms of distress and anxiety as a result of their experiences in higher education. This effect of harm aligned most closely to the type of psychological or emotional harm described in the literature on social harm (see Boukli and Copson 2019; Hillyard and Tombs 2007; Pemberton 2007). Participants identified the negative impacts of erasure as both creating and compounding mental health issues:

> [Erasure] has a negative impact on my mental health, due to constant misgendering and the need to decide whether to correct people or just put up with it. (Postgraduate student)
>
> Experiencing erasure saps my energy and sometimes makes me really anxious, drastically lowering my capability to do my work. (Full-time, fixed-term staff)

Another participant eloquently expressed the difficulties of navigating the effects of harm as an individual within a neoliberal structure that responsibilizes them for dealing with the mechanisms of harm.

> I am autistic, the misgendering seriously damages my mental health but the way trans inclusive policies (which I was largely unaware of) are enforced (or not) leave me responsible to correct others' language around me repeatedly, something which I struggle to do. (PhD student)

This demonstrates the interlinked cycles of erasure and harm whereby experiences of erasure not only cause distress but then responses to that distress further erase nonbinary students. Other participants attested that the anxiety caused and compounded by mechanisms of harm had a direct impact on their ability to perform academically (attendance, assignments, results etc). Such responses are especially damning of institutions that exist to facilitate learning.

Fear

A final effect of harm for participants was fear or a feeling of not being "safe." This was very real for participants even if they did not, or could not, articulate exactly what they were afraid of. Different experiences (or potential experiences) triggered fear even if the feared consequences did not occur. This particular effect of harm is a specter throughout our results that we were consistently aware of, but that rarely manifested itself in a tangible way. Participants clearly altered their behaviors to avoid the perceived consequences of what caused their fear, for example:

> Generally feeling unsafe to say "actually, I'm not cis" because I was afraid that it would be considered "wrong." (Undergraduate student)
>
> People have made fun of non binary genders and trans people in general. I do not feel safe being open about my identity, or wearing anything that clearly identifies me as a trans person. (Undergraduate student)

Some participants' fears were the direct result of being in universities and social worlds where there is open and unchallenged transphobia. Indeed, we have deliberately not reproduced some participants' responses here so as to ensure their anonymity and safety. Other participants revealed how a more general atmosphere of transphobia both within and beyond the university contributed to them being cautious and fearful in their interactions with others in higher education spaces:

> I also feel strongly that the current media hostility around trans issues in general is having a very negative impact. While I used to assume that people would be broadly open to these issues, I personally am much more cautious/wary about speaking out about these issues—as it's hard to know whether you are going to encounter hostility. (Full-time permanent staff)
>
> On three occasions at least, tutors have made offhand transphobic comments during tutorials that have left me feeling nervous and unsafe. (Undergraduate student)

Strategies for Dealing with Harm

The final section of our analysis deals with the strategies our participants engaged in to mitigate harm. Far from being passive, participants deployed various harm-reduction and survival strategies which we have divided into three main types; leaving higher education, regulating visibility, and undertaking additional labor. Those opting to leave higher education rather than endure the harms it was inflicting on them were in a minority, but for some it was an effective strategy. The other strategies were often adopted ambivalently, as a compromised response to harm. Regulating visibility, or making choices about when to be and when not to be open about gender, was one such strategy participants more often assented to, rather than one they embraced as a positive choice. Finally, we found many nonbinary staff and students in higher education undertaking additional labor to raise awareness, educate others, or lobby to change institutional policies and practices as a form of harm-reduction strategy.

Leaving Higher Education

For a small group of participants leaving higher education is the only viable survival strategy. This group consisted of undergraduate through doctoral researchers, early-career researchers, and established academics. The reasons given for leaving are often interlinked with mental health and, importantly, sometimes participants cited quite specific aspects of their university experience, such as the curriculum, as the pivotal factor for leaving.

> After my experiences with the curriculum I feel quite hesitant about continuing this journey as it feels like the discipline is not for me. (Postgraduate student)
>
> As always with misgendering and erasure it worsens my already questionable mental health… I'm close to flunking out…again. (Undergraduate student)
>
> I'm in probably one of the very best HEIs [higher education institution] to be "different" in any way and I'm still leaving! (Full-time, permanent staff)

Worryingly, one participant revealed that the current hostile environment around trans and nonbinary students and staff is a relatively recent shift that is changing their perception about a possible and continued future in higher education:

> My heart goes out to anyone and everyone who works or studies at an institution with actively hostile colleagues or instructors. I never imagined a few years ago I'd want to leave academia—this isn't entirely due to the moral panic around gender, but it surely doesn't help. (Full-time, fixed-term staff)

Regulating Visibility

The regularity with which participants "chose" not to declare or "come out" about their gender gives further context to the question about how important it is to have one's gender acknowledged in higher education. Participants' reasons for regulating visibility are complex and cannot be reduced to a simple narrative, furthermore the decision to not declare gender often (re)produced harms of its own, notably further erasure of nonbinary existence and further misgendering. We briefly outline below some of the reasons to demonstrate this complexity and how this is a choice made in a range of contexts that are often about how participants survive a harmful environment.

Some participants regulated their visibility as nonbinary as an anticipatory strategy wherein their experiences of the higher education environment suggest that being open about their gender will cause further harm. One participant anticipated "people won't understand or will think I'm just being 'alternative'" (PhD student). Many thought that nothing would change or that colleagues or students would respond poorly if they came out, reflecting a generalized understanding that their university environments are unsupportive for nonbinary people.

> I am not yet out as nonbinary in my immediate workplace. There are staff there who I suspect may respond poorly. (Full-time, fixed-term staff)

Participants' decisions to not come out were also specifically related to other people's expectations, not just that gender is binary, but that nonbinary gender will be expressed in particular ways dependent on perceived assignation at birth. As one participant explained:

> I am currently hiding behind the "she" because it's easier for other people and I'm accommodating their understanding of me. I'm non binary, AFAB [assigned female at birth], and femme presenting, and I just don't

> think people will get it. I haven't dared have the conversation to get to a point where I've been erased—but I anticipate it significantly. (PhD student)

Such responses reveal very low expectations for how colleagues, tutors, and fellow students might respond. A significant aspect is the sense that people would not want to understand, which is an important distinction from being unable to understand and reveals the hostility of the environment these participants are working and studying in. As a strategy, regulating visibility has consequences, especially around the exhaustion it causes:

> My gender is important because it's such a large part of who I am, and if I am to fully be myself at work and actually build relationships with colleagues and students it would be nice for me to be able to be more open with my gender identity in the workplace, but I don't feel that it is a supportive environment for it. The energy I spend hiding at work takes a toll mentally and physically and I definitely have low morale at work as a result. (Full-time, permanent staff)

Exhaustion is an important factor in how participants weigh their decisions. In contrast to the participant above who was exhausted by not coming out, the participants below used this strategy to avoid the exhaustion of negotiating an administration and environment unable to accommodate them:

> Outing myself can feel exhausting, so I don't tend to do this actively unless it's relevant e.g. making a point [about] the gender diversity existing in my dept or being visible to students because I want to be a figure that I needed but didn't have. (Postgraduate student)

> Misgendering is obviously constant, the question is whether it causes more pain than doing the admin to avoid some of it. (PhD student)

What is clear from these responses is that there is labor involved in negotiating whether or not to be open, and the consequences either way of those decisions. For some participants these negotiations are not just about being open about their nonbinary identity, they also intersect with practical considerations that have material consequences for their studies and careers.

> I can't be out at work because frankly, I feel like it makes my position of employment less stable. I have a young family and so I feel like I have to prioritise keeping my job. (Full-time, permanent staff)

Students' considerations for not coming out hinged around whether being out would jeopardize their access to funding and scholarships, support services or fair treatment by staff.

> When I was applying for funding for my PhD research…I had to make the decision as to whether to be true to myself or to use the incorrect pronouns and possibly increase my chance of getting funding. I wasn't ready to stand up for myself so I went for the latter option and felt terrible. (PhD student)

> I feel like I cannot speak up because I need to stay on the good side of the tutor for when I need approval for disability accommodations. (Undergraduate student)

This strategy has particular implications for people with intersecting identities, as illustrated further by the participant below whose decisions extend beyond their time as a student into career and financial considerations.

> I am a visibly queer disabled immigrant researching a highly stigmatised topic. I feel unable to come out as nonbinary, because this would add another layer of other-ness to the way my institution and possible future employers see me. I know how difficult the academic job market is, and how conservative my field (business) is, and I know that by coming out I would shoot my already precarious opportunities in the foot. My current goal is to come out once I am safely and securely employed. (PhD student)

Additional Labor

A final strategy some participants undertook as a response to harm was to take on additional, usually unpaid or voluntary, labor. This often involved work such as campaigning for gender-neutral toilets, developing inclusion policies as part of "equality, diversity and inclusion" committees or giving talks/workshops to train or raise awareness amongst staff and students. For these participants this was often a future-oriented strategy and was a way of making their university a better place for the nonbinary people who would follow them. Some participants appear to find this an effective way of meeting some of their needs and subsequently report positive actions and change within their institutions.

> We (the LGBT+ soc committee) managed to get them to relabel some bathrooms as gender-neutral…Another time would be when I gave a talk/workshop about gender to staff. (Undergraduate student)

However, the majority of participants demonstrate ambivalence to this strategy. Participants discussed voluntary labor as a mitigating strategy regardless of whether they endorsed it or not. This may be because, as others have argued, institutions expect minoritized people to participate in equality and diversity initiatives (Ahmed 2012). While some measure of change may be achieved, this strategy also leads to exhaustion and detracts from participants' energy for study, teaching and research (see Nicolazzo 2017).

> I'm hyper aware and hyper annoyed about the privileges and elitism upon which my university is built and sustained. This makes me determined to make exclusions and inequalities in HE [higher education] visible and challenge them. Often this means being an institutional nuisance and asking awkward questions in EDI [equality, diversity and inclusion] meetings (I'm on the committee) and pushing for change…I think about this stuff constantly, which is necessary but exhausting. (PhD student)

Rather than seeking out and engaging in more formal university "equality, diversity and inclusion" work, other participants were drawn in less consensually and were expected to undertake this labor by virtue of being nonbinary. For example:

> There is an extra burden to educate people around gender that goes beyond official roles and this, while validating and rewarding at times, can be exhausting. (Full-time, permanent staff)

This type of labor is particularly exhausting because it is so closely related to participants' sense of self. This takes particular forms when students are forced to become educators and engage along hierarchical power lines with lecturers as well as other students.

> I often felt like I had to educate my professors and classmates on trans issues, and if I didn't then ignorance would continue. (Postgraduate student)

CONCLUSION

Our ultimate aim in conducting this analysis is to work towards a future in which nonbinary people, alongside all those with minoritized identities, are not harmed by their interactions with higher education institutions and rather can thrive in their work and studies in those environments. Drawing on theories of social harm has allowed us to map out some of the complex ways harm is currently manifested, but also to see how mechanisms, effects and strategies to reduce harm interconnect. For example, the mechanism of harm (abuse and ridicule) creates a further effect of harm (fear), which may cause the regulation of visibility, thus reproducing erasure, which reduces the cultural intelligibility of nonbinary people allowing for it to be ridiculed. Many participants' responses highlight the interconnection between erasure as a mechanism of harm, exhaustion as an effect of harm, and not coming out as a harm reduction strategy. Our overall analysis shows how these harms are produced structurally and how they impact on different nonbinary people in different ways, particularly along the lines of race, class, disability, neurodivergence and gender expression. As our participants' stories indicate, many institutions respond with inclusion policies or "equality, diversity and inclusion" agendas but these are often insufficient to bring about the change that participants need. As we seek to move toward spaces in which nonbinary people can thrive in higher education we must find ways to recognize social harm, to listen to and acknowledge the experiences of nonbinary people and find ways in which institutions can be accountable for the structural dimensions of these social harms.

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ORIGINAL ARTICLE

Risk and Resilience Among BIPOC Trans Youth: An Interpretative Phenomenological Study

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Despite facing multiple forms of discrimination, very little past research has focused on the experiences of risk and resilience for Black, Indigenous, and People of Color (BIPOC) trans youth. To bridge this gap, the present study utilized ecological systems theory to examine the unique experiences of risk and sources of resilience for BIPOC trans youth through qualitative analysis of interviews. In total, 12 BIPOC trans 14- to 24-year-olds participated in an online, semi-structured interview. Key themes from the interviews were derived using Interpretative Phenomenological Analysis. We found four superordinate themes: accessing community connection and fostering belonging; navigating the healthcare system; personal journey with and relationship to gender identity; and others' reactions to gender identity. Participants highlighted various risk (e.g., difficulty findings others who shared their race and gender) and resilience (e.g., having adults who took action to support their gender identity) factors in the various layers of their surrounding environment as well as ways that they wished to be treated (e.g., through others becoming informed about the unique experiences of BIPOC trans individuals). The discussion explores key themes participants raised and highlights implications of the present research for groups such as parents, teachers, and healthcare providers.

KEYWORDS BIPOC trans youth; Interpretative Phenomenological Analysis; risk; resilience; marginalization
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There is limited research available on Black, Indigenous, and People of Color (BIPOC) trans[1] youth. This lack of research restricts our understanding of the well-being of BIPOC trans youth, who are known to be at risk of facing multiple forms of marginalization based on their gender identity *and* race (Purdie-Vaughns and Eibach 2008; Shelton et al. 2018). Toomey et al. (2017) found that out of 125 empirical reports in the US that focused on sexual minority youth of color, less than 10% included trans youth. Also, in a systematic review examining risk and resilience factors and their association with mental health among trans youth, approximately 20% of samples did not provide any demographic information about ethnicity or race (Tankersley et al. 2021). Further, trans youth are often grouped in with lesbian, gay, and bisexual youth in research studies with little focus on issues particular to trans youth (McGuire et al. 2010; Ryan and Rivers 2003; Russell and Fish 2016; Tankersley et al. 2021).

Additionally, prior research on early experiences of trans individuals has been limited (Marshall 2019). It is important to examine the experiences of youth given that adolescence and young adulthood are key developmental time periods marked by identity questioning and exploration when being accepted has a key impact on well-being (e.g., see Choukas-Bradley and Prinstein 2014; Schwartz et al. 2013). Relatedly, researchers have noted that trans and gender diverse youth "are trying to understand who they are, mustering the courage to be their authentic selves, hoping to find acceptance, (sometimes) experiencing discomfort in their bodies, and feeling highly vigilant to peer feedback" (Tankersley et al. 2021, 184).

As it relates specifically to BIPOC trans youth, the limited research available suggests that facing multiple forms of discrimination has a negatively impact. For example, Wilson et al. (2016) found that among trans youth aged 16–24, those who were exposed to high (vs. low) levels of both racial and transgender-based discrimination were at increased risk for symptoms of post-traumatic stress disorder and stress about thoughts of suicide. Also, relative to white trans youth, BIPOC trans youth show higher rates of suicide attempts (Chan, Pullen Sansfaçon, and Saewyc 2022). Beyond knowing about the risks that BIPOC trans youth face, it is also helpful to understand their unique sources of resilience, such that we can, for example, develop better strategies to promote the well-being of BIPOC trans youth rather than continually restating risk factors (Asakura 2016; Shelton 2015; Wagaman et al. 2019).

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[1] We use the term *trans* throughout the manuscript as an umbrella term to refer to individuals whose gender identity does not align with the sex assigned at birth based on culturally defined gender norms (Egale Canada Human Rights Trust 2017). Thus, the term trans can be used to describe individuals who identify in a variety of different ways across the gender spectrum (e.g., trans woman, trans man, Two-Spirit, nonbinary, agender, genderqueer).

In order to examine risk and resilience factors for BIPOC trans youth in a holistic way, the current study was guided by Bronfenbrenner's (1977) ecological systems theory. Ecological systems theory highlights the importance of examining individuals' interactions with various layers of their environment. In particular, ecological systems theory highlights how someone is influenced by a variety of factors in their environment, including more proximal factors in their immediate environment as well as more distal factors in the broader sociocultural environment around them. Given the current lack of research on BIPOC trans youth, there is a limited understanding of risk and resilience factors for BIPOC trans youth at different levels of their surrounding environment (e.g., experiences with peers and parents, in healthcare settings, with the media). Thus, our study filled an important gap in the literature by further exploring experiences of risk and resilience for BIPOC trans youth at different levels of the environment around them.

EXPERIENCES OF RISK FOR BIPOC TRANS YOUTH

BIPOC trans youth are at risk of experiencing discrimination based on both their racial and gender identities in a variety of settings. For trans youth in general, victimization in their proximal environment at school is pervasive (Day et al. 2018, 2019; Hatchel et al. 2019; McGuire et al. 2010; Reisner et al. 2015), and victimization has been shown to be related to outcomes such as suicidality and substance use among trans youth (Day et al. 2017; Hatchel et al. 2019; Perez-Brumer et al. 2017; Reisner et al. 2015). As it relates to race, some research has shown that racialized (vs. non-racialized) trans youth experience higher levels discrimination, victimization, and lower levels of school belonging (Chan, Pullen Sansfaçon, and Saewyc 2022; Hatchel et al. 2019; Hatchel and Marx 2018). In addition, BIPOC trans youth and adults often experience heightened discrimination and difficulties, such as economic instability, homelessness, community harassment, and being targeted by police, which can contribute to negative mental health outcomes (Bauermeister et al. 2016; Chih et al. 2020; Reck 2009).

Another risk factor deserving of attention involves barriers that BIPOC trans youth face when attempting to directly access care and support (e.g., accessing healthcare; Gridley et al. 2016; Navarro, Johnstone et al. 2021; Veale et al. 2015). Research has shown that accessing gender-affirming healthcare can foster well-being and resilience among trans youth (e.g., Achille et al. 2020; Kuper et al. 2020; Tordoff et al. 2022). At the same time, BIPOC trans youth face stigma in healthcare settings (Goldenberg et al. 2021), and experiences of violence for BIPOC trans youth have been associated with foregone physical health care (Chan, Pullen Sansfaçon, and Saewyc 2022). Additionally, research with those aged 14–65+ has shown that in comparison with non-racialized respondents, racialized trans individuals reported feeling more unsure about whether they would seek gender-affirming care (Chih et al. 2020).

An additional risk factor for BIPOC trans youth is the more distal factor of the political climate surrounding trans rights. In 2023, there have been a record number of 70 anti-LGBTQ laws put into place in the United States, which include laws that ban gender-affirming care for trans youth (Peele 2023). In Canada, where the rights of trans people are protected under Bill C-16, people are nevertheless concerned about "waves of anti-trans activism" (Bellemare, Kolbegger and Vermes 2021, para. 3) and recent legislative changes that dial back rights and protective factors for trans and gender-diverse youth (Bai 2023). This kind of political climate has been shown to have a negative impact trans youth, such as by increasing depression and suicidality (Paceley et al. 2023).

EXPERIENCES OF RESILIENCE FOR BIPOC TRANS YOUTH

Despite exposure to discrimination and marginalization, BIPOC trans youth also show high levels of resilience. Singh (2013) interviewed 13 trans youth of color who identified as resilient. Participants described ways in which they were resilient, including through self-defining their racial/ethnic and gender identities, navigating times when adults asserted power and privilege over them, advocating for themselves within school systems, finding their place within the LGBTQ+ community, and using social media to affirm their identity. Other research found that being connected to a supportive community, having adult and family support, experiencing acceptance, having close relationships with others, being able to use their chosen name and pronouns, and experiencing school belonging were key resilience strategies for trans youth (e.g., Hatchel et al. 2019; Pollitt et al. 2021; Singh, Meng, and Hasen 2013, 2014; Veale et al. 2015, 2017; Wagaman et al. 2019).

Community Support for BIPOC Trans Youth

Some research has shown that inclusive policies and programs related to sexual orientation and gender identity (e.g., presence of Gender and Sexuality Alliance/Gay Straight Alliance club in schools) have positive impacts on trans youth (e.g., associated with increased grades; Greyta, Kosciw, and Boesen 2013; Day, Ioverno, and Russell 2019). However, previous research has found that even when policies and programs are in place to support LGBTQ+ youth, they do not always address issues specific to gender identity and the experiences of trans youth (e.g., bullying that is based on one's gender identity; Allen, Hallack, and Himes 2012; Day, Ioverno, and Russell 2019). Further, policies and programs in place to support youth with diverse sexual and gender identities do not always address the needs of racially diverse youth (Pritchard 2013; Poteat et al. 2015). As a reflection of this, compared with white youth, racial/ethnic minority youth participating in Gender and Sexuality Alliance/Gay Straight Alliance clubs reported lower support and attended meetings less frequently (Poteat et al. 2015). At the same time, some research suggests that racialized trans youth do not experience lower levels of belonging in LGBTQ groups (Fish et al. 2019). Thus, more research is needed to understand the experiences of BIPOC trans youth accessing community and support groups.

THE PRESENT STUDY

Bringing the aforementioned ideas together, the present study examined risk and resilience for BIPOC trans youth within a holistic, ecological systems framework (Bronfenbrenner 1977). In doing so, it fills an important gap in the literature by focusing on the unique experiences of BIPOC trans youth—a group that, despite being at risk of facing marginalization based on multiple aspects of their identity, has received limited attention in the research literature. Further, the present study focuses on both sources of risk and resilience for BIPOC trans youth, whereas previous research has often focused solely on sources of risk (Wagaman et al. 2019). Also, the present study fills in a gap in the literature by focusing on young BIPOC trans individuals.

The use of a qualitative methodology (see further elaboration of methodology below) in the present study allowed participants' descriptions of their lived experiences to be highlighted and ensured that each participant's own unique words and experiences were centered (Pietkiewicz and Smith 2014; Smith, Jarman, and Osborn 1999; Smith, Flowers, and Larkin 2009). In addition, our approach allowed for great depth of insight into the unique experiences of BIPOC trans youth in their interactions with proximal and distal factors in their surrounding environments (e.g., Callary, Rathwell, and Young 2015), which is helpful for highlighting key areas for future research focused on such youth (e.g., Smith, Flowers, and Larkin 2009). Overall, then, this study aimed to provide critical information for groups such as parents, teachers, and healthcare providers about how to best support the well-being of BIPOC trans youth.

METHOD

Ethics Statement

This study was approved by the University of Toronto research ethics board.

Participants

Participants in the present study needed to be 13- to 24-year-old individuals living in Ontario, Canada who were BIPOC and trans (e.g., trans woman, trans man, nonbinary, genderqueer, gender questioning, Two-Spirit, agender, third gender) and could understand, read, and speak English. Participants were mainly recruited through Facebook/Instagram advertisements and contact with community organizations that shared information about our study. Participants who saw information about our study were first directed to an online intake form, which provided information about the study, including information about eligibility criteria. Participants who provided their email address via the intake form were contacted by the first author to schedule an interview.

In total, 14 BIPOC trans individuals took part in an interview for the current study. This sample size was in alignment with the coding method used in the current study, which was Interpretative Phenomenological Analysis (IPA; see detailed description below). IPA studies often rely on relatively small sample sizes in order to focus on nuanced data at the level of individual participants (Pietkiewicz and Smith 2014; Smith, Jarman, and Osborn 1999; Smith, Flowers, and Larkin 2009; Smith and Osborn 2003). As there is no ideal number of participants for an IPA study, IPA samples have ranged from one to fifteen participants, and although larger samples are possible, they are less common (Pietkiewicz and Smith 2014; Smith and Osborn 2003). Thus, our sample size was in alignment with previous literature. Having a sample size on the higher end of this spectrum allowed us to gather data from a range of BIPOC trans youth who differed in their experiences based on factors such as gender identity, ethnicity/race, and age.

Interviews took place between September 2020 and August 2021. Two of the individuals who took part in interviews did not meet age requirements for the study based on information provided during the interviews and were not included in the final sample. Thus, the final sample included 12 BIPOC trans youth between ages 14 to 24 years, with a median age of 17.50 years and a standard deviation of 3.58 years. Participant demographic information is presented in Table 1. As shown in Table 1, there was a diverse range of participants in the present study, including participants who differed in terms of their families' socioeconomic status and race/ethnicity. Further, our participants had a variety of gender identities (e.g., multigender, genderfluid, agender, trans man). Of note, most of the participants were Asian or Black. The majority of the participants were nonbinary, transmasculine, and/or trans men, and no participants identified as transfeminine or as a trans girl/woman (see Discussion for further commentary).

Procedure

While designing the study, meetings were conducted with a community advisory board, including two BIPOC trans or gender-nonconforming youth/young adults. Members of the community advisory board discussed and provided feedback on the study and the interview questions to ensure that all questions asked were as inclusive and representative as possible. Edits to the study were subsequently made based on community advisory board meetings (e.g., asking if participants wanted to be asked questions related to healthcare, asking a question about one's gender journey).

Interviews were done entirely online given restrictions related to COVID-19. Participants were given the option to take part in an audio only call or a video call, and all interviews were audio recorded. All participants provided informed consent. Requiring parental consent may have biased our sample toward participants with supportive parents/guardians. Further, not requiring parent or guardian consent minimizes the risk of participants being "outed." A recent study with cisgender and trans adolescents waived participant consent for those as young as 14 (Salk, Thomas, and Choukas-Bradley 2020).

Interview questions were asked in a semi-structured format such that all participants were asked the same baseline questions, but the first author asked participants follow-up questions as she saw fit. A list of the demographic questions asked at the beginning of the interview (e.g., "What words do you use to define your gender identity"; Singh 2013) are provided in Supplementary Table S1. Following demographic questions, participants were asked the main interview questions (e.g., "Have you felt welcomed into LGBTQ+ spaces?"; "Whether it be at school, your place of worship, online, with your parents, or any other place, how would you like to be treated so that you feel supported?"), which are included in full in Table S2 in the Supplementary Materials. Participants were asked additional questions added as needed by the interviewer (e.g., "Do you want to talk more about x?"). Questions asked during the main interview addressed how participants' multiple marginalized identities impacted their experiences with peers, family members, school and/or work, healthcare providers, and community. Thus, as per ecological systems theory (Bronfenbrenner 1977), questions were designed to address BIPOC trans youth's experiences with a variety of layers in their environments.

Interviews ranged in length from 17–82 minutes (average of 32.5 minutes). Next, the audio recordings were transcribed and all identifying information provid-

Table 1. Demographic information

ID	Pronouns	Age	Area of residence	Religious background	Family socioeconomic status	Highest level of education completed	Words used to define gender identity	Words used to define race or ethnicity
P01	They/them	23	Suburban	Don't have one	Middle class	College diploma	Nonbinary	Black
P02	He/him	21	Suburban	Roman Catholic	Middle class	High school diploma	Male, transmasculine, trans	Southeast Asian, Filipino
P03	They/them	23	Urban	Muslim	Working class	Bachelor's degree	Nonbinary	South Asian, Brown
P04	He/him	18	Urban/suburban	Raised Muslim, Islam	Middle class	High school	Transgender male, masculine terms, regular ordinary guy	South Asian, Pakistani, Canadian, Brown
P05	She/her	21	Suburban	Agnostic	Middle class	High school	Nonbinary. Also accept agender and gender queer	Asian, East Asian, Chinese
P06	He/they	24	Suburban from an urban standpoint, technically more urban	Spiritual	Upper-middle class/ middle-upper-middle class	Some college but never finished	Transmasculine, nonbinary, multigender	Mixed-East and Southeast Asian, South Asian
P07	They/them	14	Urban	Grew up Catholic, personally atheist	Working class	Grade 8	Nonbinary, fluid, bigender	Filipino, half Maltese
P08	They/them	16	Urban	Family is diverse but own is Comatic Pagan	Working class	Grade 10	Still figuring out labels, nonbinary	Guyanese, Indo-Guyanese, West Indian
P09	He/him	14	One urban and one pretty rural (but mix of suburban and rural)	Atheist/none	Middle class	Elementary school	Gender fluid, been staying male for a few weeks but changes	Chinese
P10	He/him	17	Suburban	No religious background	Middle class	Elementary school	Transgender man, comfortable using all male/masculine words	Black or mixed
P11	They/them, testing out he	17	Rural	None	Middle/working class	Currently in high school	Nonbinary as an umbrella term but not sure if that is accurate	Mixed, Chinese-Canadian, white something, unsure of white side
P12	He/him	16	Suburban	Buddhist	Middle class	Elementary school	Trans guy, male	Chinese, Chinese-Vietnamese-Canadian

ed by participants was removed. Transcribed interviews were then analyzed in NVivo, version 12.6.0 (2019). Following each interview, participants were given a $30 eGift card as an honorarium.

Data Analysis

To analyze the transcribed interviews, we used IPA (Smith 1996). IPA is predominately concerned with understanding how participants make meaning out of their lived experiences (e.g., Smith, Jarman, and Osborn 1999; Smith, Flowers, and Larkin 2009; Smith and Osborn 2003). Further, IPA is an idiographic approach that works with a small number of participants who often share similar lived experiences in order to gather comprehensive and nuanced individual-level data about each participant's experiences (Pietkiewicz and Smith 2014; Smith, Jarman, and Osborn 1999; Smith, Flowers, and Larkin 2009). As stated by Smith and Osborn (2003): "The assumption in IPA is that the analyst is interested in learning something about the respondent's psychological world... This involves the investigator engaging in an interpretative relationship with the transcript" (66).

The coding procedure we used in the present study was modeled closely from the procedure presented by Smith et al. (2009). Firstly, each transcript was read and listened to simultaneously. Then, the transcript was re-read again. During these initial stages, coding was done. Specifically, the descriptive (e.g., key words), linguistic (e.g., breaks in speech, laughter), and conceptual ideas (e.g., meaning the participant made of their experiences) brought forth by the participant were coded, which helped the researcher to be fully emersed in the transcript.

Following, the initial codes were reviewed and the first author began coding for emergent themes, which were short descriptions of all the main ideas brought forth by participants during the interviews. Following, all emergent themes were reviewed and grouped into larger thematic categories to create an overall framework for the thematic ideas presented by the participant. These larger, organizing themes are called superordinate themes within the IPA framework. At this stage, not all emergent themes fit under a superordinate theme. This process (i.e., initial coding, coding for emergent themes, coding for superordinate themes) was repeated for each transcript.

The final stage of coding involved looking across all emergent and superordinate themes from each transcript. At this stage, the first author created a master list of the most present/important/poignant superordinate and emergent themes across all transcripts. This stage involved "reconfiguring" and "relabelling" (Smith, Flowers, and Larkin 2009, 79) themes as well as moving themes to a higher level of abstraction in order to find similarities across themes. Not all emergent and superordinate themes from the individual transcripts were captured in the final list. While engaging in this level of coding, only emergent and superordinate themes were retained if they were represented by at least 50% of the participants (i.e., at least 6 participants).

Two different coders engaged in parts of the analytic process. In terms of positionality, the first coder is a white, cisgender woman in her twenties who familiarized herself with the literature on BIPOC trans youth. Based on her identities, she does not have the lived experience of a BIPOC trans person. The other coder is a Black African, queer man in his early-twenties. He has some familiarity with the literature on BIPOC trans youth. He also has lived experience as a BIPOC queer youth.

The first author conducted the interviews and engaged in all the steps of the coding procedure described above. The second author transcribed the audio recordings, listened to/re-read the transcripts, reviewed the emergent and superordinate themes created for each transcript as well as the transcripts overall, and discussed/offered feedback on the emergent and superordinate themes with the first author. The two coders discussed the coding for each individual transcript and the final coding structure.

Both coders also engaged in journaling at various stages throughout the coding process. Journal entries were a space where the coders reflected on how the coding process was progressing and what insights were emerging. In addition, journaling offered a space for the coders to reflect on their own biases, assumptions, and preconceptions about BIPOC trans youth (e.g., beliefs about BIPOC trans people's experiences of risk and resilience; see Callary, Rathwell, and Young 2015; Smith, Flowers, and Larkin 2009) in order to minimize any possible impact of the coders' beliefs on the coding process (Larkin and Thompson 2012).

RESULTS

Four superordinate themes with 3-4 emergent themes within each emerged from the coding, which are described below. Whenever a quote was included below that involved an interaction between the participant and the interviewer, only the participant's words were included. Table 2 includes all the superordinate and emergent themes. Additional quotations are presented in the Supplementary Materials.

Table 2. Superordinate and emergent themes

Superordinate: Accessing community connection and fostering belonging
Being or finding a mentor or role model
Feeling represented
Finding connections based on both race and gender
Superordinate: Navigating the healthcare system
Attitudes, policies, and knowledge about gender diversity within the healthcare system
Experiences with concealing or sharing gender identity with healthcare provider
Ways that accessing healthcare is inaccessible
Superordinate: Personal journey with and relationship to gender identity
Coming out process and experiences
Desires for treatment around gender identity
Fostering own self-identity
Superordinate: Others' reaction to gender identity
Exposure to unsupportive and limiting views of others
Having gender identity questioned or invalidated
Ways that others have shown acceptance and respect of gender identity

Superordinate Theme: Accessing Community Connection and Fostering Belonging

Participants described a variety of experiences related to connecting with others and feeling a sense of belonging in the world. Participants discussed how their racial and gender identities impacted their ability to feel connected with mentors or role models, represented, and welcomed into spaces for queer and trans people. Although many participants found that having multiple marginalized identities was a barrier to accessing community connection, some participants also found people and spaces where all aspects of their identity were accepted.

Emergent Theme: Being or Finding a Mentor

Several participants described that a risk factor for finding connection was having difficulties finding mentors or role models who had similar racial and gender identities. In other words, it was challenging for participants to find mentors who were also BIPOC trans people, including those who came from the same specific culture background that they did. As an illustration of these dynamics, P05 said:

> it's something at least for me it's kinda hard to find like mentors, whom are also like a transgender uh people of color so person of color so shlll aww it's a bit lacking there from my experiences but you know *titter*. –P05

Despite these negative experiences, other participants discussed their successes finding mentors or role models in particular environments, such as social justice spaces and art communities, that served as important avenues to foster resilience and connect with mentors. Further, several participants expressed ways that they personally served or wish to serve as mentors or role models for other people, such as by becoming a teacher or gender therapist. For example, P10 said:

> I'm very very interested in helping people and making an impact especially with you know trans kids, trans youth. Uh LGBT youth who don't know exactly where they fit with their identity or themselves. Uh for a while I'm I was considering becoming a gender therapist, so I could offer that support on a professional level. –P10

It is possible that participants in the present study felt even more empowered to mentor others since, as mentioned above, they did not always have access to mentorship from others who shared their identities and experiences.

Emergent Theme: Feeling Represented

Participants discussed how their gender and racial identities were often not represented by others around them, including in the media, which put participants at risk of feeling invisible. In addition to discussing a general lack of representation, participants also mentioned how the representation they have seen of queer and trans people is often inaccurate or stereotypical. As an illustration of this, P11 discussed how nonbinary people are often only portrayed in one way in the media:

> Uh you know uh so I think, especially like being nonbinary a lot of uh, a lot of the focus of nonbinary people especially like in media is a assigned female at birth, white uh nonbinary androgenous maybe masc more masculine kind of uh persona uh and uh it's odd because it's it to me at least it feels like a lot more than that. –P11

Emergent Theme: Finding Connections Based on both Race and Gender

Another risk factor for participants' access to connection was difficulty finding other people or groups that felt inclusive to both their gender identity and race. In a broad sense, several participants mentioned that they found it challenging to connect with others who shared both their gender *and* racial identities. For example, P06 discussed challenges finding others who were queer and Asian:

> back when I transitioned I I would not see I wouldn't even see queer queer Asian people let alone queer trans people. –P06

Some participants discussed being able to connect with others, often through community organizations, that were accepting and inclusive to their racial and gender identities, which helped to foster their resilience. For example, one participant said:

> there's like a nonprofit organization over there that like um provides services for like the Asian LGBTQ+ community um and that's where I was able to connect with um more people who are like, Asian and um like, transgender, as well as you know like LGBTQ um and uh with LGBTQ identities in general. –P05

However, participants also noted spaces that are inclusive to queer people do not always feel safe and welcoming to them as racialized individuals:

> I would say, like LGBTQ+ spaces that are um like explicitly anti-racist um and things like that I've felt safe in but like, generally if if something is like, let's say like something is marketed as like a LGBTQ event then I'm usually like, "oh it's probably, it's probably like a bunch of white people." –P03

Superordinate Theme: Navigating the Healthcare System

Experiences interacting with the healthcare system was another key topic discussed. Participants commented on how healthcare providers often lacked knowledge about trans people and did not have practices in place to support trans people. Also, participants described both positive and negative experiences talking to healthcare providers about their gender identity. Further, many participants reflected on ways that accessing healthcare was inaccessible to them.

Emergent Theme: Attitudes, Policies, and Knowledge about Gender Diversity Within the Healthcare System

Participants discussed the attitudes, policies, and knowledge that healthcare providers have about trans people. Specifically, a risk factor that hindered the well-being of participants was that healthcare workers and those in other similar professions, such as social workers, had a lack of knowledge about the experiences of trans people. This led participants to feel a lack of support and a desire for healthcare workers to be more informed about these topics. In addition to limited knowledge about the experiences of trans people, participants also noted that healthcare forms are not always inclusive of people who have diverse gender identities that do not match their sex assigned at birth:

> So like I feel like especially in terms of like filling out forms and other like administrative um stuff like that it's like um most of many of them don't have they still don't have the third option for gender gender which you can fill in if you're transgender or like or like say like nonbinary

> or something like that there they tend to be still like male and female ughm so that already says enough frankly about these insti-institutions ughm *chuckle*. –P05

Emergent Theme: Experiences with Concealing or Sharing Gender Identity with Healthcare Provider

Given the perceived lack of knowledge that healthcare providers have about trans people, it is unsurprising that several participants in the present study discussed concealing their gender identity with a healthcare provider, unless it felt necessary, out of a fear of their response. The following quotation from P01 illustrates this:

> I mostly don't out myself in situations like that unless I am going to like a gender-specific, umm clinic. Like my family doctor doesn't know that I'm trans. I decided to go through like a gender clinic specifically for my trans needs because it's just easier because she's been my family doctor since I moved here and like I don't know how she's going to take it and like how that would work. –P01

Relatedly, participants discussed both a range of positive and negative experiences that they had with sharing their gender identities with healthcare providers, such as being misgendered as well as having their gender identity respected. For example, P08 recalled a positive experience at the dentist:

> they used my chosen name and pronouns so I found that to be a particularly good experience it made me feel really good especially for someone who just kinda came out. –P08

It is noteworthy that positive healthcare experiences bolstered participants' resilience and contributed to positive well-being. At the same time, negative experiences and concern were common.

Emergent Theme: Ways that Accessing Healthcare is Inaccessible

The inaccessibility of gender-affirming healthcare services was a risk factor that was raised several times by participants in the present study. Participants discussed how information about gender-affirming healthcare and insurance can be difficult to access and compile, especially as a young person without support. To illustrate, P01 said:

> umm, most of the healthcare I access isn't in my region. Umm, I access the gender clinic [omit] which is fine because it's online now and that's where I work so it's not a huge deal but the majority of the programming, for like support groups or like hormones or any of that stuff is in the city and I live in [omit]. So like yeah I could take the [omit] or drive [omit] to go see it but it's, it is a barrier because it's like do I have the money to do that at the time or do I have the gas and stuff. –P01

Additionally, participants discussed how difficult it was to access gender-affirming healthcare services if they did not live in a major city, which was related to their access to income. In particular, not living in a major city resulted in limited healthcare options; therefore, accessing gender-affirming care required significant transport time and was a financial burden. Also, mental health barriers restricted access to gender-affirming healthcare.

Superordinate Theme: Personal Journey with and Relationship to Gender Identity

Participants also discussed their own personal experiences with their gender identity. Specifically, participants highlighted key moments in their gender journeys, including making decisions about sharing their gender identity with others, and ways that they have fostered their own self-identity. Participants also discussed various ways that they wished to be treated to feel supported.

Emergent Theme: Coming Out Process and Experiences

Several participants commented on their thoughts about disclosing their gender identity with others. Participants talked about their concerns as a result of having close or extended family members, including those living in other countries, who did not hold accepting views about trans people. Also, participants commented on how they had to strongly consider context when deciding to or to not discuss their gender identity with others in their proximal environment (e.g., only talking about gender identity to certain students at school). The stress and anxiety that participants experienced based on these factors was a risk factor for their well-being. As it relates to race, another idea raised was that the coming out process is different for BIPOC LGBTQ+ people. Specifically, P05 said:

> it's okay for me to not be out especially if you're like um LGBTQ+ like people of color, um if you're a person of yeah if you're like queer and trans person of color because um because coming out does not uh does not look the same as when frankly when um white LGBTQ+ people come out right? –P05

Emergent Theme: Fostering Own Self-Identity

Participants described how, as they developed their own self-identity and self-understanding over time, they experienced different moments of change and transformation throughout their gender journey. Relatedly, participants' gender journeys were often nonlinear. For example, several participants addressed how their use of pronouns and/or gender identity labels shifted over time as they fostered their own self-identity. As they continued to develop their own self-identity over time, participants' gender presentation changed (e.g., wearing a binder). For example, reflecting on their own gender journey, P09 said:

> wearing a binder is super important to me, uh having my nice really awesome short hair which I really like is really important to me and um, I'm looking at starting testosterone soon. –P09

In addition, finding information online about gender identity and expression was an important part of participants' gender journeys. As an example of this, P03 said:

> so with like online spaces as well I was asking this question a little bit to um, other queer and trans Muslims um especially around hijab because, it didn't like for myself I was like, "okay if if I'm not a women then why am I wearing this thing, on my head?" … I've been asking that question to other, queer and trans Muslim and, the kinda main themes that came from those conversations was like, "if it's gender affirming

> for you, wear it if not then, don't feel like you have to wear it," which made a lot of sense to me. –P03

As illustrated through this quote, participants were able to feel affirmed in their gender identity through seeking out online information, which helped to foster their resilience.

Emergent Theme: Desires for Treatment around Gender Identity

Throughout the interviews, participants commented on ways that they would like to be treated so that they feel most supported. Firstly, some participants mentioned how they would like others to treat their gender identity as just one aspect of their identity and to be treated just like anyone else. At various points throughout the interviews, participants also mentioned the importance of listening to the stories and experiences of trans individuals in order to promote resilience among BIPOC trans youth. For example, P04 said:

> I was like this, is really important because, you know, Black, Indigenous people of color, these trans youth need to tell their stories so hopefully the the next generation doesn't have to go through some of the experiences that we've had to go through. –P04

Additionally, participants also discussed how, in order to feel most supported, others should learn about and respect the unique experiences of BIPOC trans individuals and the intersection of their racial and gender identities. Relatedly, in order to foster their resilience, there should be opportunities to seek mental healthcare for LGBTQ+ individuals, including those for specific racial groups.

Superordinate Theme: Others' Reactions to Gender Identity

In addition to discussing their own personal relationship to their gender identity, participants also talked about ways that others in their lives have responded to their gender identity. Participants shed light on myriad ways that others have and have not shown support for their identity. Participants referenced a range of experiences they have had with others who have displayed unsupportive views, questioned or invalidated their gender, and/or acted in supportive and affirming ways.

Emergent Theme: Exposure to Unsupportive and Limiting Views of Others

Participants talked about the unsupportive and limiting views of others that they have been exposed to. Notably, many discussed how others, such as family members and teachers, held restrictive and limiting views around gender diversity, which served as risk factors for participants because they caused harm. For example, it was damaging to the well-being of participants when teachers did not intervene in cases of bullying based on gender identity or when parents did not fully accept their child's identity, such as for religious reasons. P06 said:

> when they, found out I was still gay and trans after middle school, they put me though what my counsellor called conversion therapy but I was never electrocuted so I can't it it still feels weird to call it conversation therapy but basically they found out that I was still very much queer and trans. –P06

Emergent Theme: Having Gender Identity Questioned or Invalidated

Participants described how their well-being was put at risk through various moments where their gender identity was questioned or invalidated by others. For example, participants noted a variety of instances where others enforced their own gendered views and expectations onto them, such as through gender policing that occurred at school. Notably, one participant discussed how their understanding of gender identity was invalidated by a family member because of their young age. Additionally, a common theme was that participants were misgendered and asked invasive questions about their bodies. For example, P02 and P05 said:

> I think par I believe part, it's not a univer of course it's not a universal transgender experience but like part of being like transgender is, frankly, being misgendered almost all the time no frankly no matter what you do. –P05
>
> There was one girl who I wasn't friends with, and like I really didn't like her to be honest but she asked me like a lot of these like invasive questions about, like surgeries and like hormones. –P02

Emergent Theme: Ways that Others have Shown Acceptance and Respect of Gender Identity

Although participants had often been exposed to unsupportive views and had their gender identities questioned or invalidated, they also referenced different moments where others showed acceptance and respect of their gender identity. For example, one parent took their child to get a haircut and a new wardrobe, and this experience was meaningful as it felt gender-affirming. Another participant's guardians had their name changed in the school system. Reflecting on this experience, this participant said:

> so I won't get like deadnamed at school- which is nice um I'm really happy about that because I was too scared to ask my Dad to get it changed. –P07

Clearly, having parents who took steps to support their child's gender identity was a source of resilience for participants. Environmental factors, such as having gender-neutral bathrooms at school contributed to feelings of acceptance and respect. For example, P12 commented on their school by saying:

> there's some facilities like you know like gender gender neutral bathrooms so I don't really have to go through that. I don't really have to go through the process of like, "oh fuck! Do I have to go into the men's one or the girls' one?"–P12

Several participants also discussed how others getting their gender and pronouns correct made them feel supported. For example, P02 said:

> And at one point um, one of my cousins was like 'cause whenever I was there before she would always tell me like, "oh be a good little girl," like, "be a good little girl always" and I was just like "okay" but then like recently when I went home for a like big family reunion, that same cousin came up to me and she was like, "okay be a good boy huh like do, like keep making good choices and, like follow your dreams" and I just felt so like validated. –P02

DISCUSSION

The present study examined the experiences of risk and sources of resilience for BIPOC trans youth and considered them from an ecological perspective to ascertain important factors at different levels of the environment around them. IPA was used to analyze each individual participant's lived experiences closely and to understand how participants made meaning out of their lived experiences. This study filled an important gap in the literature by focusing on BIPOC trans youth, who are rarely focused on the research literature, as well as by placing a focus on sources of resilience for BIPOC trans youth, which is commonly neglected in the research literature (Wagaman et al. 2019). Through IPA, we found four superordinate themes: accessing community connection and fostering belonging; navigating the healthcare system; personal journey with and relationship to gender identity; and others' reactions to gender identity.

A central risk factor that emerged from the current study was the difficulty that BIPOC trans youth faced in connecting with others in the direct environment around them (e.g., friends, mentors) who shared both their racial and gender identities. Also, participants noted that spaces for queer and trans people often did not feel inclusive to them as BIPOC youth because these spaces predominately included white queer youth. These findings parallel previous research that has found that groups specifically for LGBTQ+ youth do not always feel inclusive or supportive to BIPOC LGBTQ+ youth (e.g., Poteat et al. 2015). Relatedly, past research has highlighted how, for many BIPOC trans youth, the extent to which they feel belonging in spaces for LGBTQ+ youth is dependent upon whether they discuss issues of racism and transprejudice (Singh 2013), and trans people connect more to groups that "resonated with the multiplicities of their own lives" (Stone et al. 2020, 226). Related to the theme of belonging, participants also expressed that feeling represented is important to them, but there is a lack of representation of BIPOC trans people in the media. This finding echoes previous research by Ghabrial (2017), who found that queer people of color felt disconnected from either their sexual and/or racial identities, and some attributed this to not having their identities represented in the media.

Possibly as a product of having limited chances to connect with others who shared their racial and gender identities, participants made meaning out of their experiences by actively seeking out opportunities and spaces for connection, belonging, and mentorship (e.g., connecting to and asking questions of trans Muslim people online) as well as finding information that helped them to understand themselves (e.g., queer theory). This is similar to previous research that found BIPOC trans youth use social media to understand themselves (Singh, Meng, and Hansen 2013). Further, several participants discussed a desire to be a mentor or role model for others, including for other trans youth, thus allowing them to build meaning in their lives through supporting others. These findings reflect previous research that found trans and gender-expansive youth and young adults actively pursued experiences that were missing in their lives (Wagaman et al. 2019).

In addition to having positive experiences of self-discovery throughout the course of their gender journey, participants also described frequent experiences of others misgendering them and having their identities questioned or invalidated. These results align with previous research that found that trans people aged 14–65+

experience high rates of misgendering (Navarro, Lachowsky et al. 2021). Notably, participants also indicated that the process of coming out was particularly complicated for them as BIPOC trans youth as they had to strongly consider the context they were in when deciding whether they wanted to disclose their gender identity. These findings can be understood in light of research that has found that racialized (vs. non-racialized) trans people aged 14–65+ experience significantly more discrimination on a variety of measures (Chih et al. 2020). In a similar vein to the findings from the current study, Ghabrial (2017) found that many queer people of color concealed their sexual identity in either some or all contexts, and several indicated that this was due to their ethnic/racial identity.

In addition, parents or guardians acted as either significant sources of risk or resilience for the participants in our study. Parents or guardians had a notably negative impact on BIPOC trans youth when they did not accept their gender identity (e.g., due to their religious beliefs), which adversely impacted participants' perceptions of support and belonging. By not accepting their gender identity, participants were sometimes forced to conceal their gender identity or move out of their homes. Participants in the present study also expressed how they had to forge their own path when their parents did not accept their identities, such as through finding information about gender-affirming healthcare options and insurance by themselves. On the other hand, some participants recalled how positive and impactful it was when their parents or guardians did support their gender identity. Overall, the fact that parents could be either sources of risk or resilience in the present study is similar to past research, which found that family connections could either have a positive or negative impact on trans youth depending on the specifics of the relationship (Wagaman et al. 2019). These findings also underscore past research that noted the importance of family relationships for the well-being of trans youth (e.g., Veale et al. 2015, 2017). Findings from the current study expand on this work by illuminating the impact of parent or guardian and child relationships among BIPOC trans youth.

Participants discussed ways that accessing healthcare services, a factor in their broader environment, was difficult and inaccessible. For example, participants commented on the general lack of knowledge that healthcare providers tend to have about the experiences of trans people, especially BIPOC trans people, and how this created an environment where they did not always feel safe disclosing their gender identity. These findings align with past research showing a lack of knowledge about trans experiences among healthcare providers (Goldenberg et al. 2021; Navarro, Lachowsky et al. 2021). Participants also mentioned that the gender identity options provided on healthcare forms did not always feel inclusive to them as trans youth. Similarly, past research found that among trans youth, only 25% reported that they were given forms from their primary healthcare provider that were inclusive of them as a trans or nonbinary person, and only 57% reported that their primary care provider used their name, pronouns, or gendered language correctly (Navarro, Johnstone et al. 2021). Lastly, it was noted in the current study that a barrier to accessing gender-affirming healthcare was geographic location. Past research has found similar results, whereby approximately one out of five trans people could not afford to travel to gender-affirming medical care (Navarro, Lachowsky et al. 2021).

Overall, there were many topics that emerged in the current study that seemed particularly unique to BIPOC trans youth. These topics included having difficulties in connecting with others who shared their identities in terms of both race and gender; not feeling included in spaces for queer and trans people; dealing with healthcare providers who lacked knowledge about BIPOC trans people; and experiencing a lack of representation of BIPOC trans people in the media. Also, BIPOC trans youth in the present study discussed having particularly complicated coming out experiences as a result of unsupportive family members and being at the intersection of experiencing discrimination based on both gender and race. It is also worth noting that in the current study, BIPOC trans youth appeared in several instances to have fewer sources of resilience given their multiple marginalized identities. For example, participants discussed how LGBTQ+ spaces tended to not feel welcoming because they were predominately white spaces. Also, an idea brought forth in the current study was that experiences with healthcare providers are particularly negative for BIPOC trans individuals given how they are treated negatively based on both their race and gender. Thus, having multiple marginalized identities seemed to put BIPOC trans youth in the current study at risk of facing negative experiences and reducing their sources of resilience. Overall, the present study provides nuanced detail about the unique experiences of BIPOC trans youth.

Implications

There are many important implications of the present research. As it applies specifically to day-to-day interactions with healthcare workers in their more proximal environment, findings from the current study indicate that it is imperative that doctors and other healthcare providers become informed about the unique experiences of BIPOC trans youth who experience marginalization based on both their race and gender identity. As it relates more broadly to accessing gender-affirming healthcare services, participants highlighted the importance of healthcare forms, including comprehensive gender identity options that capture the range of identities that individuals hold (e.g., not only including “other” as a third gender option). Also, findings from the current study underscore the importance of offering gender-affirming healthcare services in locations beyond major cities and keeping costs associated with accessing care as low as possible (Paceley, Ananda et al. 2021). Participants indicated that it would be helpful if online information about gender-affirming healthcare options were easier to locate and more centralized (Paceley, Ananda et al. 2021). Another implication of the present study is that more mental health services should be created specifically for racialized trans individuals (e.g., specifically for Asian trans individuals), especially given the unique sources of risk and resilience that face different subgroups of racialized trans youth.

In the immediate environment that surrounded them, participants also found it difficult to connect with mentors who shared experiences with them related to both their race and gender. These findings indicate that BIPOC trans youth should be provided with more opportunities to connect with role models (e.g., through community groups, online) in their day-to-day lives. Relatedly, participants noted that they often did not feel safe or included in queer and trans spaces due to their race. Thus, community-level groups in place to support queer and trans youth must do more work to create spaces that are inclusive of racialized individuals. For example, non-racialized members should educate themselves on racial justice issues, and leaders within the groups should create policies and practices that support racialized members.

In addition, findings indicate that teachers should become educated about the experiences of trans individuals and directly intervene when bullying based on gender identity occurs in the school context. Also, teachers can support trans students by normalizing the use of gender pronouns in their classrooms. Lastly, teachers should ensure that schools have gender-inclusive spaces (e.g., gender-neutral bathrooms).

Participants in the present study also discussed the negative implications and fear associated with knowing that their parents, who often exist in the direct environment around BIPOC trans youth, do not accept their trans identity. For example, participants discussed examples of how parents' lack of acceptance of their child's trans identity was tied to their religious beliefs. It is vital that parents attempt to unlearn negative attitudes they have toward trans individuals and gain awareness that not accepting their child's gender identity can significantly negatively impact their child's well-being, self-worth, and feelings of belonging.

In addition, at a broader societal level, participants mentioned that their gender and racial identities were not fully represented in media, which echoes past research (e.g., Paceley, Goffnett et al. 2021). Therefore, there is a need for increased representation of the specific experiences of BIPOC trans youth in media outlets. Importantly, as indicated in the present study, care must be taken when representing the experiences of BIPOC trans youth to not incorrectly represent or only stereotypically represent their experiences and identities.

There are also several broad implications of the present study related to how BIPOC trans youth want to be treated in general. Firstly, several participants highlighted how they wish others would understand that their trans identity is a part of who they are but not the entirety of them, and how they wish to be treated just like anyone else. Further, people who are not racialized and/or trans need to listen to the stories and experiences of BIPOC trans youth to, for example, gain understanding, awareness, and empathy. Lastly, participants noted that they do not want to be asked invasive questions or feel that their gender is questioned or invalidated when interacting with others.

Based on these findings, future researchers may consider designing interventions focused on teaching others about the unique experiences of BIPOC trans youth to increase understanding and acceptance. One intervention may involve having children watch videos of BIPOC trans youth discussing their unique experiences of having multiple marginalized identities. This intervention idea aligns with research by Flores et al. (2015), which found that as people were more informed about trans people, they had more positive attitudes toward trans people. Another possibility is for future researchers to extend on past research conducted by Broockman and Kalla (2016), which found that attitudes toward trans people were improved when, as part of an intervention, adults were asked to think about a time when they were judged negatively for being different and relate this experience to how trans individuals are treated.

Limitations and Future Directions

A strength of the current study is that it provides a depth of knowledge about the experiences of youth who were predominately nonbinary, transmasculine, and/or trans men. At the same time, the present study did not capture the unique experiences of transfeminine youth or trans girls/women. The lack of representation of transfeminine youth or trans girls/women is somewhat unsurprising when considered alongside recent data collected from Trans Pulse Canada, which found that in a sample of 991 trans youth, only 12% identified as women or girls (e.g., Navarro, Johnstone et al. 2021). Other studies have also noted that there are more adolescents assigned female (vs. male) at birth when analyzing clinic samples (e.g., Arnoldussen et al. 2020; Sorbara 2019). Thus, given the small sample size of the current study, it was not unlikely that we would not have recruited any transfeminine youth or trans girls/women. Future researchers should seek to represent the unique experiences of BIPOC transfeminine youth and trans women/girls, which may involve deliberate recruitment of this population (e.g., through contacting community organizations specifically for this group). Another limitation of the present study is that the majority of participants were Asian or Black. Thus, our study did not capture the experiences of all BIPOC trans youth (e.g., Indigenous or Latinx/e trans youth). Further research is needed in order to capture the experiences of ethnically/racially diverse trans youth who were not represented in the current research.

The present study chose to focus on participants from Ontario, Canada in order to ensure that all participants lived in a similar environment. Thus, our study did not capture the experiences of BIPOC trans youth in other cultural environments, including those where attitudes toward gender diversity may be significantly more negative (e.g., Kwan et al. 2020; Nabbijohn et al. 2021; Winter, Webster, and Cheung 2008). It would be worthwhile for future researchers to conduct studies among BIPOC trans youth who live in different Canadian provinces or territories, or different countries. In addition, we did not perform analyses that divided participants into separate age groups. In order to more clearly understand age-related differences in experiences for BIPOC trans youth, future researchers may consider honing in on a more specific age group (e.g., 13- to 18-year-olds). Overall, we caution readers from overgeneralizing our findings given that they are based on one-time interviews with a small group of individuals.

Conclusion

Using IPA, this study explored the unique experiences of risk and sources of resilience for BIPOC trans youth. Participants in the study discussed challenges they faced in finding others, including mentors, who they could connect to who shared their race and gender identities. Participants also discussed experiences they had throughout their gender journey, including moments where they were or were not accepted and supported by others (e.g., parents, friends) in exploring their identity. For example, participants noted unique challenges they faced as BIPOC trans people when discussing their gender identity with family members. Finally, BIPOC trans youth in the current study noted difficulties they faced in trying to access healthcare services, such as having to interact with healthcare professionals who lacked knowledge of trans people. The insights gained from this study raised several implications regarding the practices and behavior of people such as parents, teachers, and healthcare providers.

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ORIGINAL ARTICLE

Barriers and Facilitators to Integrating Gender-Affirming Care and HIV Prevention/ Treatment in Illinois and Missouri: Formative Interviews with Implementation Practitioners

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Transgender people experience vast disparities in HIV prevalence, incidence, linkage to care, treatment, and prevention. Recent scholarship has highlighted that gender affirming care (GAC) may facilitate HIV treatment and HIV prevention. However, few researchers have examined how best to integrate these forms of care outside LGBT-focused clinics. Twelve interviews were conducted with key informants in community-based organizations, HIV clinics, and health departments in urban and rural Illinois and Missouri. Interviews were analyzed using a rapid qualitative analytic process, involving the production of analytic memos, coding of memos in NVivo using the Consolidated Framework for Implementation Research, and production of matrices for within-site and cross-site comparison. Key informants were highly excited at the possibility of integrating gender affirming care and HIV services. They highlighted numerous barriers that need to be targeted, including local attitudes and conditions, equity-centeredness, provider capability, and policies and laws. They also highlighted barriers to HIV care alone for transgender patients, including transportation, cost, stigma, provider capability, and homelessness. While numerous barriers exist, provider and funder acceptability are high. Attending to the needs of trans patients may support efforts to end the HIV epidemic by increasing organizational adoption of evidence-based and equity-centered interventions.

KEYWORDS gender affirming care, HIV, implementation research, qualitative research, transgender health
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Trans people experience vast disparities in HIV prevalence, treatment, and prevention (Sullivan et al. 2021). In a recent survey of trans women in seven major US cities, 42% of participants were living with HIV (Centers for Disease Control and Prevention 2021). However, disaggregated by race, 61.9% of Black trans women surveyed were found to be living with HIV compared with just 17% of white trans women (Centers for Disease Control and Prevention 2021). This disparity in HIV prevalence is only surpassed by the difference observed between cisgender men who have sex with men (MSM) and cisgender heterosexual individuals, highlighting a profound health inequity within the trans community (Sullivan et al. 2021). Transmasculine individuals have also been found to have an HIV prevalence of 2.8%, which, while significantly lower than trans women and cisgender MSM, is considerably higher than the national prevalence rate of 0.4% (Radix et al. 2022).

Trans people of all genders are less likely to be retained in HIV care and adherent to antiretroviral therapies (ART) than all people with HIV (Klein et al. 2020; Teti et al. 2019). Being retained in care is directly correlated to facilitating viral suppression, or the reduction of HIV in an individuals' blood to non-detectable viral level (Mugavero et al. 2012; Tripathi et al. 2011). Viral suppression not only improves patient outcomes and quality of life but also prevents transmission of HIV (The Lancet HIV 2017; LeMessurier et al. 2018). Disparities in retention in care, ART adherence, and viral suppression may be mediated, in part, by anti-trans stigma, homelessness, incarceration, poverty, and other social determinants of health (SDOH), or the "material circumstances and psychosocial and behavioral characteristics" shaping individuals' health outcomes and access to care before they become ill or step foot in a clinic (Illinois Department of Public Health 2024; Jain et al. 2023).

Research indicates that trans individuals exhibit lower rates of engagement with and adherence to pre-exposure prophylaxis (PrEP), a preventative measure against

HIV that includes either an oral pill or a bimonthly injection for those not infected with HIV (Downing et al. 2022; Reisner et al. 2021). This is even though trans people generally demonstrate a high awareness of PrEP and express significant interest in utilizing it (Centers for Disease Control and Prevention 2021; Reisner et al. 2021). PrEP initiation is particularly low among Black and Latina trans women (Poteat et al. 2019). Reasons for this gap between awareness and uptake include the predominant marketing of PrEP to cisgender MSM, a prioritization of hormone replacement therapy (HRT) over HIV prevention methods, and fears of deportation and criminalization for undocumented trans women, among other structural barriers (Zamantakis et al. 2023).

Recent scholarship has demonstrated the positive effect of integrating gender-affirming care (GAC) into HIV treatment (Sevelius et al. 2014; Sevelius et al. 2022; Sevelius, Chakravarty, et al. 2021). Gender-affirming health care environments lead to healthcare empowerment for trans women of color. This sense of empowerment is a crucial factor in achieving viral suppression (Sevelius, Chakravarty, et al. 2021). While access to HRT has been identified as a facilitator of retention in HIV care and viral suppression (Sevelius et al. 2022), access to GAC may also serve as a potential facilitator of PrEP uptake and adherence (Connolly et al. 2020; Doan et al. 2022; Nieto et al. 2021; Restar et al. 2023; Sevelius et al. 2016; Sevelius, Glidden, et al. 2021; Starbuck et al. 2022; Zamantakis et al. 2023; Zamudio-Haas et al. 2023).

In March 2022, the Health Resources and Services Administration (HRSA) released a letter that encouraged Ryan White HIV/AIDS Program (Ryan White, henceforth) service providers to use available resources to implement GAC, including HRT and mental health services (Cheever 2021). Ryan White is considered a payer of last resort for HIV treatment, meaning if there are no other resources to fund the care, Ryan White will provide funding. Thus, Ryan White providers tend to see highly marginalized populations, such as Black and Latine communities, individuals living below the federal poverty line, and people who are either on public insurance or lack any insurance coverage at all (Health Resources and Services Administration 2023). While HRSA now expressly allows Ryan White funds to be used for GAC, clinics and community-based organizations may not have the tools, knowledge, or expertise to immediately integrate GAC and HIV treatment.

Implementation science (IS) provides the tools, frameworks, and methods to analyze how best to integrate GAC and HIV treatment/prevention in varying contexts. It identifies key determinants, such as barriers and facilitators, affecting the delivery and reception of services (Bauer et al. 2015; Bauer and Kirchner 2020). Furthermore, it devises implementation strategies, or processes, policies, trainings, and other tactics for provider, clinical, and systems-level modifications, aimed at overcoming these barriers and leveraging facilitators (E. K. Proctor et al. 2013). Implementation researchers intend to enhance the reach, effectiveness, adoption, implementation, and sustainment of evidence-based interventions (Glasgow et al. 1999; E. Proctor et al. 2011). Further, IS aims to close the seventeen-year gap between when a practice is found to be evidence-based and when it is implemented in real world settings (Morris et al. 2011), which is necessary to achieve the goals of the National Ending the HIV Epidemic initiative (Fauci 2013).

Our team decided to conduct this study in response to reviewer comments on a proposal we submitted for funding from the National Institutes of Health to expand research on this topic. The reviewer argued that a weakness of the proposal was a focus on Illinois where "trans people can access HIV prevention and care along with GAC." They further argued that Illinois is a site of high access to GAC. At first glance, this could appear to be true. Illinois law protects patients and their parents from outside states from prosecution or extradition for seeking out GAC in Illinois (Gender-Affirming Care 2024). Illinois law further protects providers' licenses for providing legal care, like GAC, even when such care is illegal in other states, and state initiatives, like the Transgender and Gender Diverse Wellness and Equity Program, provide additional state funding to health care organizations to expand access to GAC (Department of Human Services 2024; Wholesale Drug License-Various 2023).

However, laws do not guarantee the availability or accessibility of care. This is evident regarding disabled individuals' access to care. Despite legal provisions requiring providers to make care accessible to disabled individuals, the CDC reports that 25% of do not have a "usual health care provider" and 25% have unmet health needs because of an inability to afford care (Centers for Disease Control and Prevention 2024). Similarly, Illinois law allows residents to have an "X" gender marker on identification cards, yet implementation of this in practice has proven difficult, even years after the passage of this legislation (Gorner 2023). The actual enforcement and implementation of a law requires active and intentional attention to the barriers present for providers and organizations to carry out these changes.

Thus, we carried out formative key informant interviews with providers at HIV/AIDS-focused community-based organizations (CBOs), trans-focused CBOs, and Health Departments (HDs) in Illinois and Missouri to identify preliminary barriers to patient access of GAC and HIV services, identify barriers to provider and clinical level integration of GAC and HIV services, and understand the landscape of GAC access within these two states. This work will inform the next steps in developing implementation strategies to facilitate integration of GAC and HIV services.

METHODS

We conducted semi-structured key informant interviews with providers in HIV/AIDS-focused CBOs, trans-focused CBOs, and one HD in Illinois and Missouri. The objective was to conduct formative research to understand patient, provider, and clinical-level barriers to accessing GAC, accessing HIV/AIDS prevention and treatment services, and integrating GAC and HIV services. Illinois and Missouri were selected as two priority-designated areas within the Ending the HIV Epidemic initiative. While Illinois has state protections for trans healthcare, Missouri has attempted to pass or passed several bills preventing access to trans healthcare. The two states share a border, with nearly 100,000 vehicles crossing the Poplar Street Bridge connecting St. Louis, MO and East St. Louis, IL daily (Department of Transportation 2022). HIV prevalence in Cook County, IL is among the highest in the country, with 586 people per 100,000 living with HIV (Sullivan et al. 2020). While 60.9% of people living with HIV in Cook County were virally suppressed in 2021, only 53.9% of Black people living with HIV were virally suppressed compared to 73.8% of white people living with HIV (Sullivan et al. 2020). In Missouri, 252 people per 100,000 were living with HIV in 2021. Of the 13,103 living with HIV, 66.8% were virally suppressed, with disparities between

Black/Latine and non-Latine white individuals living with HIV (Sullivan et al. 2020).

Sampling

While patients and providers both provide necessary input that is critical for the design and implementation of evidence-based interventions (EBIs), IS is particularly concerned with provider input, as these individuals have firsthand insight regarding how to deliver an intervention. Prior research mentioned above has identified a great desire by trans individuals for an integration of GAC and HIV treatment and/or HIV prevention. Thus, what is needed now is an understanding of how to make that possible in practice. Future research should attend to joint patient and provider perspectives of how best to integrate GAC and HIV treatment and/or HIV prevention in a way that is feasible for providers and accessible for patients.

We first compiled a list of all CBOs providing or linking trans and nonbinary individuals to GAC, HIV treatment, and/or HIV prevention within Illinois and Missouri, as well as a list of HDs across Missouri. For Illinois, we included a list of HDs who coordinate HIV treatment and prevention in "Care Connect" regions. Illinois HIV Care Connect functions as statewide care coordination within eight regions that cross the entire state. Providers refer patients to Care Connect where they are linked to HIV care and resources for SDOH (e.g., linkage to the Food Bank; Illinois Public Health Association 2024). We emailed organizations asking to speak with a member of high-level leadership to coordinate which provider had the greatest interaction with trans and nonbinary individuals and the greatest level of understanding of barriers to care for these populations. After two emails, we called organizations at three time points as follow-up recruitment. We received Institutional Review Board (IRB) approval to carry out this research in July 2023 from Northwestern University.

Data Collection

Between July and December 2023, we carried out 12 key informant interviews. Interviews were conducted over Zoom, led by the first author, a PhD-level researcher with expertise in traditional and rapid qualitative analysis. The interview guide was informed by the Consolidated Framework for Implementation Research (CFIR; Damschroder et al. 2022. CFIR is a compendium of implementation determinants, or barriers and facilitators to implementing an evidence-based intervention or practice. CFIR includes five domains: 1) innovation characteristics (e.g., barriers and facilitators related to GAC); 2) outer setting (i.e., contextual factors within the larger community, state, or nation that influence implementation, such as policy and financing); 3) inner setting (i.e., factors within the organization or clinic that may hinder or enable implementation); 4) individuals (i.e., do providers and patients have the capability, opportunity, and motivation to carry out implementation); and 5) process (i.e., what components of the implementation process are in place to facilitate implementation, such as data collection and analysis).

Interviews were recorded, and the interviewer took notes throughout the interview using a structured template based on the interview guide. Interviews lasted an average of 28 minutes, with a range of 23–62 minutes. Interview participants were compensated $100 for their participation.

Data Analysis

We used a rapid qualitative research process common within IS (Hamilton and Finley 2019; Mwamba et al. 2023; St. George et al. 2023). Rapid qualitative analysis, in comparison to traditional qualitative analyses (e.g., grounded theory), can be conducted within a much shorter time frame (40% less time) and with fewer costs due to eliminating the need for transcriptions and fewer person hours needed to complete the analysis (Nevedal et al. 2021). This shorter time frame does not eliminate the quality of the analysis. A comparison of both approaches to qualitative research has found both approaches to provide methodological rigor, in-depth analysis, and nuanced description, given the proper training of research team members (Nevedal et al. 2021). Rapid qualitative research, though, meets the demands of health services and implementation research, which aim to reduce the amount of time between which research is conducted and findings are translated into practice (Hamilton and Finley 2019). With this in mind, the interviewer refined the notes into an analytic memo within 36 hours of the interview, adding to notes already taken by returning to the recorded interview and compiling memos at the end of the interviews. Analytic memos were uploaded to NVivo software (Lumivero 2023) for data analysis and coded according to CFIR to produce matrices for within-site and cross-site comparison.

RESULTS

Demographics

Key informants (KIs; *N* = 12) were roughly split between Illinois and Missouri, with slightly over half (*n* = 7) from Missouri (see Table 1). Most KIs (*n* = 7) were from metropolitan and rural areas outside Chicago and St. Louis. KIs were interviewed at HIV/AIDS-focused CBOs (*n* = 9), trans-focused CBOs (*n* = 2), and a health department in ru-

Table 1. Organizational Descriptions of Key Informants

Informant	Type of Organization	Area
1	HIV/AIDS-focused CBO	Chicago
2	HIV/AIDS-focused CBO	Chicago
3	HIV/AIDS-focused CBO	Rural Missouri
4	HIV/AIDS-focused CBO	St. Louis
5	HIV/AIDS-focused CBO	St. Louis
6	Health Department	Rural Illinois
7	HIV/AIDS-focused CBO	Rural Illinois
8	Transgender-focused CBO	Urban Missouri
9	Transgender-focused CBO	Urban Illinois
10	HIV/AIDS-focused CBO	Urban Missouri
11	HIV/AIDS-focused CBO	Urban Missouri
12	HIV/AIDS-focused CBO	St. Louis

Note. Key informant demographics (i.e., race and gender) are not listed along with organizational descriptions to prevent identifiability. Urban Missouri and Illinois refer to urban and metropolitan areas outside Chicago and St. Louis. For anonymity, we have chosen to designate these simply as urban areas.

ral Illinois (*n* = 10). Most KIs were Black (*n* = 8), with four white KIs. Most were cisgender (*n* = 6 cisgender men; *n* = 3 cisgender women), with 3 trans KIs (*n* = 2 trans women; *n* = 1 nonbinary participant).

Determinants of Integration

The most frequently mentioned determinants included local attitudes (*n* = 11; i.e., the sociocultural values and beliefs within the larger community), local conditions (*n* = 11; i.e., social, environmental, political, and economic factors within the community, state, and nation), equity-centeredness (*n* = 8; i.e., the value of providing equitable care to all patients within an organization or clinic), capability (*n* = 8; i.e., do providers have the psychological and physical skills necessary to integrate GAC and HIV services), and engaging (*n* = 8; i.e., engaging providers and patients in process of integrating services to facilitate successful implementation). The least mentioned included design quality and packaging (*n* = 1; i.e., how GAC and HIV services are designed and marketed), structural characteristics (*n* = 1; i.e., whether organizations have the physical, information technology, and work infrastructure necessary to integrate GAC and HIV services), relational connections (*n* = 1; i.e., how connected various departments are within the organization), communication (*n* = 1), culture (*n* = 1; i.e., the culture of the organization, how individuals work together, what they value), knowledge and beliefs about the innovation (*n* = 1; i.e., what do providers think about integrating GAC and HIV services), planning (*n* = 1; i.e., whether plans already exist to integrate GAC and

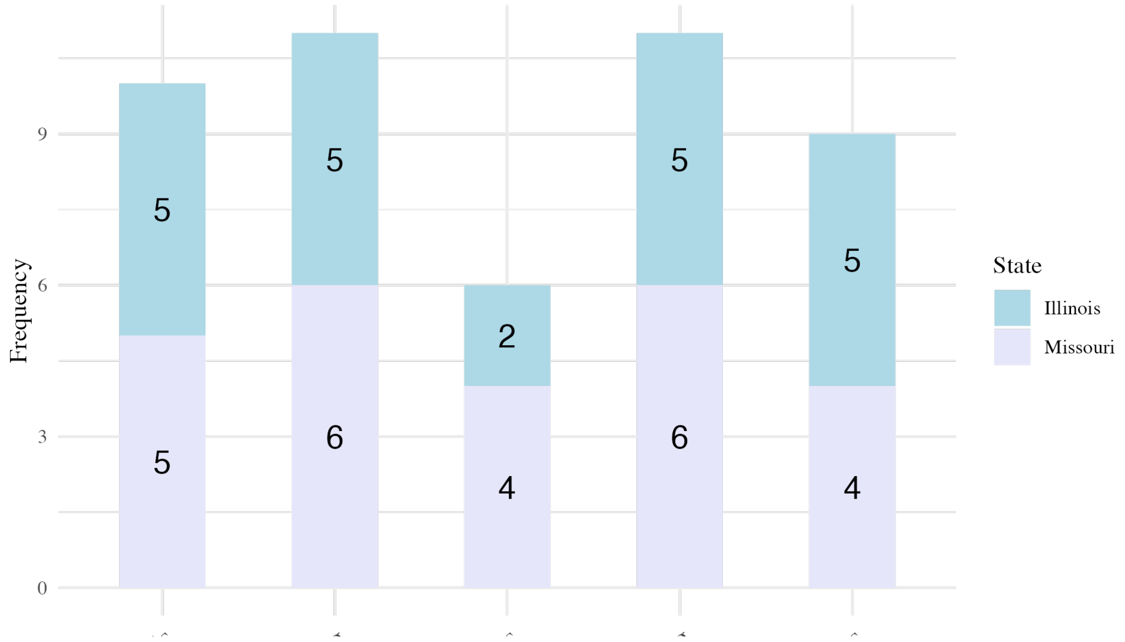

Figure 1. CFIR domain by state

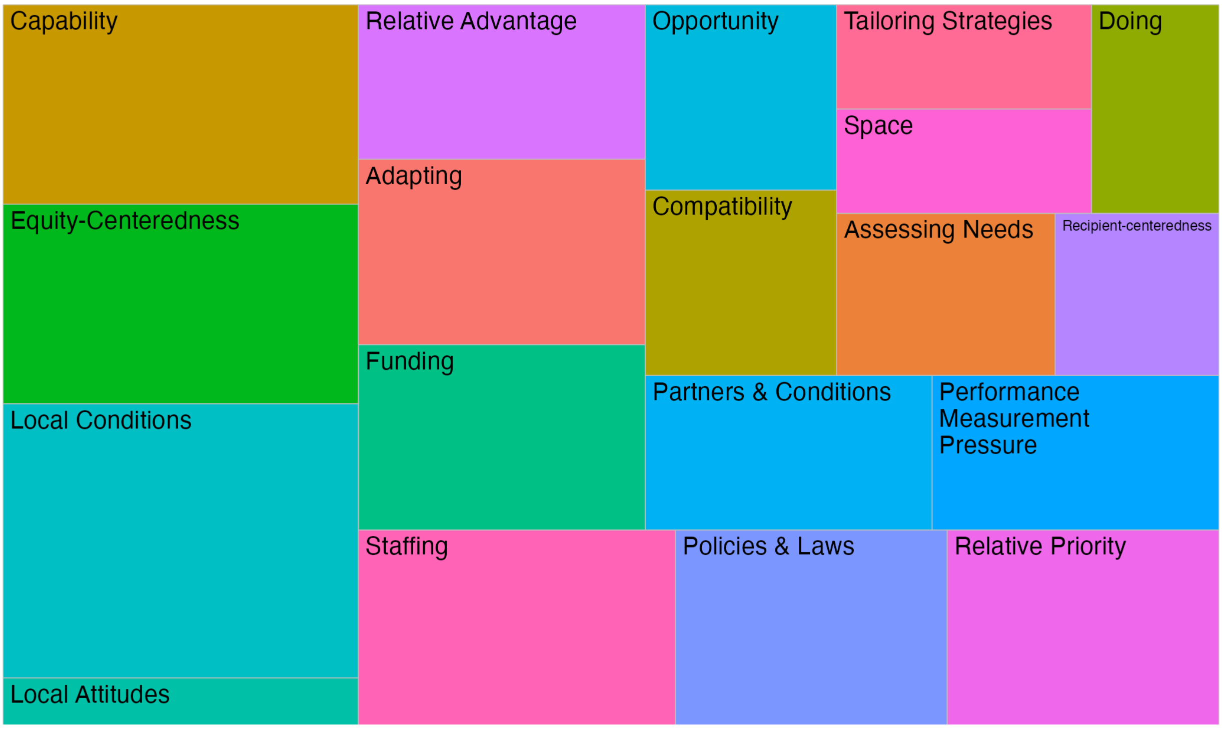

Figure 2. Determinants mentioned by three or more key informants

HIV services), and reflecting and evaluating ($n = 1$; i.e., whether the organization has processes to collect and analyze data to determine how to successfully carry out implementation). There were no meaningful differences in how frequently different domains were mentioned by participants across Illinois and Missouri (see Figure 1). Interestingly, there were also no differences in domains mentioned by trans KIs and cisgender KIs. This may, in part, be due to the smaller sample size, as well as due to the predominance of Black KIs, who, like trans KIs, spoke from the viewpoint of both being a provider and a marginalized patient. Below, we elaborate on determinants mentioned by at least one-third of KIs (see Figure 2 for a visual rendering of these determinants).

Innovation Characteristics

Relative advantage

Within the innovation characteristics domain, only relative advantage was mentioned by one-third or more KIs ($n = 5$). Relative advantage refers to whether integrating GAC and HIV services is advantageous over other existing practices within the organization or clinic. Three of the KIs who mentioned relative advantage highlighted the advantage of integrating GAC and HIV services on health outcomes. One KI from rural Missouri explained:

> If they're [trans patients] getting their trans care at the same space, they're much more likely to stay engaged in care, on meds, and suppressed. It's nice that we can have those conversations with our patients about who should be on PrEP and make sure they're getting those ser-

> vices in addition to their trans care. Makes it easier to wrap around all those services.

By bundling care, clinics would be able to increase access for trans patients and increase engagement in care. Other KIs highlighted, for example, that many trans patients experience barriers to transportation. Having to find rides, pay for car shares, or take public transit long distances decreases the likelihood that patients will make multiple trips for health care, they argued. If patients could access these forms of care at the same place, then prioritization of GAC over HIV services would no longer be a barrier.

Two KIs also highlighted that providing GAC and HIV services in the same space increases "comfort" for patients to receive their PrEP or HIV care. Clinics offering GAC would have received training in providing such care and staff would have increased familiarity with trans patients. Thus, KIs felt patients would not have to worry about bias or discrimination within the clinic. A KI from St. Louis, Missouri argued, "More girls would get tested and on PrEP. 'This place is helping me [as a patient] with this, why not go ahead and do it?'"

Finally, two KIs also highlighted that integrating GAC and HIV services would serve to not only increase engagement in care, ART adherence, and PrEP uptake but would also increase GAC access. KIs explained the distance patients travel to receive GAC. For patients in rural Southern Missouri, accessing many forms of GAC may result in a 3-hour trip to St. Louis. For patients in Kansas City, it may be a 4-hour trip to St. Louis. For patients in parts of Illinois outside Chicago, the trip is upwards of 2 hours. One KI in upstate Illinois regularly drives trans patients to Chicago (a 2-hour distance) to access HRT. While two hours may seem a shorter distance, she explained that, for working, poor, and homeless individuals she serves, a 2-hour trip requires time off work, a vehicle, money for gas, and money for food, in addition to the costs of health care. Thus, integrating GAC and HIV prevention/treatment would be a "huge relief," as the upstate Illinois KI stated "right now, we are spending a lot of time and money on taking people to appointments. This [traveling] is not effective."

Outer Setting

Local attitudes

Eleven KIs discussed local attitudes as a barrier to accessing HIV care. Each of these KIs discussed this as "stigma," homophobia, transphobia, or racism. For example, one KI in Chicago discussed a patient who told her about their experience attempting to get STI testing at a local clinic. The patient had to partially disrobe for the provider's assessment, and the provider mocked them for their genitals not matching their identity. Another KI in rural Missouri highlighted:

> I think it's just important that there are safe spaces for any patient, especially folks who are really a minority among other patients and who you know, I have patients all the time who come in and say I talked to my doctor about trans care and they "fired me" or they wouldn't give me a new appointment and so we live in an area of the country where there is very little experience dealing with sexual and gender minorities.

In addition to these experiences of discrimination, KIs also discussed the role that internalized stigma and a lack of education plays. When patients are told they are living with HIV, they experience shame and fear. As one KI stated, "Once you have your status, who's going to accept you?" Internalized stigma coupled with medical transphobia emerged as blockades that need to be addressed to increase access for trans patients.

Local conditions

Eleven KIs also discussed the role of local conditions as barriers to accessing care. This includes a lack of housing for trans individuals and safety for them if they are living at home. For some KIs, substance use was the largest barrier in the communities they serve due to high rates of substance abuse. Others raised issues of poverty, high rates of mental illness, and a lack of familial and social support. These SDOH impede patients' ability to prioritize HIV care, let alone other forms of care. Substance use and mental illness result in difficulties remembering to take one's PrEP or ART daily and to attend medical appointments.

Others also highlighted the role of transportation in rural and urban areas. For those in urban areas, the availability of buses and subways does not necessarily dismantle the barrier, as trans individuals may not feel safe on public transit due to fears of discrimination and violence. One KI in Kansas City elaborated:

> We may give a bus ticket to someone but taking the bus may not be safe for someone, so we've had to advocate for Ubers or cab rides. In the long run, it saves money because someone in care saves the system a lot of money in the long run. Some trans people don't use public transit at all. If they don't have a ride, they aren't going.

For those in rural areas, distance served as the mechanism through which transportation became a barrier. One KI in rural Illinois serves an area of nineteen counties. As a result,

> Some of them travel 150 miles round trip to get here. That's one of the reasons we're trying to develop more community partnerships because we know being centrally located has some advantages. We're just a couple miles from [university] but we know that there are a lot of care prevention and service deserts in these rural areas that have communities anywhere from 300-3,000 residents so getting here or even having to come here to get any of those services we offer…that needs to be something that they can access in their community.

Thus, a lack of access in rural areas and safe transportation in urban areas presented barriers to trans patients seeking out care. Another KI in North Illinois highlighted that they have nearby providers of GAC, but these providers are located immediately across the border in Wisconsin. As most of their patients were on Medicaid or Medicare, they had to instead travel several hours to Chicago to receive care, because state insurance only pays for care in Illinois.

Finally, political conditions exacerbated disparities in access to care in Missouri. In 2023, Missouri passed legislation criminalizing the provision of GAC to minors. Minors already receiving care are allowed to continue receiving care, but new patients cannot be served. The KI explained:

> We can accept no new minor patients. They'd have to go four hours to Illinois to get any care. Previous legal proposals wanted people to be in mental therapy for 18 months and any mental illness would disqualify

> you from gender affirming health care. So, the care providers were instructed they couldn't do it any longer, and they were told they would no longer be allowed to provide any. Currently we are the only one in [region of] Missouri [providing this care]. Our service area is 21 counties.

This KI further highlighted that they are the only provider of PrEP in this same service area. Thus, patients lack access to GAC and HIV prevention.

Partners and connections

KIs discussed the critical necessity of partnerships and connections with other providers, health care organizations, and hospital systems. As one KI from Chicago stated, "Partnerships are essential to ensuring under resourced organizations and HDs can succeed." These partnerships took various forms. KIs in rural and urban areas of Missouri provided linkage-to-care for gender affirming surgeries, HRT, and even to clinics that provide Botox and other fillers to ensure use of sterile syringes and surgical grade Botox. While these partnerships allowed organizations to overcome gaps in services they provide, referring patients out again relies on transportation, which KIs identified as a key barrier.

Policies and laws

Policies and laws were highlighted as barriers and facilitators by six key KIs. In Missouri, the policy environment hindered integration of GAC and HIV prevention/treatment. In August 2023, Missouri banned puberty blockers, hormone replacement therapy and gender affirming surgery for minors. The same legislation barred state Medicaid from covering any form of GAC for people of all ages and prohibited access to GAC in all prisons, jails, and correctional centers. Prior to the law's passage, previous legal proposals included requirements for trans patients to receive mental therapy for at least 18 months prior to receiving care and would disqualify any patient from GAC if they were diagnosed with a mental illness. The law's passage and the previous wording of attempted legislation led to many providers closing their facilities due to fear and due to diminished access to patients.

In Illinois, the policy environment functioned as a facilitator, as Illinois passed legislation in 2021 protecting providers from legal attacks for providing care to patients traveling from states with GAC bans. However, KIs highlighted the need to continue working with policymakers to increase access to care and to ensure all individuals impacted by HIV would have access to transitional, supportive, and permanent housing. A KI in Chicago highlighted the difficulty in making legal and administrative changes:

> With legislative work, there's a clear path, with administrative [work], it's like who's the right person in the right bureau to champion this? With any policy, the implementation part inevitably takes longer and is more challenging than getting through the hurdles of getting the words on the paper approved.

Some policy changes, like revoking legislation banning GAC, require legislative changes. However, others, like integrating care, may require administrative changes (e.g., altering funding schemes, developing standardized protocols). Further, the policy change must be implemented and enforced to ensure it has its intended impact.

Another KI in Southern Illinois reported frustration with the lack of access to care despite a supportive policy environment. He shared:

> I think there are a lot of people in St. Louis that would love the state support that we have in Illinois, but they do have the masses and the industry [to reach people]. I wish that we had, I think if we had more industry in southern Illinois, we would be able to grow our population centers and attract people from other parts of the Midwest and really be able to have more points of access for GAC for individuals.

Thus, a facilitative policy environment in combination with a supportive economy and growing population may be necessary to achieve successful integration of GAC and HIV prevention/treatment.

Financing

Seven KIs discussed the need for increased funds from local, state, and federal agencies to expand resources. Some KIs highlighted that they were already experiencing decreases in funding from Ryan White, forcing them to find other revenue streams. One KI in rural Missouri, though, discussed this as an opportunity, explaining:

> There's a need. No one else is doing it. As a Ryan White clinic providing care to folks living with HIV, our funding is 10% less than when we were taking care of 200 PLWH and now we have 800. Without increasing our services and providing additional funding streams, the organization won't survive. I'm pushing to expand services, pushing us to become a look alike and then FQHC to bring in the income we need to continue to exist as an organization and thereby provide services to folks who can't otherwise get this type of care.

Expanding services can provide new mechanisms to fund an organization, ensuring the survival of CBOs. However, this may need to happen in tandem with expanding insurance coverage. One KI in Southern Illinois noted, "If the insurance doesn't have robust coverage for folks, then that's going to drive them to underground practices. Buying hormones off the dark web and don't know if they're safe or not." When states like Missouri ban Medicaid from covering GAC, it may not result in all trans people no longer accessing GAC; instead, it may lead some to seek out care from less safe sources.

Performance measurement pressure

Performance measurement pressure, or pressure from contract requirements, reporting, and other "formal mechanisms of performance accountability" (Raghavan et al. 2008) was only mentioned by KIs outside Chicago. Only one KI in Illinois discussed performance measurement pressure. While performance measurement pressure can force CBOs to increase the volume of care they provide, it can also result in barriers to implementation. A KI in Southern Illinois highlighted:

> A lot of the organizations that serve similar populations, they're often funded by the same grants, so they can become ultracompetitive, so it can become a hinderance to them working together and better. Most of us here just want everyone to succeed but underneath that, there's still this sense of I don't want to give away any potential reimbursements because that's money I need as well.

This sort of pressure and competition can hinder the development of partnerships and connections, as CBOs need to be reimbursed by their HD or other sources of funding to continue providing care. However, collaboration could prove more fruitful to develop new services, expand resources, and facilitate referrals.

Inner Setting

Equity-centeredness

Within the inner setting, equity-centeredness, or a clinical culture that values equity, justice, and the provision of care to marginalized populations, was the most mentioned determinant (*n* = 8). KIs discussed this in terms of 1) developing an equitable culture for staff and 2) centering equity as the guiding force of integrating GAC and HIV prevention/treatment. The two themes are interrelated, as who staffs an organization and how staff are treated and valued shapes the clinical care patients receive. In terms of developing an equitable culture for staff, KIs highlighted work they had accomplished to develop racial equity committees, carry out compensation reports, bring in specialty consultants, rehaul compensation, and reconfigure insurance benefits and job descriptions. Doing so provided staff and providers with the resources needed to carry out their roles.

KIs further highlighted the need to move beyond cultural responsiveness training. Rather than only providing trainings to staff on how to work with and treat marginalized populations, they spoke of a need to target the barriers patients experience in accessing care. This included ensuring patients have access to housing, food, work, and other resources to address SDOH. One KI referenced Cornel West's (2001) concept of providing services that do have a "non-market value." He stated, "They may not bring a profit or revenue, but they build up the community. This is what is needed to prevent HIV."

Providing equity-centered care also requires investing in trans communities. A KI in St. Louis noted:

> A lot of the times the people in the trans community like to go here, because they know the girls who are here. We do have trans girls that work here. I wouldn't want to go somewhere I wouldn't be understood. So, because we go through a lot of the same issues [regardless of status], we still go through the same stigma, the same pain. They want to go somewhere they are understood.

Hiring trans people, developing their skills, and fostering an inclusive and equitable organization brings in clients, as it shows to them that they will be respected and affirmed.

Ultimately, KIs felt that eradicating barriers and developing equity-centered organizations would translate into improved health outcomes. One KI from Kansas City explained, "If people feel like there are space that genuinely care for them, genuinely want to see them living, and thriving, and vivant, then they are more likely to keep up their care." Integrating GAC and HIV prevention and treatment, hiring trans people, and supporting the staff at an organization were seen as critical to carrying out their mission to end HIV.

Relative priority

Six KIs discussed the relative priority of integrating GAC and HIV prevention/treatment in comparison to other ongoing work. All six highlighted integrating GAC into their HIV services as a high priority. They explained that their goal is to end HIV and provide care to individuals living with HIV. Integrating GAC into their HIV services aligned with this goal, as they viewed this process as increasing access, uptake, and adherence. KIs reported a desire to integrate GAC, explaining they just need the resources or connections to do so.

Staffing

Many KIs reported staffing as one of the main barriers, in addition to funding ($n = 8$). KIs' organizations already provided bundled services to mitigate the impact of SDOH. These organizations had food pantries, clothing closets, showering stations, primary care, HIV care, patient navigation, and other services to address these needs. Most already had primary care providers or nurses within the organization; therefore, the need became training staff to provide trans health.

Two KIs spoke of the need to hire clinicians to carry out this work. One KI in St. Louis noted, "We have the space to do it. We would just need the clinicians to do it…and the funding support to do it. If we could get the clinicians and the funding support to do it, it's a no-brainer." Integrating GAC and HIV services was viewed as highly compatible with their existing infrastructure, mission, and the needs of the populations they serve. Training clinicians, in addition to funding, became the barrier.

Individuals

Capability

Eight KIs identified provider capability as an additional barrier. Capability refers to both physical capability (i.e., having the skills to implement the intervention) and psychological capability (i.e., having the knowledge and training to do so). When KIs discussed capability, they primarily focused on psychological capability regarding the provision of GAC, as well as psychological capability to provide equitable services.

Regarding GAC, one KI in Northern Illinois discussed barriers to patients accessing care at pharmacies. Even if patients have providers who will prescribe HRT, some pharmacy technicians may not understand why or how to fill these prescriptions. Thus, there is a need for training not only of providers within a clinic but also of all medical personnel who may be involved in the provision of care. Another KI in Chicago also discussed the need for training, noting that all staff in a clinic need to be trained. While some may focus on just training medical doctors, this KI emphasized that nurse practitioners, physician's assistants, receptionists, administrative staff, and administrators all need to be trained to understand the necessity and priority of GAC.

Regarding the provision of trans-inclusive care, KIs spoke to barriers within HIV clinics broadly, as well as barriers within HIV clinics providing GAC. One KI in rural Missouri explained:

> Educating the staff is kind of the biggest barrier and making sure that people are comfortable working with that population. Not everyone is and we've lost staff because of it. When we're looking to hire people, it's difficult, we have an intensive interview process where people are confronted with scenarios about trans folks, actively psychotic folks, actively injecting drug users, so that weeds people out of the application process.

The KI described the importance of this application process and training staff to ensure all patients can access the care they need. However, this process also results in a loss of potential applicants. Thus, larger cultural shifts and greater training around sexual and gender diversity in educational institutions may be needed as an upstream intervention to increase the cultural competence of the workforce at large.

Finally, while some providers may already be integrating GAC and HIV services, this does not ensure patients have access to competent care. One KI in Southern Illinois elucidated this:

> I know a lot of providers who are starting to get into hormone therapy or GAC because they're starting to see more money come into it through Medicare or Medicaid but they're not culturally competent so they could still be doing harm to folks. That is probably the biggest barrier. A lack of culturally intelligent services and service providers.

Integrating GAC and HIV services will require training on the provision of various forms of GAC, including HRT, but will also include training on best practices vis-a-vis providing equitable care to trans people to ensure that care is accessible to patients.

Opportunity

One-third of KIs (*n* = 4) also spoke of patient opportunity as a barrier. Opportunity includes physical opportunity (i.e., having the resources needed to access care) and social opportunity (i.e., having the social support from family, friends, and the larger community to access care). The KIs who spoke of this were mainly in Missouri, with one in Southern Illinois. In discussing opportunity, patients primarily spoke of physical opportunity, highlighting barriers, such as transportation, knowledge of where to get tested, and awareness of existing resources and where "safe" clinics are located. However, they also described barriers related to social opportunity, including repeated discussion of stigma (both HIV stigma and anti-trans discrimination) as critical barriers impeding access to care. KIs also highlighted mental health as an additional barrier that needs greater attention within clinics and organizations. Finally, they discussed the role of staff and providers in limiting patients' access to care. For example, a KI in Kansas City who serves homeless and low-income patients stated:

> I don't want a physician looking at someone who's been on the street for four days, like 'You've got this stench about you.' Can we drive them to our comprehensive building and work with them to get showered and groomed. They may not have access, so let's provide the fucking access.

Thus, providers' capability, as discussed in the previous section, limits patients' opportunity. Provider training increases capacity to implement this type of care and expands patient access to care.

Process

Assessing needs

KIs (*n* = 4) discussed assessing the needs of patients as a facilitator to providing new sources of care. One KI discussed how they built out new services based on conversations with patients:

> We put together HRT kits for people who are engaged in transitioning and hormones with intramuscular syringes, gauze, Band-Aids, and al-

> cohol. We did that because, for folks who are transitioning or are on hormones, they say, "I can get my hormones covered by insurance but can't get the rest covered so I don't have access to those." We built that specifically on the feedback of the trans folks who engage in our services."

By soliciting feedback and listening to the needs of patients, their CBO developed a resource that filled specific gaps in care. While patients on insurance may be able to access GAC, they may not have access to specific items, like syringes, associated with that care.

Engaging

Finally, eight KIs reported the need to engage trans patients in developing new services. They highlighted that it is not enough to develop resources and organizations addressing patients' needs. The patients themselves must be involved as leaders and subject matter experts. For example, a KI in Chicago quoted author adrienne marie brown (2017), stating:

> All organizing is science fiction because we're creating the world that we want to see. So that is the essence of how to be successful to me in the policy arena, because why are you doing this if the people who are impacted are not leading the way? How do you even know if this is what they want? So, I have no problem stepping back. I like to curate the space and then do what's necessary to nudge conversation and help people feel comfortable and I think that has led to—actually—I know that has led to us being super successful.

Providers and administrators may understand the technical and medical aspects of providing care, but for that care to be patient-centered, accessible, and impactful, it must include the very patients it aims to service. Integrating GAC and HIV prevention/treatment necessitates the involvement of trans patients in research and implementation.

DISCUSSION

Trans individuals face a disproportionately high impact from the HIV epidemic (Centers for Disease Control and Prevention 2021; Sherwood et al. 2021; Sullivan et al. 2021). Despite this, the integration of GAC—which has been shown to have a potentially lifesaving effect on the health of trans people (Lee et al. 2024; Stoehr et al. 2022)—into standard HIV prevention and care protocols is still lacking. This study aimed to explore the determinants influencing the implementation of GAC in clinics offering HIV services across two states and among various providers, aiming to enhance GAC integration in these environments. We identified determinant across several domains: the inner setting, the outer setting, characteristics of individuals, and aspects of health equity, which include culturally relevant factors, the clinical encounter, and the societal backdrop. Notably, our research is among the first to assess these determinants within the primary spaces frequented for HIV services, providing important insights for the incorporation of GAC.

As noted in the introduction, we conducted this study in response to grant reviewer comments that there is already high access to HIV prevention and GAC in places like Illinois. While that may be true in clinics based in Chicago, our KIs highlighted that it is not true across the board in Illinois. Our KIs spoke of the burden of transporting clients to and from Chicago to access GAC. While telemedicine is increasingly an option for patients in rural communities, there remain barriers for homeless populations and those without insurance, which many of our KIs serve. Further, despite differences in cultural and political climates between Illinois and Missouri, the barriers and facilitators KIs identified were largely consistent across borders. This elucidates a need for increased attention to access to GAC and HIV care in "blue" states and otherwise. It is important to note, though, that differences do exist between the two states. Integration of GAC and HIV prevention/treatment will require policy changes in Missouri, as it is illegal for providers to prescribe minors puberty blockers or HRT (Missouri Save Adolescents from Experimentation [SAFE] Act 2023). The same Missouri law also prohibits the state's Medicaid program from covering GAC and prevents individuals who are incarcerated from accessing GAC. Thus, researchers will need to partner with community advocates and organizers to overturn legislation currently preventing trans individuals from accessing lifesaving care.

Further, it is necessary to note the role that movement across states plays regarding health care access and policy barriers. Individuals do not live stationary lives, remaining in one state or another. Instead, the modern economy and policy environment often require individuals to move across states and regions on a frequent basis. The passage of anti-trans health care legislation also provides further impetus for movement across states. In the wake of anti-trans legislation across the nation, including in Iowa, Missouri, Tennessee, Kentucky, Indiana, Ohio, and Arkansas—all states surrounding or near Illinois—patients and their families have begun flocking to Illinois as a "safe haven" for medically necessary care (Henderson 2023; Lubbers 2023; Sfondeles 2024). While there is not available data detailing HIV prevalence among those fleeing to Illinois to maintain access to care, we can presume many of them either require access to HIV prevention or HIV treatment.

Despite these policy barriers, KIs across both states displayed a high level of acceptability of integrating GAC and HIV prevention/treatment. Their acceptability was based on the provision of equity-centered care and diversifying services offered in their organizations. Future researchers should attend to the development of implementation strategies (i.e., methods of targeting organizational and provider behavior and knowledge) and structural interventions to target policy. Implementation strategies like trainings on how to provide HRT, hiring trans staff, and developing mechanisms to cover or bill for GAC services may help to facilitate the integration of GAC and HIV prevention/treatment. Structural interventions like policy changes and increasing access to transportation will be needed to enable integration of GAC and HIV prevention/treatment in states like Missouri but will also help trans patients access services in all states across the country.

Our findings should be considered with the following limitations. Our study only involved twelve key informants, limiting generalizability. Our sample exhibits wide geographic variability, with the 12 KIs spanning both states, ranging from small, rural areas to dense, urban cities. Further, our KIs had a high level of variability in terms of their purview regarding implementation of HIV care and GAC. Thus, while our sample included individuals with a high level of knowledge on their settings, it was not a homogenous sample. Finally, we only conducted interviews with providers and funders. No interviews were conducted with patients as the focus of this study was on determinants of integrating HIV care and GAC. Future research should attend to how best to integrate these two forms of care in ways that are feasible for providers and accessible to patients. Despite these limitations, this study provides formative data for future researchers developing implementation strategies to integrate GAC and HIV prevention/treatment. Our next steps include conducting surveys and interviews with clinics, providers, and patients to develop implementation strategies and adjunctive interventions to integrate these two forms of care.

CONCLUSION

Integrating GAC and HIV prevention/treatment can increase uptake of and adherence to HIV prevention and treatment interventions. However, further research is needed to understand how best to integrate these two forms of care. Our research identified barriers and facilitators to accessing GAC and HIV prevention/treatment, as well as critical barriers to integrating these two forms of care. While numerous barriers exist, provider and funder acceptability are high, suggesting a need to develop implementation strategies to increase organizational capacity for integration. Attending to the needs of trans patients may support efforts to end the HIV epidemic in the U.S. by increasing organizational adoption of evidence-based and equity-centered interventions.

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ORIGINAL ARTICLE

Using Discord in the Community, and Other Means of Online Collective Trans Care: Decision-making and Storytelling in Online Transgender Health Support Groups

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For many transmasculine and nonbinary people, the decision about whether to have a gender-affirming surgery known as "top surgery" is an important part of gender transition. To examine how online support communities may influence top surgery decision-making, we conducted four online asynchronous focus groups ($N = 21$) using Facebook and Discord. As we show, different factors (including societal expectations and participants' race, disability status, and gender) can influence both decision-making and the ways that people seek support; the research spaces themselves—the focus groups on Discord and Facebook—became supportive environments that helped with participants' decision-making, and many participants eventually sought top surgery using non-traditional approaches that they had learned more about in these (and other) online communities. We discuss how top surgery-related online support communities can facilitate trans care. We also discuss the many types of storytelling that participants engaged in in these spaces—one of the key elements, we posit, of participants' decision-making. Finally, we provide recommendations for future researchers, discussing how focus group composition impacts intracommunity dynamics and how Discord can be used to facilitate online focus groups.

KEYWORDS transgender identity; health and wellbeing; online focus groups; top surgery; Discord

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Online communities and spaces are important for LGBTQ+ people broadly, and trans people specifically, because they enable social support, identity affirmation, information seeking and sharing, education, development of community knowledge, and recognition of shared experiences (Craig et al. 2021; Cipolletta, Votadoro, and Faccio 2017; Dowers, Kingsley, and White 2021; B. Miller 2017; Prinsloo 2011; Rawson 2014; Selkie et al. 2020). Trans people often turn to online community spaces for health-related information and support exchange for several reasons: the current anti-trans political climate, as well as a long history of medical gatekeeping, trans exclusion in mainstream healthcare systems, and disregard for trans expertise about trans bodies (shuster 2021). Online spaces can help fulfill trans people's unique health and transition needs (Chuanromanee and Metoyer 2021; Hawkins and Gieseking 2017; Prinsloo 2011). In online communities, trans people can find meaningful information (Cannon et al. 2017; Huttunen and Kortelainen 2021) and feel safe to share about their own experiences (Cipolletta, Votadoro, and Faccio 2017; Hawkins and Haimson 2018) through storytelling, which can help them and others make sense of gender transition and its dominant narratives (Horak 2014). Previous work on online support spaces has examined online identity formation, intra-community dynamics, and the benefits and harms that can arise in online LGBTQ+ support groups (Scheuerman, Branham, and Hamidi 2018; Walker and DeVito 2020).

Transmasculine and nonbinary "top surgery" is often a part of gender transition for assigned-female-at-birth transmasculine and nonbinary people; it is a medically necessary gender-affirming procedure that removes breast tissue to produce a flat chest (Bluebond-Langner et al. 2017; Nolan et al. 2020; Wilson et al. 2018). This is a common, safe outpatient surgery (Bluebond-Langner et al. 2017) that substantially increases quality of life and mental health and decreases gender dysphoria for many transmasculine and nonbinary people (Nolan et al. 2020; Poudrier et al. 2019; Puckett et al. 2018).

Past work in transgender studies has challenged traditional views of gender transition (Rachlin 2018) such as the linear narrative and examined gender confirmation surgery from different perspectives (Heyes and Latham 2018), but these findings have not yet been empirically examined in relation to trans people's use of technology or to their expressed needs. To address this gap, we pose the following research questions:

> ***RQ1***: What is the role of online support groups for decision-making in surgery? How do participants use information found from these groups?
>
> ***RQ2***: What kinds of surgery-related decisions do participants discuss in online support groups? To what extent does active and passive participation in these groups impact the decision being made?
>
> ***RQ3***: How does the choice of platform (e.g., Facebook, Discord) influence focus group dynamics in asynchronous online focus groups? How can a platform's affordances affect group member interactions and support?

To explore these questions, we conducted four asynchronous focus groups with $N = 21$ participants using Discord and Facebook. We collected qualitative data on online support groups' role in decision-making and in identity formation and understanding via storytelling. We found that while participants gathered a variety of helpful information inside and outside of online support groups, the stories told through these groups were invaluable in influencing participants' decision-making and their thoughts about themselves and their transitions. We also observed that focus group participants demonstrated trans care and collective self-care (Malatino 2020) within the groups. We did find some differences in the focus groups on Discord and those on Facebook; these differences indicate that Discord may be the more appropriate platform for facilitating focus groups on trans-related topics.

RELATED WORK

To understand how online communities can support people considering top surgery, we must first understand how trans people's decision-making about surgery is shaped by their access to care—both medical care and care from their communities. Top surgery is a common surgery pursued by many transmasculine and assigned-female-at-birth nonbinary people (Bluebond-Langner et al. 2017; Wilson et al. 2018), but access to top surgery is often limited. Historically, surgery candidates were evaluated based on how well they performed their desired gender and how closely the personal narrative they provided matched with doctors' conceptions of what trans narratives should include: binary gender identities, heterosexuality, and stories of being "trapped in the wrong body" (Denny 2004; Stone 2013). Similar gatekeeping and harmful expectations surrounding trans narratives continue today (Lau and Kwok 2009; Pitts-Taylor 2020). The former "transsexual model," which posited trans identity as a mental illness that could be cured by medical procedures, has been replaced by the newer "transgender model," which views medical options like surgery as one of many potential paths or steps that may be part of a person's transition (Denny 2004; Stryker 2017).

While for many people top surgery is a crucial part of gender transition, it involves substantial cost and several weeks of recovery time, and many barriers separate trans people from the medical procedures they need. Trans medical gatekeeping is common in many countries (Ashley 2019; Gill-Peterson 2018; Pearce 2018; shuster 2021): in the U.S., insurance and cost barriers are prevalent, and in countries like the

U.K. where trans healthcare is covered by the state, barriers include long waitlists (Pearce 2018). In addition, many trans people lack family support (Nolan et al. 2020; Puckett et al. 2018) for surgery after-care.

Some of these gaps can be filled by community-based care work and mutual aid (Piepzna-Samarasinha 2018; Spade 2020). This type of care is what Hil Malatino (2020) calls "trans care," which he defines as "what we owe each other" and a "commitment to showing up for all those folks engaged in the necessary and integral care work that supports trans lives, however proximal or distant, in the ways that we can" (Malatino 2019). Trans care describes all the ways that trans people care for each other, including caretaking around trans surgeries. But not all trans people have access to trans community and trans care in their physical locations. Online communities thus become an important mechanism for expanding trans care, increasing access to trans surgeries and reducing trans people's reliance on traditional healthcare systems by providing vital health information and peer support. Trans care flourishes in online spaces, filling the gaps left by traditional systems that do not meet trans needs.

Online Health Communities for People with Marginalized Identities

An increasing body of health research examines the specific health needs of people with marginalized identities. For example, Keyes et al. (2020) encouraged researchers to center "(gendered) marginalized health"—to focus on marginalized people's health needs and make fewer assumptions about alignment between bodies, identities, and genders. In the spirit of this call, here we center trans men's and nonbinary people's medical and online community-based needs, thus making these marginalized groups more visible in social computing.

We focus on online spaces because they are especially helpful for trans people, who use them to find meaningful connection and support and share their experiences and personal narratives about their identity, both in recent years and historically (Buss et al. 2021; Dame-Griff 2023; Yeadon-Lee 2016). Participation in online health communities can help people cope with their condition, manage stress, and improve wellbeing (Rodgers and Chen 2005), and discussions of health conditions can help people translate medical concepts into practical knowledge (Pols 2014). In addition, health conditions can become part of one's identity, and online health communities allow people to connect with others who share that identity (MacLeod et al. 2015). This is doubly true for people with health conditions who also have other marginalized identities, such as trans people; according to Pohjanen and Kortelainen (2016), trans people's most important sources for information about gender transition were other trans people, who often provided reliable and detailed information about transition that was not available elsewhere.

There are other benefits to online community spaces for trans and LGBTQ+ people. The combination of anonymity and visibility that characterizes many social media sites allows users to explore and express their identity (Haimson et al. 2020; Haimson et al. 2021; Kitzie 2018; Kitzie 2019); online communities allow people to easily create and communicate multiple identities in ways which are often not possible in physical spaces (Haimson 2018; Haimson et al. 2021; Hanckel et al. 2019; R. Miller 2017). LGBTQ+ people can use online communities to connect with similar others, learn about gender and sexuality, and explore identities outside of their typical networks—an especially important function for people who are not yet out (Byron et al. 2019; Cavalcante 2016; Dame 2016; Dym et al. 2019; Haimson 2018; Haimson et al. 2021; Hanckel et al. 2019; Oakley 2016; Simpson and Semaan 2021).[1]

Online communities are especially crucial for trans people, who face a severe lack of quality online health resources (Evans et al. 2017; Horvath et al. 2012). It is difficult to find accurate information about trans surgeries online (Karamitros et al. 2017), and even surgeons who perform gender affirming procedures sometimes provide inaccurate medical information about surgical procedures and complication rates (WPATH Open Letter). Similarly, photos of trans surgery outcomes can be difficult to access. (While post-surgery photos of trans patients are sometimes included in published research papers, these photos are often unethically published without patient consent; Marshall et al. 2018.) Online trans communities help with this problem also: many trans people share surgery outcomes on crowdsourced sites like Transbucket and social media like YouTube and Tumblr, as a way to visually track and document their transitions and to build community with others (Haimson et al. 2021; Prinsloo 2011; Raun 2015). Trans people use online spaces to connect with other trans people; to research gender and transition; to find resources; and to discuss and work through gender dysphoria (Chuanromanee and Metoyer 2021). However, these communities can be difficult to find, and as with any online resource, platform policies and misinformation sometimes hinder people from finding the health information they need (Augustaitis et al. 2021; Evans et al. 2017).

Storytelling, Narratives, and Decision-Making in Online Spaces

Online trans communities offer a form of peer health navigation (Dowers, Kingsley, and White 2021) that positions trans people, rather than medical professionals, as experts on transness (Dame 2013). In these communities, people both adopt and critique common medical narratives to help them better understand themselves and their transitions (Psihopaidas 2017). Narratives are stories humans tell, individually and collectively, that transmit information and help them make sense of experiences. Storytelling can be a tool for community empowerment (Grimes et al. 2008), for it can be used to challenge dominant narratives (Gastaldo, Rivas-Quarneti, and Magalhães 2018) and provide community (Dym et al. 2019). Online storytelling has also been found to be useful for individuals, offering support (Høybye et al. 2005), solidarity, and activism (Gallagher et al. 2019).

Yeadon-Lee (2016) examined the role played by online narratives and storytelling in nonbinary identity formation and identity recognition across different age groups and stages of life. According to Yeadon-Lee, identity stories told online frequently presented certain elements: 1) authors used current labels to situate their identity within a shared framework of understanding, 2) authors expressed the inadequacy of these known terms and narratives to accurately describe their identity and experiences, 3) authors sought to reconstruct their own past histories in light of their current under-

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[1] However, online spaces are not trans and queer utopias. Trans people are sometimes restricted from participating in online spaces (Haimson and Hoffman 2016), and may face disproportionate harassment (Scheuerman, Branham, and Hamidi 2018). Further, some LGBTQ+ online spaces involve intracommunity conflicts and harms (Walker and DeVito 2020).

standings of themselves, and 4) authors sought to relate their bodies to their identities (2016). These stories illustrate several of the ten features of narrative identified by Bruner (1991): they often *breach* or conform to *canonicity*, *accrue* through Internet archives, and either conform to or challenge *normativeness*.[2] We build from Yeadon-Lee's work to examine how transmasculine and nonbinary people in online health communities situate themselves and their identities alongside or in opposition to more commonly-told stories, and how this may affect decision-making.

In addition to enabling identity-related storytelling, online groups can also play an important role in health-related decision-making. Online groups may include not only patients themselves (Visser et al. 2016), but also healthcare providers and patient caregivers or supporters (Lau and Kwok 2009). Historically (and presently), healthcare providers have had undue decision-making power about trans people's medical care (shuster 2021), but online communities are changing this power dynamic, allowing patients to independently gather information about treatment options (Rupert 2016). We are interested in the role of online groups in decision-making surrounding gender confirmation surgery, given the paucity of information (relative to other, non-transition-related health information) and the unique social dynamics of such groups.

Platform Affordances for Health Communication and Storytelling

Both health communication and storytelling can be discouraged or encouraged by platform affordances. To support health communication, affordances should support anonymity, pseudonymity, and privacy, because these enable people to comfortably share sensitive health information and information related to LGBTQ+ identity (Cho 2018; Hanckel et al. 2019; Kitzie 2019). Safety is also crucial; platform features that increase perceived safety in online spaces include privacy settings and enforcement of community standards to prevent harassment (Redmiles 2019). To support storytelling, affordances must also encourage sharing narratives and asking and answering questions (Hinson 2017). Health-related storytelling is supported by affordances related to flexibility, such as open-ended text boxes and tagging systems that use community-constructed terms—features that also enable identity exploration (Haimson, Dame-Griff et al. 2021; Oakley 2016). To promote LGBTQ+ storytelling and community building, platforms should have self- and audience-related affordances like high presentation flexibility and low identity persistence—features that are found on, for example, Tumblr (DeVito et al. 2017). Software for online health communities need not be technologically complex; the most important elements of supportive online spaces are affordances that enable strong community development (Maloney-Krichmar and Preece 2005).

We used both Facebook and Discord to hold online focus groups, offering insight on how each of these platforms' affordances may support health communication and storytelling. Discord is an excellent example of a platform that encourages strong community development: its social affordances promote self-expression and commu-

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[2] According to Bruner (1991), narratives have ten characteristic features: narrative diachronicity, particularity, intentional state entailment, hermeneutic composability, canonicity and breach, referentiality, genre, normativeness, context sensitivity and negotiability, and accrual. These features of narrative can be identified in stories people tell around gender transition and trans surgeries.

nity building, offering a sense of togetherness and community for people who are far apart (Vistisen and Jensen 2021). The platform enables text, audio, and video communication, and its affordances thus include synchronous and asynchronous communication, ephemeral and non-ephemeral content, custom user roles with visual markers, pseudonymity, and ability to host multiple communities (Bajpai et al. 2022). Discord's voice-based affordances can help to build community and enable storytelling, but they can also make moderation difficult (Jiang et al. 2019), and consequently, toxic environments and networked harassment are common on Discord (Heslep and Berge 2024). Yet prior work has not examined the extent to which Discord's affordances may uniquely support online health communication and storytelling; it is important to understand how platform affordances may hold important potential for trans people seeking health information, as we examine in this paper. In contrast, Facebook emphasizes affordances that tend to discourage both health communication and identity-based storytelling. First, it emphasizes identity persistence (DeVito et al. 2017), expecting people to represent their "real" selves on the platform -- an expectation that can make both trans identity presentation and sensitive self-disclosure difficult (Haimson and Hoffmann 2016). Second, Facebook is oriented toward "default publicness" rather than privacy, which can be dangerous for LGBTQ+ people (Cho 2017).

STUDY AND ANALYSIS

In four asynchronous focus groups (two on Discord, two on Facebook), composed of $N = 21$ total participants, we asked participants about top surgery and their decision-making process. We also asked how their online support communities (or lack thereof) affected their experiences. We chose to use asynchronous online focus groups (MacLeod et al. 2017; Prabhakar et al. 2017; Reisner et al. 2018) because the population of interest is both geographically distributed and stigmatized. This research was approved by the University of Notre Dame's Institutional Review Board, and each participant signed a consent form prior to participating in the study.

Participants

We recruited $N = 21$ participants who were either in the process of seeking top surgery or had had top surgery in the past. Participants' ages ranged from 18 to 31, with a mean age of 23.4 years, a median age of 24 years, and a standard deviation of 3.6 years. Twelve of the participants are currently in online support groups or have participated in them in the past; nine had no previous experience with online support groups. We recruited participants through several venues: social media posts on Twitter, Reddit, Facebook, and Tumblr; posts in online top surgery communities on Facebook, Discord, and Reddit; and our existing mailing lists of people interested in participating in research studies.

Participants reported a range of genders. Two participants were agender, eight participants identified solely as nonbinary, and three were both nonbinary and male. Five participants were male. One additional participant selected male and also wrote in "trans male," another wrote in "transmasculine," and one wrote that they were unsure whether they were "nonbinary or transmasc nonbinary." When referring to a specific individual in this paper, we use their indicated pronouns.

Eight participants were white, four were Asian, three were Hispanic/Latino, one was Black, and five were mixed race. Nine of the participants indicated that they were disabled. Nineteen participants lived in the United States, one lived in Norway, and one lived in Canada at the time of the study.

Sixteen participants were "pre-op." Of these, five reported that they wanted top surgery, but were unsure of how to get it. Three reported that they were trying to decide whether top surgery was something they wanted to pursue. The other eight participants were actively pursuing top surgery, taking steps such as saving money, scheduling appointments, or working with insurance companies to determine coverage. The other six participants had already had top surgery, from three months to five or more years before. Because of the potentially sensitive nature of the topics of discussion, our recruiting materials stated that the focus group moderator was in the transgender community and was familiar with top surgery. Participants were compensated with a $30 payment via PayPal or Venmo.

Before submitting this article for publication, we gave participants the opportunity to read it and provide comments and corrections regarding their quotes and the overall narrative. One participant requested minor corrections of their quotes, which we adjusted before submission.

Focus Group Structure

We conducted four online focus groups, two on Facebook and two on Discord, with each lasting three days. We chose Facebook because it has previously proven suitable for asynchronous online focus groups (MacLeod et al. 2017) and is beneficial for conducting research with hard-to-reach participants (Lijadi and Van Schalkwyk 2015). We included Discord, an online messaging platform focused on social connections and gaming, because it has recently become an important host for online trans communities, and the platform felt natural for many participants. While other platforms such as Tumblr were previously widely used by the trans community, the timeline format of the platform as well as the changes enacted in 2018 (Haimson et al. 2021) that alienated many trans users caused us to exclude it as an avenue for research.

Each day, in each community, the moderator posted two sets of prompts, one in the morning and one in the evening. This format is similar to that used by Reisner et al. (2018) and Augustaitis et al. (2021). In the Facebook groups, each set of prompts was posted as a separate post, and participants posted their replies in the comments. Participants could react to others' comments and respond to them if they wished. Responses can be threaded, and participants can mention the poster of the comment using their name to clarify who the message is addressed to. In the Discord focus group, the structure was slightly different due to the platform's setup. Each Discord group is called a "server"; usually there is one server owner and multiple moderators. Each server can have multiple channels (text or voice) for different topics or uses. Each member of the server can customize their name and avatar (and it can be different across different servers users belong to); members can send text, images, stickers, and files asynchronously to the server. Within each text channel, Discord allows replies and threading. This produces a free-flowing conversation format that can support multiple conversations occurring simultaneously.

In each focus group's server, we created multiple text channels, each with its own topic. The channels were:

> #rules-info: used for posting the study information, informed consent documents, and rules for discussion.
>
> #general: used for communication not directly related to the prompts or their responses.
>
> #prompts: for the moderator to post the prompts. Posting privileges were restricted to only the moderator.
>
> #prompts-responses: for participants to post their responses to the prompts, and to have conversations about topics related to the prompts.

We also had one voice channel open in case participants wanted to use it, but stated that this channel was completely optional.

The prompts on Discord and Facebook were the same. First, we asked participants to share their identities and backgrounds (if they were comfortable doing so) and where they were in terms of top surgery. We also asked them where they received support, their information-seeking habits, and the community dynamics of any online support groups they were in. Finally, we asked about their top surgery decision-making and what influenced that process.

Analysis

We analyzed all data from each of the focus group transcripts (including images shared by participants and participants' use of platform-specific features) using open coding and axial coding (Strauss 1987). Axial coding helped us organize the data around larger themes and uncover the connections between themes. To keep participants' interactions and responses in context, we noted participants' use of emoji reactions during analysis (Reisner et al. 2018). Each member of the team separately conducted line-by-line open coding on the first focus group transcript. The team then met to discuss, refine, and consolidate codes, creating a collaboratively generated codebook. We then conducted axial coding (Strauss 1987). Finally, one of the authors used the collaboratively generated codebook to finish coding the rest of the focus group transcripts.

RESULTS

Several themes emerged from our analysis, including participants' need for more comprehensive and inclusive representation of top surgery experiences, inequalities in accessing top surgery, and differing approaches to pursuing and obtaining top surgery.

We found that participants' experiences varied along each step of the top surgery decision-making process, which was deeply affected by internal and external factors such as health, socioeconomic status, access to care, social relationships, and identity discovery and presentation. Participants who had already had their surgery and who had previously participated in online top surgery support communities noted the online community's role in their surgery process and their experiences of gender dysphoria and gender euphoria.

Most, if not all, of the participants approached the decision about whether to have top surgery as a momentous and significant one. Out of the 16 pre-op participants, eight were saving up for or were actively pursuing top surgery. Of the other eight, five wanted to have top surgery, but their present living, social, or financial situations prevented them from pursuing it; the other three were deciding whether or not they wanted to pursue top surgery. One of the three participants who was still deciding said they were torn because they feared regret post-surgery. Another participant decided to postpone making their decision until they have been on testosterone for at least a year.

The participants who had decided that they wanted top surgery reported various triggers for their decision. For instance, P6 started seriously considering top surgery less than a year ago, when they realized that their negative feelings from past years were not "sensory issues" but dysphoria. P18 said that they decided they wanted to have top surgery after they came to terms with their identity. For P16 and P6, factors affecting their decision and timing for top surgery included gender dysphoria and misgendering.

Other participants' experiences were differently linked to social dynamics. For instance, P10 said that if it were not for societal expectations, he would not pursue top surgery. However, he felt uncomfortable sharing this information with other members of his focus group, and instead opted to directly message us with the following: "If there was a way for me to be shirtless as I am, or just un-bra'd un-binding as I am and still be respected as a male I don't think I would have top surgery… There is a part of me that isn't happy that I need surgery to have that kind of perception. To me, it's almost a sacrifice I have to make." P4 said almost the opposite: "I really do like the feeling of having a flat chest, as even if I don't seem male, I do seem a lot less feminine, and that just feels so nice. (obligatory presentation =/ [does not equal] identity)."

Online Communities and Decision-Making

The narratives (or lack thereof) and social situations that participants encountered helped them decide to pursue or delay pursuing top surgery. Many participants said that reading others' stories in online support groups helped them decide to pursue top surgery: for example, P4 said, "I've looked at pictures of traditional top surgery, read and watched videos about people's surgery experiences, and just read trans and nonbinary experiences in general and how they came to want top surgery." Similarly, P4 reported that reading and watching others' stories was helpful in deciding whether to pursue top surgery. For these participants, the stories found in online communities helped them decide to begin the process. Online groups provide participants with spaces to share these experiences, which can in turn help others with their decision-making processes.

Not everyone who decides to seek top surgery can immediately take concrete steps towards surgery. A number of participants said that it was impossible for them to get top surgery in the near future for many different reasons: progress in transitioning (P11), finances (P11, P1) and logistics (P1), and having other priorities for transition (P11, P18, P6), such as starting HRT. For many, the next step after deciding to pursue top surgery was waiting and gathering information and resources. The information participants gathered about top surgery came from many sources, including web searches, surgeons' websites, and online communities on platforms such as Facebook, Reddit, online blogs (P1), Youtube (P13, P14, P15), and TikTok (P15). While in this waiting phase, participants used online communities and resources more for support than for active decision-making, since there were not many concrete surgery-related decisions to make at this point. These communities helped participants cope with often uncontrollable life circumstances and barriers and provided them with a source of comfort and hope. Participants said that reading and viewing others' experiences with top surgery was helpful and served as a form of online self-care. Many participants reported feeling gender euphoria through seeing others' photos, which helped them through the period of waiting. P10 expressed: "I feel like most of the time when I look at top surgery results I'm kinda comforting myself, and I'd feel very comforted if I could see results that look like mine may look." Although P2 described feeling "a bit envious" when seeing others' results, they said, "It mostly gives me that gender euphoria feeling seeing fellow trans folks living their best lives and thinking about how someday that can be me!"

For most people who undergo top surgery, surgeon selection is a major decision—one that many participants made with the help of online communities. Many participants, including P4, looked for online recommendations before selecting a surgeon. We found that participants prioritized different criteria in making their surgeon selections; the criteria each person used to make decisions depended on their goals for the procedure. For example, P7's main criteria for surgeons were aesthetic—a preference that was informed by looking at others' results online. However, for P10, scars did not matter much, since "the biggest impact to my public life will be how clothes fit me on top, so the kind of scarring isn't something that I prioritize highly."

Not all participants found online communities equally useful for surgeon selection. In some countries or areas, there are stricter requirements for surgery or a limited number of surgeons. Most of the participants in our study described feeling at least somewhat limited in their surgeon selection. For instance, P20 lives in Canada, and is on a waitlist to speak with a surgeon. Due to local requirements, his top surgery would be fully covered if he were on hormones for at least one year. He said, "I have no say in that unless I pay extra money out of pocket. I just hope my surgeon and I get along well enough so I'm not afraid to say what I want." As P20's story shows, geographic restrictions and financial barriers sometimes combined to reduce participants' choice in surgeon selection. We see the same combination in P10, who is on an insurance plan that will fully cover top surgery, but only for select surgeons, only two of whom are in his state. These participants may find limited utility in online communities that share information primarily aimed at informing surgeon selection. In general, participants with more access and more choices tended to find online support groups more helpful.

Other participants may have criteria for surgeons that do not reflect most group members' criteria. Participants who inhabit bodies that are considered outside the norm (whether due to race, size, ability, or other factors) consistently reported a need for increased representation and support, and we found that their background and experiences can affect both their expectations for top surgery outcomes and their decision-making processes. For instance, some participants felt it was important to see a surgeon who has expertise or experience working with patients of their own race and/or body type. For P16, finances and experience with marginalized groups mattered the most. They remarked, "I think it would depend on whether there's any surgeons that are in network for my insurance, but also I would highly prefer to see a surgeon who people of color had a good experience with." While P19 went to a surgeon who did not have much experience with Black patients, he appreciated his surgeon's honesty about this: "I remember at my surgery consult she was very upfront with me about having not done top surgery on a person with my skin tone so she didn't know how the scars would turn out. This made me trust her way more in the process."

Many participants noted a need for more diverse representation in size, shape, race, and ability in online groups (echoing findings from Andalibi et al. 2022), surgery narratives, and pictures of results. As P16 put it: "[I] would love some resource that is more QTPOC centered or QTPOC only and to readily be able to see how top surgery looks on a variety of bodies (skin tones, body shape, and fat level, etc)." Similarly, P15 remarked: "I wish it was easier to see results. I also wish there were more resources available for people who aren't thin/have smaller chests." P19 said, "[I was] on [a popular Facebook top surgery group] specifically wanting to talk to black folks who had had top surgery and there was virtually no one...We put the trans guys who have top surgery and have minimal scars or scarring, didn't have to do nipple grafts, and were buff before surgery and buff after surgery on a pedestal as what everyone wants to look like and what everyone will look like. I think it's cool to see results but I wish we focused on results from all body types and races and not just trans guys who win the genetic passing lottery." For P19, because most resources showed "ideal" results, he was not able to find and connect with other black trans people (P19 here echoes prior work that described lack of online examples of trans surgery results for people of color; Haimson et al. 2021). However, some participants were able to find support from others with similar backgrounds in larger, more mainstream groups; P21 was able to find support and representation in a large general top surgery group when other Asian people posted their results, and P11 used others' experiences online to determine what decisions he needed to make regarding top surgery: "I try to find others who have similar body types to me and similar experiences, so I know which decisions would work best for me." Although he said that he may change these decisions after talking with a surgeon, others' stories helped provide him with a jumping-off point to make his preliminary decisions.

We also saw some evidence that participants' disabilities affected their decision-making and expectations. P11, who is disabled, expressed: "I'd like more experiences from disabled trans men such as myself. Being disabled can mean top surgery/gender confirmation may be less priority than working on other health issues, and some disabled people may not even be able to have gender confirmation surgeries at all. When looking up information about disabled trans peoples' experiences with transition, it can be difficult to find any information." P11's difficulties in finding other disabled trans people's stories applied not only to top surgery but to gender transition in general. P20 recognized the limitations of top surgery as it relates to his disability and adjusted his expectations, saying, "My severe scoliosis would make it impossible to achieve a natural looking result."

Other participants, such as P15, wanted more support and representation of people of size: "I am currently a size 16 and I have rarely seen resources/topics for people my size and up." This is a concern often grouped together with a more general desire for increased representation of marginalized bodies, as P15 and P16 expressed above. P7's surgical decision-making also included deciding whether to have liposuction as an additional procedure during their top surgery; participants' perception of their bodies can affect their satisfaction with their surgical decisions and results.

Just as participants wished for better representation of race, body type, and ethnicity in online top surgery communities, they also reported a need for more resources for people with non-traditional experiences of gender. Many participants did not strictly consider themselves transmasculine, and they described feeling that there was a lack of online spaces where people would accept them. For instance, P6 said: "I think a lot of top surgery discussions tend to be geared exclusively toward binary trans men, which can make anyone else interested in the possibility of getting it feel kind of lost, or forgotten." Such groups can feel alienating for somebody who does not identify as a binary trans man. Many participants in this category gravitated toward non-traditional top surgery procedures, pursuing a reduction rather than a complete removal. P5 learned that breast reduction was an option through seeing others' experiences on TikTok: "I didn't realize other people were like this until like a month ago when a gender surgeon on tiktok posted something about how 'many genderqueer people go for reductions that make it easier for them to bind!' and I got very excited that this was AThing, and it solidified it in my mind as something that was possible to achieve."

Although, as these participants' stories show us, trans resources online are not thorough, all-encompassing, and perfectly suited to every type of body and situation, there is value for most in spending time in online trans communities as they make their decisions about top surgery. Online platforms can empower people to feel more knowledgeable and in control over their decision-making processes, in part because these communities provide space for people who have finished their surgeries to share their stories. These stories were valuable whether or not participants interacted directly with other members of the online communities. Many participants said that seeing others' results and learning about options regarding different surgery procedures helped them feel more prepared to make their own decisions, even if they did not necessarily interact directly with other group members. P4 pointed out, "[Lurking in online groups] ha[s] been helpful in consolidating a variety of information, from details about finding doctors, talking about how some places have prerequisites to getting top surgery, the recovery process, as well as different people's experiences throughout that process. [This] has been helpful in figuring out insecurities regarding it, or doubts I've had."

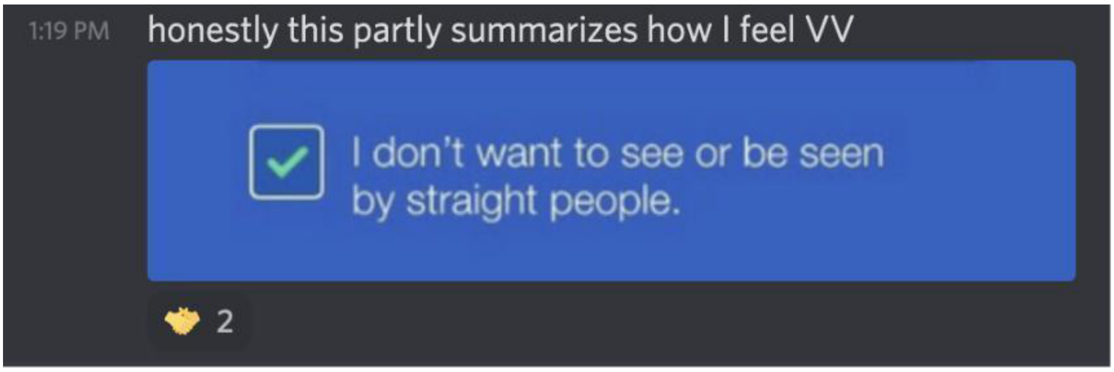
Many participants described prioritizing both physical and mental health when navigating online communities and making decisions regarding top surgery, including P10: "I'm just happy to be able to get the surgery for free and I don't want to undermine my own happiness being picky or extra selective." This prioritization of self-care also extended to making decisions about continued participation in surgery- or trans-related groups. For example, P19 left a top surgery-related group because "It skewed my perception on what my results should look like. I think it ended up saving my mental health and self esteem by leaving the group because my results were so drastically different than the results being posted by other people at the time." Similarly, P17 noted that "When I joined groups before knowing if I could transition, I had a lot of jealousy and needed to pause participation for a while for my own mental health." P19 also noted that group dynamics were harmful at times: "Definitely jealousy was super common. I also think it was common to bad mouth results especially when people had really dark scars or nipples/areolas that weren't perfect circles. It was definitely pretty toxic at times." While many participants found online groups helpful and supportive, others chose to remove themselves from such groups because of the harm that comes from comparison and jealousy.

Role of Storytelling

Many participants said that their decision-making processes benefited from others' storytelling in online trans communities—posting before and after pictures or writing about their experiences. For example, P4 mentioned that reading about others' experiences helped them consolidate information and feel more confident and less insecure in pursuing top surgery and making decisions. Several participants said that these stories helped them decide what questions to ask their surgeons, set expectations for their own processes, and realistically understand potential results. P4 commented, "Stories like that would be very helpful for people figuring themselves out."

In the focus groups, we learned that participants found several different types of storytelling – including text/photo-based and vlog-based storytelling –helpful for their decision-making. Stories that include both text and photos (usually before and after pictures of the person) may be fairly comprehensive, documenting the entire process before and after surgery, or they may be smaller in scope, documenting individual segments of the person's journey, such as the recovery process post-surgery. Vlog-style videos invite the viewer to participate in the storyteller's experience, as the teller and the viewer share the "sense of the passing of time" (which can affect expectations of transition timelines; Horak 2014). Videos documenting top surgery-related experiences may allow viewers to feel more personally connected to the storyteller (Raun 2015) (which can be a form of parasocial relationship; Horton and Wahl 1956), creating a more immersive experience than text- and photo-based stories.

Most of the five post-op participants mentioned that after surgery, they stayed in the top surgery groups that they were active in before surgery. P17 remained in online groups to impart his knowledge and experiences to others. P8, who had surgery



1:19 PM honestly this partly summarizes how I feel VV

☑ I don't want to see or be seen by straight people.

Figure 1. A screenshot of a post shared by P2, who used this image to convey their feelings surrounding being perceived by others. The handshake emoji reactions are from two other participants, which shows signs of supportiveness and camaraderie.

less than six months before he participated in this study, was still using online support groups to get reassurance and answers to questions about healing and scar care routines because it felt less overwhelming, intimidating, and anxiety-inducing to ask group members than to contact his surgeon directly. P14 had a similar experience with a transmasculine Asian American online group chat.

Many participants found the research spaces themselves to be supportive online community environments. Participants were engaged with the focus group discussions, with 20 of 21 participants responding to a majority of prompts posted, and 18 responding to all prompts. Participants interacted not only with the prompts we posted, but also with each other (e.g., by commenting on and reacting to each other's posts). In one Discord group, P6 expressed that he had never considered a reduction as a possibility until he talked with P4: "I hadn't even thought of a reduction mammoplasty; I'm already so glad I joined this group because that had never occurred to me but might be something I'd be interested in because of my concerns about sensation. Hmmm, I'm definitely gonna check that out."

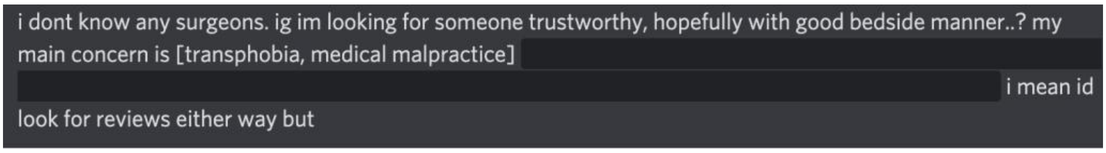
Even within the structure of the focus group, P6 and other participants expressed positive emotions about the benefits they received from participating in the focus groups. P6's participation in the focus group also influenced his decision-making process. P6 remarked, "After the conversation I had with P4, I'm definitely going to look into reduction as an alternate possibility." From his conversations with P5, P6 will think about changing the type of procedure he pursues, which adds another factor into his decision-making process.

Discord and Facebook Affordances That Shaped Research Spaces into Supportive Online Community Environments

Affordances on the two focus group platforms shaped participants' communication with each other throughout the study, primarily in ways that enabled lightweight expressions of support. Discord contains user-applied content (or "spoiler") warnings, while Facebook does not. We saw that the Discord groups intentionally utilized trigger or content warnings and hid potentially triggering content under spoiler tags (which hide the content unless the reader clicks on it) without prompting from us or the other participants. Content warnings help people in online communities care for each other by giving others the choice to not read or view content that may be difficult for them at that time; for instance, a person facing insurmountable barriers to surgery may find it difficult to read about others' successful surgery journeys (Haimson et al. 2020).

Furthermore, the anonymous nature of Discord and the network separation offered by the platform through using separate servers (and usernames and avatars) could have allowed participants to feel more comfortable sharing different, more personal information compared with Facebook. Although we told participants that they could create or use a different account that is not their personal account to participate in the Facebook focus groups, most participants used a profile that could be linked to their identity. Facebook by nature uses participants' full names (and often images of themselves), which were publicly available to other focus group participants.

We see the potential impact of these affordances in how the different focus group members participated in the study. Across all of the focus groups on Discord and Facebook, participants sent 793 messages consisting of 23,960 words. The average length



i dont know any surgeons. ig im looking for someone trustworthy, hopefully with good bedside manner..? my main concern is [transphobia, medical malpractice] [redacted] i mean id look for reviews either way but

Figure 2. A screenshot of a post by P5, which includes a content warning and use of spoiler tags to hide the sensitive content. Focus group participants who choose to read it can click on the black bar to reveal the text.

of messages varied for each group, with the highest being 38 words (a Facebook group) and the lowest being 26 words (a Discord group). Both Discord and Facebook provide ways for participants to support each other through reactions and replies, and these "react" or "like" features were used by participants in all focus groups. One Discord group had the highest number of reactions: 45 in total. The lowest was the other Discord group, with four in total. The Facebook groups had 24 and 19 likes, respectively.

DISCUSSION

Most participants' experiences were likely affected by the current anti-trans political climate, especially in the U.S., where most participants lived. This hostile climate made in-person spaces for gathering knowledge and support increasingly precarious, likely influencing people's use of private online spaces to discuss top surgery decisions. Thus, it is important to explore the role these online communities play as spaces for holding and sharing knowledge and supporting trans care. In the following sections, we draw from and extend previous literature to discuss the relationship between storytelling, sensemaking, and decision-making and examine how online communities support trans care and collective self-care. We offer suggestions for online platforms that wish to encourage trans storytelling and community and provide suggestions for researchers using asynchronous focus groups, pointing out the usefulness of Discord as a research tool.

Implications for Online Communities

Storytelling affects sensemaking and decision-making

Previous research about storytelling found that it is a valuable tool for centering marginalized experiences. We extend this research by focusing specifically on stories told about gender affirming surgery and the ways in which group members receive and process such stories, examining how several of Bruner's narrative features manifest and are challenged in these narratives. The narrative features we focus on are canonicity, breach (often through deconstruction), genres, normativeness, and accrual (Bruner 1991).

In the case of top surgery, there is a canonicity about common cultural stories about pre-transition life, in which trans people were "trapped in the wrong body" and suffer from devastating levels of dysphoria. This canonical story was breached several times during the study; participants acknowledged that this canon was not true of their own stories, challenging the cultural story surrounding top surgery. We identified genre features, noting that different narratives emerged around top surgery for trans men, nonbinary people, and people who are questioning their gender. Normativeness was explicitly acknowledged by several participants who described their experience as differing from the canonical stories about pre-transition life, top surgery, and gender. Accrual, defined as the combination of stories to create a larger shared narrative, is seen both in existing online trans groups and also in the focus groups. For instance, participants who spoke about seeking a reduction versus total removal contributed their individual stories to the group's overall narrative.

These stories and their reception in online top surgery communities help us understand collective sensemaking and show us how experiences that line up with or challenge cultural expectations are treated in these groups. The ways participants used stories in making decisions surrounding top surgery are similar to the use of stories in other decision-making processes, where stories function as information and evidence to make decisions (Metoyer et al. 2020). In this way, the stories told in online top surgery groups facilitated sensemaking among participants. More work is needed, but certain platform affordances could be implemented to help trans people aggregate information and structure their transition-related decision-making processes. To challenge the normativeness and canonicity that exclude certain trans experiences (and to ensure that these non-normative experiences accrue to larger trans stories), platforms should work to include the voices of those who inhabit more marginalized bodies, encouraging them to tell their stories and amplifying their narratives. Platforms must also provide a safe space where community members feel that they can share without fear of judgment. For example, platforms might consider giving incentives to attract content moderators and community leaders who are part of those marginalized communities, as moderation is traditionally a volunteer position. Scheuerman, Branham, and Hamidi's (2018) suggestions to focus on the more "normative, incidental, subtle, and mundane violations" and not simply more obvious and egregious issues should be considered to prevent common intra-community harms. Other platform affordances can encourage safe sharing and connection. Currently, both Discord and Facebook allow direct message functionality, however, this feature is difficult to find for people new to online communities or specific platforms. On Facebook, direct messages from non-Facebook friends go to a separate inbox that is difficult to find, and they often remain unread. It is also difficult to know whether someone is open to direct messages or not; the use of icons or other signifiers can indicate that someone is willing to engage in more personal conversation via private message. Discord offers a useful alternative to direct messaging: it allows moderators to designate certain text channels as private—available only to server members who hold certain role permissions in the server. These private channels can be used to share more sensitive or private stories with a smaller, more intimate group.

Online communities can facilitate trans care and collective self-care

Collective self-care—a form of "therapeutic collectivity"—challenges the notions of sole individual responsibility for health, recognizing that trauma is often experienced at a community level rather than individually (Chudakova 2017; Ortega-Williams 2021). Because suffering came from a social context, its resolution must be in the same context (Ortega-Williams 2021). Collective self-care thus can be a means of coping with systemic violence. Collective self-care is manifested by showing up for oneself and for one's community, supporting each other emotionally and sharing resources and information for survival (Ortega-Williams 2021). This notion of collective self-care is similar to Malatino's trans care (2020), but trans care centers care for others, while collective self-care emphasizes the personal therapeutic benefits of helping others in a community with shared oppressions.

Participating in top-surgery related trans online communities may be a form of self-care, for many participants described that such participation in online communities had helped to improve their mental health and/or gender dysphoria. For instance, P10, who is pre-op, said that viewing top surgery results was a means of comforting himself. Seeing others' results helped him envision what his own might look like, in a way giving him hope for the future. Similarly, P12 stated that seeing others' results gave him gender euphoria and helped him think about how that is in his future. Online groups thus seem to be particularly helpful during gatekeeping or waiting periods during the top surgery–seeking process.

In addition to collective and individual self-care, online trans support communities also provide trans care, which goes beyond the forms of care found in many other communities. This is because trans care is based on a feeling of solidarity and shared experience in the face of marginalization, stigmatization, and limited access to healthcare and traditional mechanisms of support such as family. In what follows, we describe how online communities can provide and facilitate trans care.

First, we saw trans care in the focus groups where participants offered each other support (such as P6 commiserating with P2 about chronic pain), even when they did not previously know each other or live in the same area. Participants also validated each other's non-normative experiences with gender and labels, such as P2, P4, and P5's conversation about the fact that none of them preferred to describe themselves using the word transmasculine. While these interactions were fairly brief, they illustrate how group members supported other trans members through validation and emotional labor. Even group members who did not share many things in common supported each other around conflicts in home life and resource sharing, proved to be means of what Malatino calls "a difficult practice of love across difference in the name of coalition and survival," which does not require sameness across all identity facets (Malatino 2019).

While the support participants received and provided not necessarily life-changing, and it did not change the institutional barriers and systemic challenges trans people face, these support acts in online communities were "guided by a commitment to trans love, small acts that make life more livable in and through difficult circumstances" (Malatino 2019). Online platforms such as Facebook and Discord facilitate such support, even when there is vast geographical distance between group members. Small acts of care or solidarity in online communities (like those seen in our groups via emoji reactions) are a form of trans care praxis that is "simultaneously practical…and ephemerally affirmative" (Malatino 2020).

In addition to trans care, many online communities also facilitate collective self-care. According to Schönbauer (2020), collective self-care is present when a space provides some respite for its participants and allows them to express parts of themselves that cannot be shown to others. In a collective self-care space, participants can shift from being a minority to being a majority, and the space helps members cope with feelings such as loneliness and isolation (Schönbauer 2020). We saw this type of collective self-care in our focus groups. For participants in our study, using content warnings was an unspoken agreement and a way of caring for one another in this online space where members were sharing sensitive and personal information. While supporting online spaces may not materially change participants' problems (Schönbauer 2020), they can help people cope with the stresses of life, transphobia, and lack of community. Spaces for collective self-care can also involve "collective engagement in which accomplishments are shared" (Schönbauer 2020); we saw these forms of collective trans self-care as participants shared stories of secondhand gender euphoria.

Trans Discord Communities as Trans Technologies

Not all social media platforms are viable for trans communities, often because of a lack of a significant trans user base, restrictive content policies, features that are not conducive to privacy, and lack of protection against abuse and harassment. Some platforms have features that make them not only viable but actively helpful for trans communities. Discord is such a platform. In Discord servers that host insular trans online communities, trans moderators can set policies and norms that make the platform very trans-friendly: they can allow people to share trans surgery content, regardless of how "explicit" it is; they can enable privacy protections; and they can protect against transphobic abuse.

While more research is needed to confirm this, and while this alone does not make Discord better than other available technologies, these affordances indicate that Discord online trans communities may be a "trans technology," as defined by Haimson et al. (2021): a technology enabling identity "realness, change, and network separation, along with the queer aspects of multiplicity, fluidity, and ambiguity, necessary for gender transition." Discord has many features that support trans experiences. First, since many Discord servers are invitation-only, they can be designated as spaces for marginalized communities to share their experiences, because the messages posted by server members are visible only to those who are part of the same community. This type of Discord server has the quality of "openness": it is a "safe and comfortable place where people could reveal sensitive information, be understood, and tell secrets" (Haimson et al. 2021). In our focus groups, the Discord groups in particular allowed participants to openly question their identities and reevaluate decisions they were making about top surgery procedures. Discord also facilitated what Haimson et al. (2021) called "network separation." Compared to platforms such as Facebook, which require that participants use their real names, Discord allows members to be anonymous, separating the content they share there from their real-life networks where they are known. The anonymity of Discord thus allowed our participants to push back against normative, prescribed transition narratives (Billingsley 2015). Discord enabled participants to speak to and interact with similar others about their lived experiences related to trans identity—one of the central features of a trans technology (Haimson et al. 2021). But we cannot say that Discord itself is a trans technology, only that particular servers that meet particular conditions may be; the same Discord features that enable trans online communities to thrive also enable hate and transphobic content in other servers (Heslep and Berge 2024).

Of course, many online spaces where trans people gather may meet some of the criteria to be considered a trans technology. However, we argue that for an online community to entirely qualify as a trans technology, it must uniquely enable trans care and support trans narratives (which Discord can at the server level, but not at the platform level). While more research is needed to fully understand the differences between how trans people practice trans care on Discord and on other platforms, in our study, we witnessed trans care much more explicitly in the Discord groups than the Facebook groups.

Discord as a Tool to Facilitate Online Asynchronous Focus Groups

Online spaces are especially important when it comes to facilitating focus groups. Here, we extend prior work on Discord's affordances (Bajpai et al. 2022; Vistisen and Jensen 2021) to show that in addition to being an important platform for community building, Discord is also specifically useful for health communication and storytelling and a useful tool for researchers. The first affordance that makes Discord useful for research is its asynchronous focus group format, which allows more time for participants to think through their answers and digest others' responses than in synchronous in-person focus groups. It is also pragmatically useful for research into topics where there is not a large local population of suitable participants—for example, areas where there is a limited trans population or representation, or where it is dangerous to be openly trans. Online groups can make focus groups possible when in-person focus groups are difficult or impossible to organize.

While using Discord to run focus groups is a fairly new approach, we found that the Discord servers we used in our research enabled participants to build connections and support each other in many ways that we did not see in the Facebook groups, as evidence from the greater number of interactions and reactions in the Discord groups. We found that Discord facilitates a more free-flowing, less-structured format for discussions than Facebook, and this allowed participants to take a more natural, conversational approach. Participants could jump in and respond to more than one person at once and react to others' messages with emoji to show support or reactions. While these activities are also possible on Facebook, the features and "culture" of Discord may have facilitated this more conversational style. Discord participants sent a higher number of messages with a shorter average message length than Facebook participants did. Discord's multiple text channels also offered benefits for focus group research, as they segmented conversations based on topic and tone and supported multiple conversations happening at the same time. This produced more in-depth conversations in the Discord groups than in the Facebook groups.

Discord also helped us as researchers build a better rapport with participants than Facebook. This may be due to the increased anonymity that the Discord server affords. Facebook requires participants to share their first and last names, and their participation is attached to their main Facebook account, which can cause self-presentation problems for trans people (Haimson and Hoffman 2016); in contrast, Discord users generally have anonymous or pseudonymous handles that cannot be used to identify the person associated with the account. This is particularly important for users who need to obscure their identity due to oppression or unsupportive environments.

We also observed that the Discord group members took others' mental health into account by using content warnings and spoiler tags (where Facebook does not have these capabilities). While emoji reactions are possible in both Discord and Facebook, it is likely that Discord's more anonymous, casual nature encouraged the use of these features. Platforms that encourage content warnings are useful for focus groups with sensitive topics, as this allows for a safer environment for participants. One caveat is that just because a focus group is on Discord, it does not necessarily mean that it will have much interaction; it depends upon the focus group composition and on social modeling (for example, of emoji reaction usage). One of our Discord groups had only four emoji reactions during the entire duration of the focus group. Discord can be a powerful tool, but it does not guarantee a high level of interaction; that depends on the participants' existing online habits and on moderator modeling of particular interaction behaviors.

Limitations

We only focused on transmasculine and nonbinary top surgery, so our findings may not be applicable to all types of gender confirming surgery. Because the majority of the participants had not had top surgery at the time of the focus groups, we saw more discussion on pre-surgery decisions than post-surgery decisions, and we were not able to ascertain how much people would continue to participate in support groups after top surgery. We also did not examine the amount of participation in such communities, the number of people who did not choose to participate in such groups, or other topics, such as the role of content moderation in these groups. Furthermore, due to participants' relatively young age range, we were not able to learn about information-seeking habits and narratives of those who obtain top surgery later in life; these habits and narratives may be different for those over 30, as well as those who live in other geographical regions. Finally, while the features for Discord and Facebook are described at the time of data collection and writing, they are constantly changing and may be different in the future. Further, we recognize that all platform affordances should be considered in the context of the platforms' and its owners' politics, which often substantially impact and constrain how marginalized communities use the site.

CONCLUSIONS AND FUTURE WORK

By analyzing data from four online asynchronous focus groups of 21 individuals who sought top surgery or have recovered from top surgery, we have improved our understanding of the forms and roles of storytelling in trans health online communities and have described how online surgery support spaces can facilitate both trans care and collective self-care. From our experience conducting this study, we provide research recommendations for conducting focus groups that are built around shared intersecting identities, and identify the benefits of using Discord, an emerging online platform, in facilitating online asynchronous focus groups. While we were able to provide insights about the dynamics of top surgery support communities, future work should focus on other forms of gender confirmation surgery to determine whether our results extend to other types of trans surgeries and other groups of participants. We focused on decision-making and storytelling in trans online health communities, but we also observed that participants also used these communities as a sensemaking tool; future work should investigate the role of online communities in individual and collective sensemaking in gender transition and health management. Additional work can also investigate the relationship between social media affordances and how support groups function, and on the use of Discord as a focus group tool for research.

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