Transgender Youth Experiences and Perspectives Related to HIV Preventive Services

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abstract

BACKGROUND: In the United States, transgender youth are at especially high risk for HIV infection. Literature regarding HIV prevention strategies for this vulnerable, often-hidden population is scant. Before effective, population-based HIV prevention strategies may be adequately developed, it is necessary to first enhance the contextual understanding of transgender youth HIV risk and experiences with HIV preventive services.

METHODS: Two 3-day, online, asynchronous focus groups were conducted with transgender youth from across the United States to better understand participant HIV risk and experiences with HIV preventive services. Participants were recruited by using online advertisements posted via youth organizations. Qualitative data were analyzed by using content analysis.

RESULTS: A total of 30 transgender youth participated. The average age was 18.6 years, and youth reported a wide range of gender identities (eg, 27% were transgender male, 17% were transgender female, and 27% used ≥1 term) and sexual orientations. Four themes emerged: (1) barriers to self-efficacy in sexual decision-making; (2) safety concerns, fear, and other challenges in forming romantic and/or sexual relationships; (3) need for support and education; and (4) desire for affirmative and culturally competent experiences and interactions (eg, home, school, and health care).

CONCLUSIONS: Youth discussed experiences and perspectives related to their gender identities, sexual health education, and HIV preventive services. Findings should inform intervention development to improve support and/or services, including the following: (1) increasing provider knowledge and skills to provide gender-affirming care, (2) addressing barriers to services (eg, accessibility and affordability as well as stigma and discrimination), and (3) expanding sexual health education to be inclusive of all gender identities, sexual orientations, and definitions of sex and sexual activity.

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WHAT'S KNOWN ON THIS SUBJECT: Transgender youth are at greater risk of HIV infection than their cisgender peers. Numerous social and structural factors contribute to this health disparity, yet limited research has explored youth perspectives and experiences with support and services associated with HIV prevention.

WHAT THIS STUDY ADDS: This study enhances understanding of transgender youth HIV risk and experiences with HIV preventive services. Results will inform development of affirming and youth-driven prevention tools and/or educational resources for adults who provide health care and support services for transgender youth.

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Numerous factors increase transgender youth risk for HIV infection. Transgender youth are more likely than cisgender youth to report first sexual intercourse before age 13 years, intercourse with 4 or more partners, drinking alcohol or using drugs before intercourse, and not using a condom at last intercourse.[1] However, transgender youth are more likely than cisgender youth to have ever received an HIV test, which is an important protective behavior.[1] Transgender females, particularly those who are racial and/or ethnic minorities, are at the greatest risk for HIV acquisition as well as the least likely to receive HIV treatment and preventive services compared with other transgender youth.[2–8] Transgender youth are also known to experience high rates of stigma, family rejection, victimization, and safety concerns at school, increasing their risk for depression, substance use, high-risk sexual behaviors, and HIV.[4,9–11] Additionally, stigma and discrimination experienced from health systems and directly from health care providers decrease the likelihood that youth will engage or remain in care, including sexual health care.[12–15]

Transgender adults' experiences with HIV prevention services vary widely and are dependent on a variety of individual, interpersonal, social, and structural factors.[15,16] It is known that gender-affirming health care settings and provider competency (eg, sensitive communication without making assumptions associated with gender identity or pronouns) facilitate preventive services among adults.[15] However, the developmental and sociocultural needs of transgender youth may indicate that they have different experiences with health systems than their adult counterparts do.[3] Additionally, health care providers report a lack of preparation to care for transgender youth, and many institutions lack policies and routine practices to support transgender youth.[12–14,17,18]

Despite a recent rise in the number of multidisciplinary clinics that provide gender-affirming care, there is no consensus on the best approach to providing that care.[19] Implementation of effective HIV prevention services targeting transgender youth is incomplete, partly because of the complex social and/or structural inequalities faced by the population.[4] This study fills a critical gap in knowledge by providing (1) a contextual understanding of factors that contribute to HIV risk among transgender youth, and (2) insights into transgender youth experiences with HIV preventive services and recommendations to improve those services.

METHODS

Population and Procedures

A purposive sample of transgender youth was recruited via advertisements posted on Facebook and with transgender-serving youth organizations (eg, the Gay, Lesbian, and Straight Education Network, a national education organization for lesbian, gay, bisexual, and transgender [LGBT] issues; and the AGLY Network, an alliance of LGBT youth) for online focus groups. Organizations posted advertisements on Listservs and social media pages. Advertisements were developed with input from a youth community advisory board (YCAB). The YCAB, convened by the research team, met monthly for 2 years and provided a forum for community input into the development of the research project. The YCAB, recruited from local youth organizations and health centers, was comprised of 28 diverse LGBT-identifying youth aged 13 to 18 years (eg, 50% transgender, 7% gender nonconforming, 38% African American, 18% Hispanic, and 7% Hispanic African American). Eligibility criteria for the online focus groups included the following: (1) age 13 to 24 years, (2) identify as transgender or gender identity differs from sex assigned at birth, (3) able to understand and/or read English, and (4) have access to a computer and/or Internet during the study dates and times. Protocols were approved by the Fenway Health Institutional Review Board. Participants were remunerated $30.

Interested youth completed an online eligibility screener and electronic informed assent or consent. Parental permission was waived for youth <18 years of age. Participants were invited to 1 of 2 3-day continuous, asynchronous, online focus groups. The online asynchronous methodology was selected because of its convenience and flexibility in time of day when youth can engage in the discussion and ease of use among a population that has fully integrated technology into their lives, thus reducing barriers to participation and increasing geographic diversity in a cost-effective manner.[20] The 2 groups were divided by age: younger participants (13–17 years old) in 1 group and older participants (18–24 years old) in another. Reminders were sent via phone, e-mail, and/or text message. Participants were assigned a pseudonym and given instructions on attending their assigned group (date, time, and login information) as well as how to use the platform. Participants were asked to engage in the online discussion at least 2 times per day, answer all of the posted questions, and engage with each other by responding to each other's posts. Questions were posted each morning, and as youth responded to the questions, additional probing questions were added throughout the day. Youth could join in the discussion from different time zones before or after school and other activities at their convenience.

The focus groups were conducted in March 2018 and April 2018, and

InsideHeads (the owner and operator of the online platform) provided technical support. One investigator led the discussions, and 3 investigators observed throughout the day, taking field notes and suggesting additional probing questions. Demographic data were collected online by using Qualtrics.

Measures

Demographic data included age, sex assigned at birth, gender identity, sex of sexual partners (if sexually active), sexual attraction, sexual orientation, race, and ethnicity. Sexual orientation and gender identity response options were offered to participants by using established best practices of sexual orientation and gender identity data collection[21] and were ultimately determined by participant self-report. Sexually active was defined as having had oral, vaginal or frontal, or anal sex. Our discussion guide, which was informed by leading experts in the field and available literature, was developed to uncover how gender identity contributes to or intersects with HIV risk and HIV prevention; we explored the following: (1) identity formation and social support, (2) forming romantic and/or sexual relationships, (3) sexual education, and (4) knowledge and/or attitudes related to HIV prevention and experiences with HIV preventive services (Table 1). We sought to understand how youth communicated with family, friends, romantic and/or sexual partners, and health care providers about sexual activity. We asked about where they obtained sexual health information, their views on sexual health education, and their experiences with accessing or obtaining HIV preventive services.

Analysis

Transcript data were downloaded from the online platform and managed by using NVivo 11 (QSR International). Content analysis was used to objectively engage the data and identify thematic patterns.[22,23] Three investigators (H.B.F., T.W., and S.G.) conducted preliminary coding and developed a topical codebook. Two investigators (T.W. and S.G.) continued coding the complete data set and routinely met to review codes, definitions, and concepts to ensure accuracy across coders. Then, the entire analysis team (H.B.F., T.W., S.G., S.R.C., and B.P.W.) reviewed coded data, examined relationships, and combined codes into broader categories and themes. Ongoing discussion and reexamination led to the development of final themes. Descriptive analysis of demographic data included means for continuous variables and percentages for nominal data.

RESULTS

Demographics

A total of 30 transgender youth participated (Table 2): 11 13- to 18-year-olds and 19 18- to 24-year-olds. The average age was 18.6 years. The racial and/or ethnic demographics were 70% white, 7% African American, 3% Asian American, 17% multiracial, and 3% other; 10% identified as Hispanic. Participants were given multiple options for how to self-identify their gender by using recommended terms. Reported identities were 27% transgender male, 17% transgender female, 10% transgender, 10% genderqueer, and 7% male; 27% used ≥1 term, and 3% identified as unsure. The majority reported being assigned female sex at birth (80%) and being sexually active (70%). Youth reported a wide range of sexual orientations. There was representation from all geographic regions of the United States, with about half of the respondents residing in the Northeast.

Youth were active participants in the online discussions. Including additional probing questions from the research team, a total of 55 questions were asked, and the mean response rate was 54.7 responses. Plus, youth averaged an additional 7 responses from comments from other participants. It was evident that youth spent meaningful amounts of time articulating their responses because typed words per question or probe ranged appropriately, depending on the type of question, from 1 to 400 words and averaged 31 words. Level of engagement did not differ on the basis of participant age or which group they attended.

Qualitative Analysis

Four common themes emerged: (1) barriers to self-efficacy in sexual decision-making; (2) safety concerns, fear, and other challenges in forming romantic and/or sexual relationships; (3) need for support and education; and (4) desire for affirmative and culturally competent experiences and interactions. Themes were consistent across individuals and age groups. Themes and exemplar quotes are detailed in Table 3.

Barriers to Self-Efficacy in Sexual Decision-making

Participants expressed a need for services to help them build communication skills for sexual consent. The majority described communication with their romantic and/or sexual partner as challenging. Several had difficulty with self-advocacy, particularly when negotiating sexual preferences with cisgender partners. When discussing condom use and safer behaviors, one participant shared, "I almost never ask for things because of what I think is internal pressure to be grateful. In my head, I'm like, 'They're already willing to have sex with me; I shouldn't push my luck,' which is terrible, but as a result, I ask for as few things as possible."

Participants' primary reason for delaying or avoiding sex was dissatisfaction with their body. Youth mentioned feelings of self-hate, feeling uncomfortable with their

TABLE 1 Example Questions From a Semistructured Script

Topic Theme	Sample Questions
Forming romantic and/or sexual relationships	Who do you talk to about your crushes? What do you talk about? Who can you ask for advice about dating guys?
	Does the relationship advice that you get support your gender identity (meaning, support you as a transgender youth and respect your gender identity)?
Sexual education	If your parent or guardian had a conversation about sex with you, what did they say? What was helpful about it? What could have been better?
	Imagine that you have been given the opportunity to develop a sex education class for high school students. What information should be covered? Who should teach it? How?
	Tell us about a time when you had a conversation about sex with your doctor or nurse. What do you talk about? What was helpful about it? What could have been better?
	Sometimes, we learn about sex from people and places other than parents or guardians, at school, or from doctors or nurses. These other sources include online, TV and movies, pornography, friends, sexual partners, and church. Have you learned about sex from any of these sources? If so, which were helpful? Why? What did you like about them? What could have been better?
	Tell us about a time when the health care you got supported your gender identity (by supported, I mean made you feel comfortable and cared for by someone who is knowledgeable about transgender health).
HIV prevention	What do you think about using condoms and lubrication every time for anal sex and vaginal or frontal sex?
	How realistic is it to get PrEP from a doctor and take it every day? What would make it hard to do this? What would make it easier to do this?
	How realistic is it to take medication every day if you have HIV?
	Does being transgender affect your ability to ask for what you want from a sexual partner? How and why?
Identity formation and social support	What support do you get related to your sexuality? What is most helpful?
	What support would you like?
	What support do you get related to your race and/or ethnicity? What is most helpful? What support would you like?
	Where do you get support for being transgender? What is most helpful? What support would you like?

body, and needing to be in the "right headspace" to engage sexually. Participants noted that sex requires more communication when experiencing gender dysphoria, and inability to negotiate safe behaviors might lead to feeling "abused or taken advantage of." Participants reported seeking other transgender partners who could relate to their experiences.

Participants viewed access to care, including access to condoms and lubricant, as more difficult for transgender youth. Insightfully, one noted that transgender youth are "more likely to be homeless, impoverished, mentally ill," and these structural issues would be barriers to care and resources.

Safety Concerns, Fear, and Other Challenges in Forming Romantic and/or Sexual Relationships

Participants voiced concerns related to fear and safety in forming romantic and/or sexual partnerships. Several recalled harassment and perceived discrimination on social media and dating applications (apps). One described, "On [this dating app], while some gay men will ignore transgender people, many of them have been blatantly transphobic to me by sending threatening messages, slurs, and telling me to leave the app." Others described being ignored or told they "aren't gay" and "should not use the app." Challenges related to being fetishized or threatened by prospective cisgender partners were also discussed. Participants wanted others to understand that dating as a transgender person is "scary as hell."

Participants did not relate to narrow heteronormative definitions of sex taught by health care providers, parents, and schools "because they don't apply to LGBT people." Youth described experiences with cisgender persons (both partners and/or providers) who believed that sex must include penetration. This disconnect exacerbated the existing barriers to effective communication with peers and providers about sex.

The participants' definitions of sex were fluid and broad because "every couple is going to have a different balance of what they're comfortable with and what they're, like, physically capable of doing, so sex is going to mean a different thing for basically any encounter." Youth wanted sex definitions to be inclusive of transgender identities and broad ranges of sexual behaviors. This undefined nature of sex led to difficulties in dating cisgender people who did not relate to the experience of being transgender.

A Need for Support and Education

Youth wanted comprehensive sexual health education with "gender-neutral language, representation of different types of relationships, and information/statistics on LGBT health" facilitated by an adult who is able to foster "open, honest discussion, someone who's willing to acknowledge the silliness of the topic

TABLE 2 Demographic Characteristics (N = 30)

	Focus Group 1 (13–17 y Old; N = 11)	Focus Group 2 (18–24 y Old; N = 19)
Age, y, mean (SD)	15.5 (1.7)	20.4 (2.2)
Race and/or ethnicity, *n* (%)		
White	8 (72.7)	12 (63.2)
African American	0	2 (10.5)
Asian American	1 (9.1)	0
Hispanic	1 (9.1)	1 (5.3)
Multiracial	1 (9.1)	4 (21.1)
Gender identity, *n* (%)		
Transgender male	4 (36.4)	4 (21.1)
Transgender female	3 (27.3)	1 (5.3)
Transgender	0	3 (15.8)
Genderqueer	1 (9.1)	2 (10.5)
Male	2 (18.2)	0
Female	0	1 (5.3)
>1 identity	1 (9.1)	7 (36.8)
Unsure	0	1 (5.3)
Assigned sex at birth, *n* (%)		
Male	3 (27.3)	3 (15.8)
Female	8 (72.7)	16 (84.2)
Sexual orientation, *n* (%)		
Gay or lesbian	2 (18.2)	2 (10.5)
Bisexual	1 (9.1)	7 (36.8)
Queer	7 (63.6)	9 (47.4)
Heterosexual	1 (9.1)	1 (5.3)
Sexually active with, *n* (%)		
Males	1 (9.1)	1 (5.3)
Females	4 (36.4)	4 (21.1)
Males and females	2 (18.2)	6 (31.6)
Not sexually active	4 (36.4)	5 (26.3)
No response	0	3 (15.8)
US region, *n* (%)		
Northeast	5 (45.4)	10 (52.6)
Southeast	0 (0.0)	3 (15.8)
Midwest	2 (18.2)	0
Southwest	1 (9.1)	1 (5.3)
West	1 (9.1)	4 (21.1)
No response	2 (18.2)	1 (5.3)

without invalidating how important the information is." Participants frequently asserted that sexual assault and consent should be a part of curricula.

Participants wanted social support for their sexual, gender, and racial and/or ethnic identities. Some mentioned support from school but identified the need for "more representation and education for LGBT identities in school and media," and they "would like more people to have conversations with them about sexuality while being nonbinary." Those who also identified as a member of a racial and/or ethnic minority expressed a need for support associated with multiple minority statuses and intersectional identities. One found support from other "black, genderqueer, nonbinary people" and recognized how critical it is to have role models in their own identity formation.

Desire for Affirmative and Culturally Competent Experiences and Interactions

Participants frequently discussed the need for affirmation and cultural competency in 4 contexts: (1) HIV prevention services, (2) interactions with health care providers, (3) interactions with parents and/or other adults, and (4) accessing information online.

HIV Prevention Services

Participants had variable levels of HIV prevention techniques, including condoms and/or lubricant, finding nonpenetrative ways to be intimate, HIV testing, HIV preexposure prophylaxis (PrEP), and effective communication with partners. Primary barriers to services were accessibility and affordability and a fear of exposing their sexual activity, gender identity, and/or sexual orientation to parents. Participants noted difficulty in delaying sex and/or engaging in low-risk behaviors with potential partners, especially cisgender men, because they viewed penetration as a sexual requisite. Many described difficulty in communicating with and negotiating sexual acts with partners. One mentioned learning about nonpenetrative forms of sex primarily from LGBT community spaces.

Participants reported a general understanding of the importance of HIV testing. The youth described facilitators of HIV testing as learning how to ask their partners to obtain an HIV test, having a free clinic nearby that is open late (after school), and viewing HIV testing messages at community events, such as LGBT Pride. Barriers included cost, accessibility, and fear of others learning of their sexual behaviors. One suggested that advertisements for testing should be in locations frequented by the people at greatest risk, with an online emphasis. Many participants were aware of PrEP; however, one described a health care provider dissuading PrEP use because they "would not like the side effects."

Interactions With Health Care Providers

Youth emphasized the need for gender-affirming care. Important aspects of gender-affirming care included inclusive intake forms (section for gender identity) and providers who were open and assessed their unique care needs.

TABLE 3 Illustrative Quotations

Themes and Illustrative Quotations
Barriers to self-efficacy in sexual decision-making
"Being transgender affects my ability to ask for what I want from cisgender sexual partners. I am significantly more comfortable sleeping with other trans-masculine people than cis men because (a) they understand my anatomy better, and (b) they understand dysphoria and hard boundaries. If I ask a cis sex partner for them to perform oral sex on me and tell them that I am uninterested in penetrative sex, then (at least a couple times) they decide they don't want to have sex with me at all." G2, transgender, genderqueer and nonconforming, Northeast
"Dysphoria caused me to not even think about sex for years. It made me feel terrible because I wasn't like other men my age. Having sex with a trans person means you have to take dysphoria into account and avoid certain words or touching certain areas. It amplifies the amount of communication you have to have with a partner. For me, my dysphoria also makes my sex life less active because I have days where I just can't interact with my own body or stand for someone else to." G1, transgender male, Southwest
"My friends help hold me accountable…encouraging me to take space and enforce my boundaries when necessary because just because I'm trans and masculine presenting doesn't mean that I don't get to be vocal about my needs (because I've also been socialized as a black AFAB [assigned female at birth] person) to not take up space and that my needs are not a priority." G2, genderqueer and nonconforming, Northeast
"Dysphoria, it makes me feel uncomfortable, it doesn't feel right; if I am not in the mood or in the right headspace, I feel abused or taken advantage of." G1, transgender male, Southwest
"…[to be told or educated] that it's okay to ask to stop if sex is uncomfortable even if it's just dysphoria would have been so nice." G2, transgender male, location not identified
"I also know that, statistically speaking, people of color and trans people more often have trouble getting their partners to wear protection. I am not a part of that statistic. If someone is pressuring me or disrespecting my needs, I let them know. If it goes too far, we're done. The only thing that may make it difficult to ask for what I want is if I've gotten into the habit of giving and not receiving." G1, transgender, genderqueer and nonconforming, Northeast
"I already can't ask for what I want, so I would do whatever my partner wanted and deal with the consequences later. …I feel scared to ask for a condom mostly because of fear of judgment from others that I might be a person who has sex a lot, and I can't ask for what I want mainly because of how I grew up." G2, transgender, Northeast
"I don't have experience having sex with cis men, but I wouldn't know how to communicate the best ways to alleviate dysphoria while having sex. It's much easier to communicate with other trans people." G1, transgender male, Southwest
Safety concerns, fear, and other challenges in forming romantic and/or sexual relationships
"A lot of cis boys treat me like garbage." G2, transgender male, genderqueer and nonconforming, Northeast
"Being trans does come up because dating cis boys is scary when you don't know if they're accepting or not or if they're just using you for some fetish or something." G2, transgender male, genderqueer and nonconforming, Northeast
"One person I talked to one time told me that I couldn't call myself 'gay' if I was trans and attracted to guys, so I don't like to talk about it with that group of people anymore." G2, transgender, genderqueer and nonconforming, Midwest
"Online dating has always scared me. I'm in constant fear of being used as someone's fetish rather than seen as a competent human being." G2, transgender female, West
"I've had partners, too, that only dated me because I'm trans; I had a girlfriend that would call herself a lesbian while we were dating even though I had just come out as trans because she couldn't be with a boy, but a trans boy, oh man, that was arm candy for her and made her feel like she was doing such a service for the world." G2, transgender male, genderqueer and nonconforming, Northeast
"I don't fit into a gender binary, so I feel like my dating pool is limited to bisexual guys, especially because [I've] encountered a lot of guys on apps like Grindr that are transphobic or at least not open minded about it. From conversations I've had with transgender or gender nonconforming friends who date women, it seems like women are more open minded about dating trans people than men (not sure if this is true, but it's what I have gathered)." G2, transgender, genderqueer and nonconforming, Northeast
"I really don't know what counts as sex because I feel like the traditional definition (penetrative, penis in vagina) is very heteronormative because it doesn't apply to LGBT people often, and some LGBT people (or straight cis people) don't prefer that kind of sex. Maybe a better way to define it could be 'sexual acts that can lead to orgasm,' but that might be too broad because some people can get an orgasm from exercising or other nonsexual activities." G2, transgender, genderqueer and nonconforming, Northeast
"Cis guys think that sex equals penetration, and it's difficult for them to see anything else as actual sex. I feel like they consider other forms of sex just foreplay. …I'd have to change a cis guy's mind about what he thought of as the only way to have actual sex for his entire life, and that would be really difficult." G2, transgender, Northeast
"[Finding other ways to be intimate] is realistic, but trans youth might not realize that those possibilities exist because most sex education focuses on penetrative sex. I had to discover other ways to be intimate from other partners and workshops at community spaces." G2, genderqueer and nonconforming, Northeast
A need for support and education
"I think they should explain that people with vaginas on testosterone that don't get their period can still get pregnant, and people with penises on estrogen can potentially still impregnate others. I feel like that's a big misunderstanding among trans people, at least in my experience." G2, transgender, Northeast
"I think having more representation and education for LGBT identities in school and media would be a very strong support system. It would educate cis/straight people about who I am and lessen the amount of misinformation." G1, transgender male, Southwest
"I don't really get any support, but I would like support in knowing that it's okay to question who you want to have sex with and it's okay to explore your body in a way that makes you feel good." G2, transgender, Northeast
"Many of my friends are cis, and they just don't get it…[people and friends] should stop treating me like a young boy instead of a genderqueer person." G2, transgender, genderqueer and nonconforming, Northeast
"Any advice I get is cis and heteronormative." G1, transgender, genderqueer and nonconforming, Northeast
"Oh gosh, I guess there's nobody in my life that I can come to for that advice. Maybe this one person I know who is AMAB [assigned male at birth] but has had experiences on all sides of the street." G2, transgender, genderqueer and nonconforming, not sure, West

TABLE 3 Continued

Themes and Illustrative Quotations
"Sex ed in school is a joke. We learn about how abstinence is the only contraception and p-in-v [penis in vagina] is the only form of sex and how sex should be for nothing more than reproduction. …It should teach more about other forms of sex and how it can be for so much more than making a child and how gay people exist and, yes, even how gay people have sex and how to prevent STDs, omg, they just tell us why they're horrible to get us to not have sex." G2, transgender male, genderqueer and nonconforming, Northeast
"No [sexual education through the school but through friends at school]. I wish they had a formal sex [education] class at my school." G1, transgender male, Northeast
"We learned an abstinence-based curriculum. We were also taught that gay relationships are at higher risk for STDs, and transgender issues were never brought up. I'd like to a see a more inclusive health curriculum in all schools that doesn't just teach abstinence and discusses gay and trans people positively. …I'd really just like classes to emphasize the difference between healthy sexual relationships and unhealthy ones, define consent, talk about how to handle abusive sexual relationships, etc." G1, male, Northeast
"[I wish I learned about] what is and is not consent, what sex can look like, healthy and appropriate ways to bring up sex with a partner, different sexualities, what they mean." G2, transgender, genderqueer and nonconforming, not sure, West
Desire for affirmative and culturally competent experiences and interactions
HIV prevention services
"I get support from my university's LGBT center, and they have really helpful information about STIs and free testing. I would like more people to have conversations about sexuality while being nonbinary." G2, transgender, genderqueer and nonconforming, Northeast
"I will probably never go to get tested for STDs because I'd be scared that someone would find out. But I think if you have a good support network and good insurance, it's definitely better to get tested just to be safe." G1, male, Northeast
"I'm not sure how much funding there would be for advertising, but finding the places online that people who are at higher risk of HIV frequent and placing ads there about what the options are would make a difference. No one teaches anything about any of this." G2, transgender male, Southwest
"Getting tested is difficult because most free clinics are during work/school hours. If there were evening or weekend hours, it would be much easier." G2, genderqueer and nonconforming, not sure, Northeast
"Three years ago, a former provider of mine dissuaded me from using PrEP under the pretense that they didn't yet know how it worked in trans men and that I 'wouldn't like the side effects.'" G2, transgender male, Northeast
"I have no idea how to go about getting [PrEP]. I haven't even heard of the medication." G2, transgender female, West
Interactions with health care providers
"I get support from my doctor, support groups, and online. The thing that is most helpful is mostly just being called by the right name and pronouns. The support that I would like is that even though I may have a different trans experience than most (I didn't know at the age of 5), my transness is still valid." G2, transgender, Northeast
"At my first appointment with a new doctor's office last year, I noticed the intake form had a section for gender identity that included more than 2 binary options, a write-in section for pronouns, and a section for sexuality. It was a relief to not have to find a way to bring it up; the doctor just immediately went with what I put down and even offered me services from the trans health program without me having to ask." G2, transgender, Northeast
"There are trans and genderqueer people featured on their brochures and pamphlets. The questions my doctor asked on the intake weren't invasive and focused on my emotional health and my support system. …When she asks about sexual behavior, rather than asking 'when was the last time you had sex with a man or penetrative sex,' she'll ask, 'Are you having any sex that could result in pregnancy?'" G2, genderqueer and nonconforming, Northeast
"Talking about sex with my PCP [primary care provider] is difficult. He is super supportive of me, but he's not that knowledgeable when it comes to trans issues. …We mostly just talk about being safe and consensual, whomever the partner. It would help if he were just a little more educated." G2, transgender female, Northeast
"On a teen survey during a general checkup, there was a question that was, 'Have you ever felt LGBT or identified as such,' which, first of all, is such a poorly worded question. Nevertheless, I checked yes. When asked about it by the doctor, she asked if I liked girls. I said, 'No, I like boys.' She said, 'You are not LGBT.' I explained to her that I am trans, and I like boys, and she completely disregarded me and moved on, later telling me that I need to find God to really understand myself." G2, transgender male, genderqueer and nonconforming, Northeast
"It's hard because of socioeconomic status, biased/bigoted medical professionals, and discomfort with getting medical help." G2, transgender male, Southwest
"I had a doctor when I lived in Ohio when I came out [who] would always refer to me as the updated name and pronouns I was using at the time. He also made sure all the nurses were on board as well. It was really great. Unfortunately, I have yet to experience a doctor like this since." G2, genderqueer and nonconforming, not sure, Northeast
"When I went to the doctor I've had since I was a kid, I noticed they had recently added an option for gender as well as sex that included trans identities. It was definitely a positive surprise. …Even though they had the option for my identity, the wrong pronouns were still used throughout my appointment. It was slightly frustrating after I had gotten my hopes up, but it was understandable." G1, transgender male, Southwest
"There was only one time that a doctor tried to have this conversation, and when I told them I had a health class they were, like, "Oh, thank god," and moved on." G1, transgender female, West
"My gender identity has never come up during a checkup. … I've never talked about sex with a doctor." G1, male, Northeast
Interactions with parents and/or other adults
"My parents have never spoken to me about sex." G2, transgender, genderqueer and nonconforming, West
"When I talk about men, my mother invalidates me by asking if they are gay. Most adults I talk to don't understand where I come from. My friends and peers give me good advice about boys, but normally, it is just from the perspective that I am a female." G1, transgender female, West
"In an ideal conversation with my mother, she would accept my identity, and with that born in mind, she would be more worried about what I decide to let someone do rather than basing every scenario off of one where I am making a decision to do something. She doesn't want me to be intimate with a person just because we both want to, but I feel like the best conversation we could have would be one where we talked about when the time was right and what you would say." G1, transgender female, West

TABLE 3 Continued

Themes and Illustrative Quotations
"I get support from my friends and family I still talk to. Validation is the best tool for me. Being referred to utilizing female terms is honestly my favorite. I'd like more support from my parents, but religion tends to make things more difficult" G2, transgender female, West
"…teens are concerned about having condoms that their guardians can find. And guardians finding condoms can lead to an angry discussion about sex and why said child shouldn't be having sex." G2, transgender female, West
"It just feels like even though people [adults] support me in my gender, they don't understand dysphoria at all or how big an impact it has on my life, and I wish people understood that better." G2, transgender male, location not identified
"Any advice I get [from adults] is cis and heteronormative." G1, transgender, genderqueer and nonconforming, Northeast
"My mom hasn't had a conversation about sex with me since I was just going into puberty, so it wasn't very helpful. …[An] ideal conversation would just be the parent making them [the child] aware of safe sex while still respecting their gender identity. Talking about dysphoria and accepting yourself are very important topics in a transgender person's sex life." G1, transgender male, Southwest
"Most of the reason I wasn't out was because she refused to acknowledge my identity until I forced the subject at the age of 20. If I tried to bring up transitioning as a teenager, she would say something like, 'I don't want you doing that to your body,' and then act like I never said anything. Eventually, I became convinced that no one would take me seriously as a human being if I transitioned." G2, transgender male, West
Accessing information online
"Most of the support I've received from other black, genderqueer, nonbinary people has been online and organizing intentional ways to meet up with each other (ie, via FaceTime, Google Hangouts, or traveling to the same conferences)." G2, genderqueer and nonconforming, Northeast
"Many reputable sites providing sex education have been slandered as 'promoting' teenage sex and thus may be perceived as biased, untrustworthy, or predatory. Which is to say, the Internet is a good resource, but you cannot tell someone to use it because there is a large chance the information they find will be subpar or worse." G2, transgender male, West
"I have a handful of friends on Tumblr that I talk to. It's easier to talk to people online because then people from school can't eavesdrop and spread rumors or target me." G1, transgender male, Midwest
"Interestingly, the best 'advice' I've gotten is sex ed from Internet sources/posters because they don't usually target a specific gender or relationship dynamic." G1, transgender male, location not identified
"Before I started going to Planned Parenthood, I got pretty much all my sexual health [information] online, honestly, mostly from articles like the ones *Teen Vogue* posts because those get fairly popular and from trans blogs on Tumblr; even if I'm not confident in the [information], I'm not necessarily hearing otherwise from anywhere else." G2, transgender male, location not identified
"I've learned everything positive I know about sex from my partners and online sources like forums. I like forums best because it's other people talking about their own experiences rather than a professional talking out of a book. I learned a lot of harmful misinformation about sex in school and church that I had to unlearn once I started to figure out what worked for me." G1, male, Northeast

Quotes were identified by focus group, gender identity, and region in the United States. G1 included 13- to 17-y-olds; G2 included 18- to 24-y-olds. cis, cisgender; G1, Group 1; G2, Group 2; omg, oh my god; STD, sexually transmitted disease; teen, teenager.

Participants wanted pamphlets and/or brochures with transgender representation and the use of sensitive and/or inclusive sexual health assessment questions.

Participants experienced negative and dismissive interactions with providers. Additionally, structural and/or institutional barriers hindered seeking care, including feelings of marginalization and lack of LGBT and cultural competence. One participant described a provider who did not "get the difference between gender and sexual orientation." Another described a provider who stated that sex "isn't really sex if you're both girls, is it?" These experiences, participants felt, devalued their gender identities and definitions of sex. Most reported fear of encounters with disrespectful and uninformed providers and wanted "doctors [who] will be helpful and respectful."

Interactions With Parents and/or Other Adults

Youth verbalized a desire to feel affirmed by adult caregivers. One wished to hear from their parent, "I see and affirm that this is who you are and am grateful that we have this level of trust that you're sharing this information with me. I am happy that you feel free to live life as your truest self. Please tell me more about your identity so I can understand it better. I'm gonna do some research as well so we can have clearer, better conversations about this. And most importantly, I love you."

Participants identified a relationship between their parents' level of support of their sexuality, gender identity, and/or sexual activity and the likelihood that they would receive appropriate sexual health information. Some were fearful that parents would find condoms, which would lead to an angry conversation about sex. Youth wanted parents to be open to discussing romantic relationships in a way that was not cisgender normative and heteronormative, but most reported experiences with "no room for the use of [transgender-friendly terms, such as] partner, significant other." Other adult role models, such as a therapist or a transgender adult, were important. One participant asked their transgender role model "questions about hormones and [sexual health] things before [they] turn to [their] doctor."

Accessing Information Online

Participants routinely accessed educational resources and social support online. However, one participant noted, "Many teens aren't equipped to determine which sources are reputable and which ones aren't."

Another mentioned, "porn [pornography] was [their] biggest teacher," and others agreed. Positively, one participant emphasized, "Community [transgender online community] has been essential to me becoming who I am and who I am becoming."

DISCUSSION

This study highlights multiple approaches to improving transgender youth experiences with HIV prevention, including (1) providing transgender health education for providers to increase knowledge and skills in providing affirming care; (2) addressing barriers to services, such as lack of accessibility, stigma, and discrimination; and (3) expanding sexual health education to be inclusive of all gender identities, sexual orientations, and definitions of sex. Building partnerships between health care institutions and community organizations, including schools, is an important strategy to address youth desire for increased HIV prevention education, access to services, and creative ways to promote mentorship (role modeling).

Educational programs for providers and/or professionals who support transgender youth are needed. Programs should include education on health disparities, stigma and/or discrimination, and how microaggressions and macroaggressions (interpersonal and system level, respectively) affect health outcomes and health-seeking behaviors.[15,24–27] Programs should provide education on language and definitions used by sexual and gender minorities and ways to engage youth and ask questions about sex and sexual partners that are affirming. Lastly, programs should include sexually transmitted infection (STI) and HIV prevention strategies, including discussion of safer sexual behaviors, negotiation and consent, sexual and physical assault, condoms, lubrication, STI and HIV testing, human papillomavirus vaccination, and PrEP. The Food and Drug Administration approved PrEP use by adolescents at high risk for HIV in 2018.[28] However, participants noted that many providers did not know about PrEP and/or were unwilling to prescribe PrEP. Instead, participants reported learning about PrEP, as well as other HIV prevention strategies, from community spaces, dating apps, and pornography.

Many of this study's findings are consistent with what is known about transgender adults. However, our results also offer insight into the unique role that parents, teachers, and school nurses have in the HIV prevention experiences of youth. Participants voiced the need for their parents and/or guardians to obtain skills and competence in providing affirmation and support. Providers, including school nurses, who have developed transgender competency can work with community partners to develop educational resource lists for youth and their parents and/or guardians. Similar to other reports,[24,29] this study highlighted a need for sexual health education to be inclusive of sexual and gender minorities. Participants described how the lack of inclusive education affected their ability to negotiate safer sexual behaviors with partners and communicate effectively with providers.

Creative, transgender-affirming ways to increase youth comfort, access, and knowledge about STI- and HIV preventive resources (including HIV testing) identified in this study include advertisements for services (including youth-friendly clinic operating hours and transportation options) at community events (eg, Pride Week) and online (eg, Facebook pages, social media apps, or dating apps). These efforts could increase access for youth who are unaware of services and/or not seeking services because of negative past experiences. Similarly, Steinke et al's[24] qualitative report on perspectives of sexual education among sexual and gender minority youth also supports the development of digital ways to provide sexual health education that foster positive identity development, a sense of community and/or belonging, and appeal to diverse sexual, gender, and other intersecting identities held by youth.

Participants discussed important concerns associated with safety and low self-advocacy in dating, communication, and engaging in sexual activities, which increased their HIV risk. Other investigators have documented high rates of victimization (forced sex and physical dating violence)[1] as well as stigmatization and concerns for safety (in person and online) among transgender youth.[24] Education and resources related to safety, dating violence, sexual consent, and negotiation and advocacy skills for safer sexual behaviors, including condom use, are needed. Feeling unsafe and not being able to articulate sexual health needs are major barriers to HIV prevention.

Our study yielded rich data, providing valuable insight into transgender youth experiences. Over 3 days, we recruited and retained a national sample of understudied adolescents in a youth-friendly and effective manner. The convenience (ability to login and engage in online, asynchronous discussions at times that are convenient for youth and nondependent on time zones and school schedules, which are barriers with synchronous discussions) and privacy of online discussions facilitated participation. Participants were aware that the study was being conducted by researchers affiliated with Fenway Health, which is a known sexual- and gender-minority–friendly health center. This possibly could have an effect on youth

willingness to participate and share openly, although we think many youth outside of Boston would not be familiar with Fenway Health.

Limitations included a necessity for computer and/or Internet access and exclusion of non–English-speaking youth (eg, Hispanic and Latino). Participants were predominantly white, non-Hispanic, and assigned female sex at birth. Recruiting youth of greater racial and/or ethnic diversity and youth assigned male sex at birth (a priority population for HIV prevention) remained challenging. Insights, specifically from adolescent transgender females of color, may differ from our findings. Future recruitment strategies would benefit from prolonged development of trusting relationships with transgender youth–serving organizations and key peer influencers (specifically transgender females and youth of color) as well as additional youth input for online advertisements and/or recruitment.[30] Lastly, we believe greater financial remuneration or small transgender-female–specific gifts (eg, makeup from transgender-popular brands) would increase participation and, potentially, diversity of participants.[30]

CONCLUSIONS

It is important to elicit transgender youth experiences and perspectives related to HIV risk and preventive services. This study provided a greater understanding of barriers to and facilitators of youth obtaining HIV preventive services and sexual health education. Results will inform the development and testing of affirming, culturally competent, and youth-driven HIV prevention tools and educational resources for adults who provide health care and support services. Tools should include basic transgender education for providers and other youth-serving professionals; address barriers, including stigma and discrimination, to transgender youth access to services; and expand sexual health education to cover consent for sexual activity, physical and emotional safety, and self-advocacy and to be inclusive of all gender identities and sexual orientations.

ABBREVIATIONS

app: application
LGBT: lesbian, gay, bisexual, and transgender
PrEP: preexposure prophylaxis
STI: sexually transmitted infection
YCAB: youth community advisory board

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