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“We deserve care and we deserve competent care”: Qualitative perspectives on health care from transgender youth in the Southeast United States

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Abstract

Purpose.—Transgender populations experience health inequities that underscore the importance of ensuring access to high quality care. We thematically summarize the health care experiences of transgender youth living in the southeast United States to identify potential barriers and facilitators to health care.

Design and Methods.—Transgender youth recruited from community settings in an urban area of the southeast United States participated in individual interviews ($n = 33$) and focus groups ($n = 9$) about protective factors. We conducted a thematic analysis of data from 42 participants who described their experiences seeking and receiving health care.

Results.—Participants reported a wide range of gender identities. The individual interview sample was majority Black (54.5%) and the mean age was 21.7 years and focus group participants were all white and the mean age was 16.8 years. Participants described numerous barriers to health care, including limited availability of gender affirming care, logistical challenges, such as gatekeeping and cost, concerns about confidentiality in relation to sexual behavior and gender identity, and inadequate cultural competency among providers regarding gender-affirming care. Facilitators included intake procedures collecting chosen pronouns and names and consistent use of them by providers, and open communication, including active listening.

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Conclusions.—Findings underscore the need for a multi-component approach to ensure both transgender- *and* youth-friendly care.

Practice implications: Providers and office staff may benefit from transgender cultural competency trainings. In addition, clinic protocols relating to confidentiality and chosen name and pronoun use may help facilitate access to and receipt of quality care.

Keywords

transgender; youth; health care; barriers

Introduction

Recent estimates suggest that approximately 2% of United States (US) high school students identify as transgender (Johns et al., 2019). *Transgender* is an umbrella term referring to individuals whose gender identity differs from their sex assigned at birth. Due in part to the downstream effects of stigma (Meyer & Frost, 2013; Testa et al., 2015), transgender youth are more likely to engage in health risk behaviors, including substance use and sexual risk behaviors, and are more likely to experience a spectrum of adverse health outcomes, including depression, anxiety, and violence victimization, than cisgender youth (whose gender identity corresponds to their assigned sex at birth) (Clark et al., 2014; Eisenberg et al., 2017; Johns et al., 2019; Pampati et al., 2018; Reisner et al., 2015; Rider et al., 2018; The Fenway Institute, 2016). These health inequities underscore the importance of ensuring transgender youth have access to quality health care. However, the limited available data on health care utilization and receipt of services specifically among transgender youth suggests both access to and delivery of care for this population is sub-optimal (Andrzejewski et al., 2020; Rider et al., 2018). For example, a survey of Minnesota public schools found that transgender and gender non-conforming students reported lower rates of preventive medical and dental checkups in the past year than cisgender students (Rider et al., 2018).

A number of barriers to accessing health care have been documented in transgender populations, including limited availability of gender-affirming care (i.e., medical care that supports and affirms gender identity), standards for which have been set forth by organizations such as the World Professional Association for Transgender Health (Coleman et al., 2012). Additional documented barriers include anticipation of and experiences with limited transgender cultural competency from providers and cost (Bauer et al., 2009; Corliss et al., 2007; Grant et al., 2011; Gridley et al., 2016; Poteat et al., 2013; Xavier et al., 2013). Further, those who can access care may not receive recommended services due to provider bias and inadequate training. In a national sample of transgender adults, 19% reported being refused medical care due to their transgender or gender non-conforming status and 50% reported having to teach their medical providers about transgender care (Grant et al., 2011).

Many studies on transgender people’s health care experiences are from adult populations (Bauer et al., 2009; Poteat et al., 2013; Xavier et al., 2013). However, the experiences of transgender *youth* warrant particular examination given the unique needs of this population (Ambresin et al., 2013). A number of quantitative studies with transgender youth have attempted to elucidate factors associated with health care access and service utilization

(Goldenberg et al., 2019; Goldenberg et al., 2020; Taliaferro et al., 2019). The few qualitative studies on the health care experiences of transgender youth have primarily been conducted in regions in the US other than the South (Corliss et al., 2007; Eisenberg et al., 2020; Gridley et al., 2016; Guss et al., 2019). Considering documented regional disparities in health outcomes and health care access for transgender adults (Centers for Disease Control and Prevention [CDC], 2020; White Hughto et al., 2016), this is a notable gap. In particular, in the South the HIV/STD burden is more pronounced, transgender residents are more likely to experience care refusal relative to other regions in the US, and laws prohibiting discrimination on the basis of gender identity or expression are largely absent (CDC, 2019; CDC, 2020; Transgender Law & Policy Institute; White Hughto et al., 2016). Given this context, we sought to characterize the health care experiences of transgender youth in an urban area in the southeast US and identify barriers and facilitators that can inform efforts to improve care for this population.

Methods

Study Design

These data are from the Resilience and Transgender Youth (RTY) study. The purpose of this qualitative, multi-phase study was to examine protective factors for transgender youth recruited from an urban area in the southeast US. The first phase involved individual, in-depth interviews ($n = 33$), and the second phase involved four focus groups ($n = 17$). Although the study addressed a range of topics, this analysis focuses on data from 42 participants who described experiences seeking and receiving health care during the individual interviews ($n = 33$) and focus groups ($n = 9$). Institutional Review Boards at the Centers for Disease Control and Prevention and ICF approved all procedures.

Phase 1: In-depth Interviews

Eligible participants were 15- to 24-years-old, and their gender identity differed from their sex assignment at birth. Participants were recruited using online advertisements, as well as flyers and palm cards distributed at universities and community-based organizations (CBOs). Some CBOs linked youth to medical and social services. Participants were also offered palm cards to share with peers who might be interested in participating. We used purposive sampling to recruit a diverse sample in terms of gender identity and race/ethnicity (Table 1). Approximately 42% of participants identified as female/transgender female, 33% as male/transgender male, and 24% as gender fluid, gender non-binary, gender non-conforming, or agender. The sample was majority Black (54.5%) and the mean age was 21.7 years. All interviews took place between February and June 2017 and the average duration was approximately one hour. Interviews were conducted in-person and addressed protective factors across the social-ecological model (i.e., individual, interpersonal, institutional, and community) (McLeroy et al., 1988). The interview guide included specific questions about health care (e.g., “How was your experience with the doctor or medical provider who took care of you during your visit?”), and participants were encouraged to describe experiences with a variety of providers. Participants received a $50 gift card for their time.

Phase 2: Focus Groups

After completing the interviews and reflecting on the lack of representation from younger youth, we chose to conduct focus groups with younger participants in order to supplement the interview data. These focus groups were a means of methodological triangulation, as younger adolescents may feel more comfortable in a group setting with their peers and the power imbalance between adult researchers and young participants may be reduced in comparison to individual interviews (Horner, 2000). Methods for the focus groups were similar to individual interviews. Eligible individuals were 15- to 19-years-old, and their gender identity differed from their sex assignment at birth. Participants were recruited from CBOs and community events. We conducted four focus groups between September 2018 and January 2019 and the average duration was one hour. Two of these focus groups included questions relating to sexual health services (e.g., “If you were to go get sexual health services, what would you want your visit to be like?”) and were used for this analysis. Among this sub-sample of focus group participants ($n = 9$), all identified as white, and 4 identified as male/transgender male, 4 identified as gender non-binary or gender fluid, and 1 identified as transgender female (Table 1). The mean age was 16.8 years and participants received a $50 gift card for their time.

Analysis

All individual and focus group interviews were audio-recorded and transcribed verbatim. We thematically analyzed the data using MAXQDA version 12 (Guest et al., 2011). The coding process for individual interviews had two stages. During the first stage, we created a preliminary codebook consisting of high-level topic codes (e.g., medical care, sexual health education, social media). Each interview was independently coded by two individuals. Coding discrepancies were resolved through discussion. In the second stage, we extracted content related to experiences seeking and receiving medical and mental health care and developed a second codebook to analyze these data. This codebook included conceptual codes derived primarily from systematic reviews on dimensions of youth-friendly health care (Ambresin et al., 2013; Brittain et al., 2015), such as provider factors (e.g., bedside manner, communication, expertise), confidentiality practices, and accessibility. Two authors (S.P., J.A.) reviewed a subset of interview transcripts and derived inductive codes from the data. Once codes and definitions were finalized, the same two authors independently coded all interview content. The two authors later applied the same codes to focus group data, resolving any coding discrepancies through discussion. We reviewed coded content in an iterative process and implemented several techniques for theme identification, including cutting and sorting and distinguishing similarities and differences across content (Ryan & Bernard, 2003), and then constructed evidence tables for each theme characterizing experiences seeking and receiving health care.

Results

Participants described experiences with a range of health services, including general preventive care, medical gender affirmation services (e.g., hormone replacement therapy), gender-affirming care (i.e., care that the youth viewed as affirming of their gender identity), sexual health services, psychiatric and counseling services, emergency care, dental care, and vision care. Participants also described experiences at various practice settings (i.e., physician's offices, hospitals, and university-based health centers) and with various health care staff (i.e., doctors, nurses, receptionists). Themes relate to both experiences seeking and receiving health care, including availability of gender-affirming care, accessing gender-affirming care, experiences with confidential care, chosen name and pronoun use, provider knowledge, comfort, and communication.

Limited availability of gender-affirming care

Participants described limited availability of gender-affirming care, including culturally competent care and specific medical gender affirmation services such as hormone replacement therapy. Some specifically attributed lack of availability to living in the South. One participant elaborated on their search for gender-affirming care: "I didn't really know any places around here because it's the South. They have laws against everything" (Interview participant). One youth who received gender-affirming care in the South saw his experience as an exception to the norm: "I think this is probably like one in a million. Especially for our area. Places in Pacific Northwest are totally different" (Interview participant). The same participant indicated the lack of local options caused him to travel significant distances for care: "I live several hours away and have to come to [City] to get the medication that I need, just to feel normal." Another participant did not get needed care due to inadequate availability: "I did a year of self-medicating [for hormone replacement therapy], which was a bad idea because it turned into me getting sick…. Because where I'm from, they don't have the resources" (Interview participant).

Logistical challenges to accessing gender-affirming care

Youth also expressed frustration with systems that created logistical challenges to accessing gender-affirming care, including specific medical gender affirmation services. For example, one participant described the process of acquiring a letter of support from a mental health professional in order to be eligible for hormone replacement therapy as unnecessary: "I wished the letter wasn't necessary. I think it's pointless medical gatekeeping" (Interview participant). Moreover, one participant described the initial challenge of meeting with a medical professional who could potentially prescribe hormones: "I was going to people that were just telling me, 'Well, come back and reschedule,' and it was a letdown in my head. Like, I'm tired of trying and no one is taking me serious now" (Interview participant). Even in instances when gender-affirming care was available, one participant described difficulties identifying these clinics and having to rely on peer recommendation.

Many participants emphasized cost as a barrier to a spectrum of gender-affirming services from mental health care to hormone replacement therapy to surgery. As an example, one participant with health insurance noted, "The reason why it's taken me so long to see a counselor is cuz I had to wait until my deductible was used up, so I can actually afford to go see them once a week" (Interview participant). One participant without health insurance described being unable to access basic preventive care: "I mean, there's some health problems that I would like to take care of if I had the money or had health insurance" (Interview participant).

Confidential care valued but not always received

Although participants highlighted a desire for confidentiality, particularly in relation to their gender identity and use of sexual health services such as STD testing, participants' experiences varied. A couple of participants described not having time alone with a provider without parents/guardians in the exam room. Subsequently, youth did not feel comfortable sharing information regarding their sexual behavior or gender identity. One participant remarked, "The nurse asked me when I walked in, in front of my mom, if I had had sex before. It was really not a good experience. I didn't feel comfortable there at all. I almost had a panic attack in the thing" (Interview participant). In addition to time alone, one youth who was on her parents' insurance expressed concerns regarding billing for any services related to gender-affirming care obtained without parental notification or consent given her parents were unsupportive of her transition.

Some youth had positive clinic experiences related to maintaining the confidentiality of their gender identity. For example, one youth appreciated front-desk staff inquiring about use of her chosen name, recognizing that it could disclose the participant's gender identity: "they asked me quietly, when I first handed my forms whether or not it was okay to call me by my preferred name in the waiting room" (Interview participant). Relatedly, another youth appreciated being called in from the waiting room via text message because this method preserved confidentiality.

Consistent chosen name and pronoun usage is important

Participants stressed the importance of providers using their chosen name and pronouns and spoke favorably of intake procedures that involved recording this information. However, this practice was seen as necessary but not sufficient given incidents where providers and frontline staff "dead-named" them (i.e., referred to an individual by their name given at birth) or used incorrect pronouns, while sometimes having the correct information included in their records. One participant even described an instance where a provider refused to use a chosen name: "one of the nurses…tried to get me to tell her my dead name, and when I didn't, I said 'no I am not comfortable with that' and she said…'you have to be comfortable with that'" (Focus group participant). In addition, a couple of participants described not having their chosen names or those of their peers on the door to their clinic rooms. For example, one participant noted after asking staff to change the name on the room, "we finally got them to add our chosen name but it was in quotation marks afterwards which I would say might even be more upsetting" (Focus group participant). In addition to causing emotional distress, there were also adverse consequences for physical health. As one participant said, "My health would have definitely been better because I wouldn't have been walking around with my IV screaming at people and trying to be like, 'Hey my name is not [Dead Name]'" (Interview participant).

Providers had limited awareness of transgender medical issues

Some participants described instances where they felt providers had limited knowledge or understanding of issues relevant to transgender populations. As one participant summarized, "My pediatrician, I don't think she even knows what a trans person is" (Focus group participant). Participants identified gaps in provider knowledge specifically about chest binding procedures, HIV pre-exposure prophylaxis (PrEP), and hormone replacement therapy. One participant cited the lack of relevant training as a possible cause: “Oh for a lot of people in the medical field, they’re just not taught this stuff. They go to medical school and they’re not taught how to handle trans people” (Focus group participant).

Youth aware of and distressed by provider and staff discomfort

Some youth recognized when providers and staff were uncomfortable with their gender identity. For example, one participant noted: “I had my nails painted that day, and they were clearly pretty uncomfortable. They never said anything to confirm that, vocally…but their mannerisms” (Interview participant). Similarly, another participant noticed a shift in provider comfort once they realized he was transgender: “As soon as they see the ID, it kind of—there’s just this shift of a lot more of this wall of, ‘Ugh… but female, but not’…and so, it just gets weird. You go into the room and you tell ‘em what’s goin’ on and they just kind of dismiss you to get you out cuz they’re not comfortable” (Interview participant). The same participant explicitly described provider discomfort as a barrier to care-seeking, “It’s hard to wanna go to a doctor that you know is already not going to treat you normal…It hurts your feelings. It makes you not wanna go.”

Open communication facilitated comfort

Youth had positive perceptions of and desired providers who took the time to explain office and medical procedures. One participant noted how provider communication eased his initial anxiety about the health care visit: “If they talk to you, communicate wit’ you, kinda like it eases the nervousness” (Interview participant). In contrast, one youth whose provider did not sufficiently communicate with her felt uncomfortable: “I really felt like a specimen…I just needed more communication about what was goin’ on” (Interview participant). Participants desired providers who not only spoke openly but also listened actively. Some youth described negative experiences with providers who would dismiss or ignore what they had to say: “Before, a lot of the doctors that I’ve seen didn’t listen to anything I said. They didn’t believe anything I said. They thought I was just being overdramatic or making it up, and they’d brush it aside” (Interview participant).

Discussion

In this study, we document multiple barriers and some facilitators to health care experienced by transgender youth living in an urban area in the southeast US. In doing so, we address an understudied population living in a geographic region where this issue is particularly important given reduced access to transgender-friendly health care and an increased HIV/STD burden (CDC, 2019; CDC, 2020; White Hughto et al., 2016). Our findings highlight implications for optimizing access to and receipt of health services for transgender youth in this context and likely beyond.

Similar to studies with youth generally, transgender youth in our study identified the absence of essential characteristics of youth-friendly care, such as availability, affordability, and confidentiality, as barriers (Ambresin et al., 2013; Brittain et al., 2015; Tylee et al., 2007). However, findings highlight some unique ways that these barriers operated given the specific needs of transgender youth. Some participants noted limited availability of gender-affirming care and attributed this to living in the South, although another study conducted with youth in Washington identified a similar theme (Gridley et al., 2016). Even when available, the cost associated with gender-affirming services was described as a barrier. Confidentiality-related barriers specific to transgender youth were also identified because of concerns about unwanted disclosure of gender identity to parents or other patients. This was a particularly salient finding—it extends the robust body of literature describing confidentiality concerns as a barrier to sexual health services for youth (Pampati et al., 2019) and it is not apparent in the literature on health care experiences among transgender adults, thus underscoring the challenge of providing both youth- and transgender-friendly care. Indeed, other studies with transgender youth have highlighted the importance of ensuring confidential care (Clark et al., 2017; Guss et al., 2019).

Of course, many barriers we identified reflect a lack of transgender-friendly care regardless of age and thus align with studies of transgender adults (Bauer et al., 2009; Poteat et al., 2013; Xavier et al., 2013). Inadequate provider knowledge and cultural competency around gender identity is particularly concerning as it not only creates a barrier to care but also contributes to stigma that undermines the health of this population (Meyer & Frost, 2013; Testa et al., 2015). Conversely, culturally competent practices, such as use of chosen names and pronouns, are associated with transgender mental health and wellbeing (Russell et al., 2018), speaking to the importance of incorporating such practices in clinical care. In fact, this practice is one of several included in recently published recommendations from the American Academy of Pediatrics and the American College of Obstetricians and Gynecologists regarding the care of transgender adolescents (American College of Obstetricians and Gynecologists, 2017; Rafferty, 2018).

Practice implications

Collectively, our findings emphasize the need for a multi-component approach to improving access to care that is both youth- and transgender-friendly (Box 1). Across themes, stigma defined many of the health care experiences of transgender youth, suggesting that addressing stigma relating to gender identity and other marginalized identities may improve care for this population (Poteat et al., 2013). It is promising that transgender cultural competency training as a part of medical school curricula and continuing education efforts have shown preliminary effectiveness (Dubin et al., 2018). However, implementation of such training remains limited; efforts to include sexual orientation-related topics in medical education can be leveraged to include gender identity-related topics. Additionally, trainings should be implemented with frontline and other office staff and address collection and appropriate use of chosen names and pronouns given confidentiality concerns.

Beyond provider and staff training, clinic-level policies and protocols that facilitate access to quality care for transgender youth are needed. Given the challenges youth reported identifying affirming care, clinics can include visual graphics indicating their commitment to providing transgender-friendly care, as well as register in online directories of transgender-friendly care. Maintaining confidentiality will require consistent implementation of carefully designed protocols, including potential alterations in electronic health record (EHR) interfaces to alert providers of chosen names/pronouns. Offering clinic support to help youth navigate the complexities of health insurance coverage and care coordination, including obtaining referrals, scheduling appointments, and ensuring follow-up, may help address logistical barriers to care. In addition to these clinic-level efforts, educating youth on their right to affirming care and how to navigate the health care system through school-based education efforts and other health promotion efforts is needed.

Limitations

Our study should be interpreted in light of both its limitations and strengths. Due to venue-based recruitment, transgender youth without ties to social and medical service organizations may be underrepresented in our sample, so it is likely that our findings do not reflect all the challenges that transgender youth in the Southeast experience seeking health care. We were unable to do a comparative analysis of our findings across provider specialties and practice settings due to the broad nature of the questions asked and the diversity of types of health care experiences youth discussed. Strengths of this study include the diversity of our sample in terms of race/ethnicity and gender identity and use of multiple modes of data collection. Although we collected supplemental focus group data with transgender adolescents, the smaller sample and limited number of focus groups prohibited us from conducting a comparative analysis of findings from individual interviews and focus groups. Further, additional work is needed to understand the unique experiences of transgender adolescents of color, as our focus group participants were all white and primarily non-Hispanic.

Conclusions

As our findings highlight, transgender youth face numerous challenges to accessing health care that is culturally competent and affirming. These barriers range from initially identifying transgender-friendly providers, to interactions with office staff and providers, to maintaining confidentiality. Eliminating these barriers will require efforts on multiple levels, including clinic-level protocols, provider and staff training, and changes to health care systems (e.g., EHRs) to ensure that care is both youth- and transgender-friendly.

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Box 1.

Practice implications for transgender- and youth-friendly care

Provider-level

- Providers and office staff can participate in ongoing transgender cultural competency trainings
- Providers and office staff can avoid making assumptions about patients' gender, pronouns, anatomy, and health behaviors
- Providers can inquire about gender identity during time alone with the patient
- Providers can practice cultural humility and assessments of personal biases
- Providers can engage in active listening

Clinic-level

- Intake procedures can collect information on chosen name and pronouns and participant preference about when they are used
- Clinic spaces can include visual graphics (e.g., posters, buttons, etc.) indicating the availability of transgender-friendly care
- Clinics can register in transgender-friendly medical provider online directories
- Clinics can provide health education materials and resource guides for transgender youth and their parents/guardians

Table 1.

Participant characteristics

Characteristic	Interviews (*n* = 33)		Focus groups (*n* = 9)	
	n	**%**	***n***	**%**
Gender Identity				
Female/transgender female/woman	14	42.4	1	11.1
Male/transgender male/man	11	33.3	4	44.4
Gender fluid/non-binary/non-conforming, agender	8	24.2	4	44.4
Assigned Sex at Birth				
Female	16	48.5	7	77.8
Male	17	51.5	2	22.2
Age				
15-17	2	6.1	7	77.8
18-21	12	36.4	2	22.2
22-25	19	57.6	N/A	N/A
Ethnicity				
Non-Hispanic/Latino	31	93.9	8	88.9
Hispanic/Latino	2	6.1	1	11.1
Race				
Black	18	54.5	0	0
White	13	39.4	9	100
Multiracial	2	6.1	0	0