Transgender and Other Gender-Diverse Youth's Progression Through the HIV Continuum of Care: Socioecological System Barriers

Gary W. Harper, PhD, MPH,¹ Laura A. Jadwin-Cakmak, MPH,¹ Elliot Popoff, MPH,¹ Bré Anne Campbell,¹ Ricky Granderson, MPH,¹ Linda M. Wesp, MSN, RN, FNP,² and the Adolescent Medicine Trials Network for HIV/AIDS Interventions

Abstract

Transgender and other gender-diverse youth (TGDY) are disproportionately affected by HIV and in need of developmentally and culturally appropriate services as they progress along the HIV continuum of care (CoC). We conducted a phenomenological analysis of 66 in-depth interviews with TGDY living with HIV (ages 16–24) from 14 cities across the United States about their experiences within the different stages of the HIV CoC. TGDY described experiencing a wide variety of barriers across each examined stage of the HIV CoC, including HIV testing, linkage to care, retention in care, initiation of antiretroviral therapy, and adherence to antiretroviral therapy. Within these CoC stages, TGDY experienced barriers to care across all socioecological systems, including the sociocultural systems, clinic/organizational systems, and interpersonal systems. Barrier themes remained relatively constant for all stages of the CoC, although the way each thematic category of barrier (e.g., the theme of societal oppression and discrimination within the sociocultural level) was experienced varied by stage. Although overall thematic categories were typically not focused solely on threats to participants' gender identity and expression, specific descriptions of the nature of the thematic barriers were related to gender identity and gender expression. Implications of the findings for future research and practice are discussed.

Keywords: transgender, youth, HIV continuum of care, qualitative, socioecological

Introduction

TRANSGENDER AND OTHER gender-diverse (TGD) populations are disproportionately affected by the HIV epidemic. Among TGD adults, transgender women are one of the populations most vulnerable to HIV, with estimates of HIV prevalence ranging from 22% to 28%.^{1,2}

Although few HIV-related studies have focused on TGD youth (TGDY), two studies have reported HIV status among convenience samples of young transgender women. In a community-based study of ethnic minority, young transgender women in Chicago (ages 16–25; $N=51$), Garofalo et al. reported that 22% of participants self-reported they were living with HIV.³ Another study conducted by the Adolescent Medicine Trials Network (ATN) for HIV/AIDS Interventions from 2005 to 2006, included a sample of young transgender women from Chicago and Los Angeles (ages 16–24; $N=151$); 19% of participants self-reported they were living with HIV.⁴

Less research has focused on transgender men, who have often been excluded from HIV-related studies.^{1,5} More recent studies are reporting relatively high prevalence of risk behaviors among transgender men,^{6–8} particularly transgender men who have sex with cisgender men, thus calling for their inclusion in future HIV research.^{9–11} Scant data exist on the prevalence or prevention of HIV among gender nonbinary or gender-diverse people.¹²

HIV care in the United States is often conceptualized along a continuum of care (CoC), starting with prevention and followed by testing, engagement in care, and treatment.¹³ When exploring cisgender youth's access to services along the CoC, only 41% of youth who are living with HIV are aware of their status, 62% of these youth are engaged in HIV care, and only 6% of those engaged in care have undetectable viral loads.¹⁴ Several studies have examined the CoC with transgender populations, although they have largely focused on testing among adult transgender women.^{5,15–17} A study in

¹Department of Health Behavior and Health Education, University of Michigan School of Public Health, Ann Arbor, Michigan.

²University of Wisconsin-Milwaukee, College of Nursing, Milwaukee, Wisconsin.

San Francisco found that 77% of transgender women living with HIV in their sample were linked to care, and of these 65% were taking antiretroviral treatment, with only 44% virologically suppressed.¹⁸

The United States National HIV/AIDS Strategy Update for 2020 calls for the engagement of those disproportionately impacted by HIV, naming both youth and transgender people as key populations.¹⁹ However, transgender people must navigate various structural barriers to access the healthcare system,^{20,21} including lack of education, insurance, and stable housing.²² TGDY often engage in survival sex work due to family rejection, housing instability, employment discrimination, and lack of access to gender-affirming healthcare.^{4,23–25}

In a study of young transgender women of color between the ages of 15 and 24, 67% engaged in sex work and 43% had a history of homelessness.²⁶ Youth under age 18 also may face limits to accessing HIV treatment without parental consent, and expanded access to health insurance under a parent or guardian until age 26 has led to an increased concern about confidentiality if the explanation of benefits is sent to the primary insurance holder.²⁷

Themes from qualitative interviews with young transgender women emphasized that a lack of respect for gender identity by healthcare providers was a significant barrier to engagement in HIV care for this population.²⁸ The gender affirmation framework suggests that transgender individuals face stigma and distress when there is a lack of gender affirmation, especially in healthcare contexts, which can lead to further health risks.²⁹ Among studies of adult transgender women, access to gender affirmation acts as a facilitator to engagement in HIV care by increasing retention in care, antiretroviral adherence, and viral load suppression.^{30,31}

Given the multiple layers of oppression and marginalization many TGDY face, as well as the additional structural barriers they may encounter when seeking health-related services, it is imperative to explore barriers or facilitators to engagement in the HIV CoC using a socioecological environmental systems' approach. Bronfenbrenner's ecological systems' theory of human development provides such a framework for exploring various levels of influence on adolescent and young adult development and health.^{32,33} The framework posits that human development occurs at different levels of social interaction and within multiple environmental systems. These processes are bidirectional and occur between individuals and their environments with the interconnectedness of each system and their consequent interaction with the individuals.

Although mounting research has demonstrated the multiple barriers to health and wellbeing that TGDY face during their developmental trajectory to adulthood,^{3,4,23,25} little is known about the specific experiences of TGDY living with HIV as they progress through the various stages of the HIV CoC. Within each stage of the CoC, youth are influenced by multiple interacting environmental systems, thus understanding factors that serve as barriers to care within these systems will assist in finding solutions to those barriers.

In addition, the majority of research with TGDY to date has focused on samples of transgender young women in major HIV epicenters (e.g., Chicago, San Francisco, Los Angeles), and has not included youth from multiple cities and youth representing various gender identities. As noted by other researchers, qualitative inquiry provides a comprehensive and inductive approach to deepen our understanding of the lived

experiences of TGDY, which will inform the development of systems and processes to improve their health and wellbeing. Therefore, this study takes a qualitative approach to the examination of barriers TGDY face at each stage of the HIV CoC, as well as across three primary socioecological systems.

Methods

The current investigation is part of a larger mixed-methods study with TGDY, as well as healthcare and social service providers working with this population. The focus of this parent study is to understand TGDY's experiences accessing general medical care and the HIV CoC, including HIV prevention and testing. The current article draws from the subset of in-depth interviews with TGDY youth who were living with HIV and focuses on barriers to HIV testing, linkage to care, retention in care, initiation of antiretroviral therapy (ART), and adherence to ART.

A Youth Advisory Board (YAB) was convened during the initial phases of protocol development to incorporate the voices and perspectives of TGDY in all aspects of the study. The YAB consisted of nine TGDY (ages 19–26) from Detroit, Boston, and Los Angeles, offering representation from three primary geographic regions in the United States (Midwest, East Coast, and West Coast).

YAB members included youth living with HIV and not living with HIV, and were diverse in terms of their racial, ethnic, and gender identities (e.g., genderqueer, trans, trans masculine, masculine-identified lesbian, trans woman). The YAB was active throughout the duration of the study, providing insight and feedback on aspects of study design, measures and interview guide development, study implementation, and data interpretation. They participated in professional development and capacity-building trainings, and received payments for all study activities.

Sample

This study was conducted through the Adolescent Medicine Trials Network for HIV/AIDS Interventions (ATN), and took place in all fourteen of the ATN's Adolescent Medicine Trials Unit (AMTU) sites, which are medical facilities where youth who are at risk for or living with HIV receive care and participate in ATN studies. A total of 193 interviews were conducted with TGDY participants at the fourteen AMTU sites located across the United States.² Of those, 66 participants self-reported to be living with HIV and were included in the current analysis.

The eligibility requirements for youth participating in the parent study included the following: (i) does not solely identify with sex assigned at birth (may identify as trans, transgender, trans woman, trans man, man, woman, gender nonconforming, genderqueer, or any other gender, so long as their current gender identity and/or expression do not match their sex assigned at birth); (ii) self-reports to be between the ages of 16 and 24 years inclusive at the time of consent; (iii) able to understand both written and spoken English; (iv) willing to participate in both a quantitative survey and in-depth face-to-face qualitative interview about gender minority identity and personal experiences seeking services across the HIV CoC; and (v) able to understand and willing to provide signed informed consent for study participation.

Within the subsample of participants living with HIV ($N=66$), the median age was 21.5 years (mean = 21.3, standard deviation = 1.89; range, 17–24). In the quantitative survey participants completed before being interviewed, youth participants identified their current gender identity as follows: trans female/trans woman (48.5%; $N=32$); female (24.2%; $N=16$); genderqueer/gender nonconforming (18.2%; $N=12$); male (7.6%; $N=5$); and “a gender not listed here” (1.5%; $N=1$; when asked to specify, this participant wrote in, “I’m not sure.”).

Although an in-depth analysis of gender identity labels is beyond the scope of the current article, it is important to note that participants frequently used different terms to describe their gender identity during the in-depth interviews than were offered as responses in the close-ended quantitative survey. The participants used and defined these self-generated terms—genderqueer and gender nonconforming, in particular—in various ways. The majority of the sample (95.5%; $N=63$) was assigned male sex at birth; 4.5% of participants ($N=3$) declined to answer this question. More than a fifth (21.2%; $N=14$) of the sample identified as Hispanic or Latino/a. The majority of the sample identified their race as black (68.1%; $N=45$), with the rest of the sample identifying as multiracial (i.e., choosing two or more racial categories; 19.7%; $N=13$), white (10.6%; $N=7$), and American Indian (1.5%; $N=1$).

Procedure

A group of 18 interviewers across the 14 AMTU sites were rigorously trained to conduct individual in-depth qualitative interviews. The interviewers were diverse in terms of educational and work backgrounds (including nurse practitioners, researchers, social workers, and outreach workers), age, race, ethnicity, gender identity (the majority were cisgender), and sexual orientation. The initial training was delivered through two live webinar sessions (2 h each), which allowed for interactive activities and interviewee questions. Interviewers then received additional individual training and feedback on mock interview sessions they conducted.

Interviewers continued practicing and receiving detailed feedback from the Project Director and/or Project Coordinator until recorded mock interviews showed that the interviewer was consistently proficient in both the principles of qualitative interviewing and the use of affirming language with TGDY. This required a minimum of two and a maximum of five mock interviews per interviewer, with training feedback calls after each mock interview that lasted 30–60 min. Finally, as the interviews were conducted, portions of the audio recordings of interviews were reviewed for quality assurance, and additional feedback and training was provided to interviewers as needed throughout the study through telephone or video conference.

Youth participants were recruited through AMTU sites’ clinic populations, community partners, peer referrals, and social media advertising. The study was approved by the Institutional Review Board (IRB) of each of the AMTU sites, as well as the University of Michigan. All but one site received permission from their IRB to waive parental consent from participants ages 16 or 17; the site that was not able to waive parental permission did not enroll participants under age 18.

We obtained written informed consent/assent from all participants. Youth in the study completed a computer-based quantitative survey that took ~45 min, followed by the in-

dividual in-depth qualitative interview that lasted between 30 min and 2.5 h. Interviews were conducted in private spaces at the AMTU site or nearby community organizations, and participants were compensated for their involvement. The amount of compensation was determined separately by each AMTU and approved by each site’s Internal Review Board to be in alignment with community norms for research participation. All interviews were audio recorded and transcribed verbatim by an external transcription company. The transcripts were thoroughly reviewed for quality and all identifying information was removed/masked. The audio recordings were destroyed following quality assurance procedures.

Interview guide

Research team members who had extensive experience working with TGDY created a semi-structured qualitative interview guide specifically for the parent study, with significant input and guidance from YAB members. The interview guide was grounded in phenomenological and constructivist frameworks, which provided a general structure for discussion but required participants to provide their own conceptualizations of terms and phrases based on their life experiences. The guide included a series of questions/probes focused on participants’ experiences across stages of the HIV CoC—HIV prevention, HIV testing, linkage to care, initiation of ART, retention in care, initiation of ART, and adherence to ART.

Within each stage, we explored influences on that stage along three nested socioecological environmental systems, including sociocultural, clinic/organizational, and interpersonal. Within the specific areas probed, youth provided accounts of their own experiences, but were also encouraged to discuss additional information that was not covered in the semi-structured interview guide but that seemed personally relevant to their experiences as a TGDY. Although the interview guide included deductive elements related to Bronfenbrenner’s socioecological model which is focused on human development,^{32,33} it also was grounded in the inductive nature of phenomenological inquiry and elicited participants’ lived experiences and definitions rather than imposing definitions upon participants based on prior research.

Data analyses

Since the focus of this study is on the lived experiences of TGDY within various states of the HIV CoC, the data collection and analyses were conducted using a phenomenological inquiry framework.^{34,35} The composite descriptions of the phenomena presented in this article offer an explanation of the underlying structure, which exists across the respondents’ experiences.^{35,36} In line with our phenomenological orientation, the analyses were conducted to assure that different voices were represented in the findings and that conceptual “outliers” were not silenced by the average or dominant perspective. Thus, all voiced themes are presented instead of only those that were endorsed by a majority of participants.^{35,36}

The team of analysts for this article included transgender and other gender-diverse individuals, as well as cisgender individuals. Racially, the analysts were all either African American or white, and their educational backgrounds were diverse. All verbatim transcripts of the interviews were

uploaded to Dedoose 7.5.9³⁷ to assist in coding and analyzing the qualitative data.

Initial *a priori* codes were grounded in both the CoC and the socioecological model. After all of the transcripts were read and reviewed, additional content codes were added to the initial *a priori* code list to capture the experiences described by participants, and a codebook was created. Transcripts were then reread and pattern codes were created to connect subsequent concepts under larger headings within each transcript. After pattern codes were assigned to appropriate segments of the transcripts, consistent patterns in meaning, concepts, and themes across all interviews were identified.^{36,38}

We provide rich and comprehensive detail when discussing our themes to assist the reader in understanding and evaluating the extent to which the conclusions drawn from the inquiry are transferable to other populations, places, and experiences.^{39,40} Such descriptions are also in alignment with an ethnographic approach to understanding a particular phenomenon among a culture-sharing group that has not been the focus of much empirical inquiry.^{36,41}

Results

TGDY described experiencing a wide variety of barriers across each examined stage of the HIV CoC, including HIV testing, linkage to care (attending an initial HIV medical care appointment), retention in care (attending HIV medical care appointments on a regular basis), initiation of ART, and adherence to ART (regularly taking ART as prescribed). Barriers were considered as those aspects of the participants' experiences that: (i) prevented them from receiving care at each particular stage of the continuum, or (ii) caused them to have a negative experience when they did receive care at each stage of the continuum.

Within the stages of the CoC, TGDY experienced barriers to care across all socioecological systems, including the sociocultural system levels (i.e., cultural, legal, religious barriers), clinic/organizational system levels, and interpersonal system levels. The following sections present the major themes and subthemes that emerged from the data, organized by socioecological level.

Barrier themes remained relatively constant for all stages of the CoC within the sociocultural, clinic/organizational and interpersonal levels, though the way each thematic category of barrier (e.g., the theme of societal oppression and discrimination within the sociocultural level) was experienced varied by stage. Representative quotes are offered to provide a richer description of the findings, along with a participant pseudonym, age, self-identified race/ethnicity, self-identified gender identity, and region of the United States where the interview took place. A thematic summary of barriers experienced at each stage across socioecological levels is included in Table 1.

Although major overall thematic categories were typically not focused solely on participants' gender identity or gender expression, specific descriptions of the nature of the thematic barriers were related to gender identity and/or gender expression. For example, "societal oppression and discrimination" was a major theme at the socioecological level for all stages of the CoC, and it broadly describes the phenomenon (*what* is experienced). Investigation of the textual data reveals that this societal oppression and discrimination is ex-

perienced by TGDY in the form of gender identity and gender expression-related oppression and discrimination (*how* it is experienced). This was true for all stages of the CoC and across all socioecological levels.

Sociocultural system levels

Within the sociocultural system, participants experienced barriers across all five stages of the HIV CoC in the following thematic areas: (i) societal oppression and discrimination, (ii) housing, (iii) law and policy, and (iv) access. The following details these primary thematic areas, as well as the subthemes that emerged within several primary themes.

Social oppression and discrimination. Within the theme of societal oppression and discrimination, TGDY described experiences of oppressive and discriminatory actions related to their gender identity, gender expression, HIV status, sex work, and sexual orientation. In addition, black community distrust of the medical system was discussed, but only for initiation of ART. This was present when youth were aware of racial injustices due to institutionalized racism within the United States' public health system and voiced hesitance to initiate medication use. One participant spoke about how the black community's mistrust of the medical system, including the belief that anti-retrovirals *cause* AIDS, made it harder for her to initiate ART:

"Ok, well the negativity I used to hear was, um, that the medicine was going to kill you that they, you know, is up to no good. Can't trust them, you know the chemist - - no I'm telling you, I'm just giving words. Like that's the type of misinformation that's out there. Lot of people don't know when to take treatment because they be thinking it going to kill them." Piper (23, black, female, South)

Youth described directly experiencing oppression and discrimination due to transphobia when accessing services, as well as the fear of experiencing such oppression and discrimination:

"You go in to pick up [your] medicine and as soon as you walk in you get these looks like, "Uhh..." Sometimes, like I said, it be, it be the security guards, it be staff members that just give you this look in there and they mumble under their breaths to another or laugh like a little kiki or whatever and you know, sometimes it's hard to deal with that." Pru (23, black, genderqueer/gender nonconforming, South)

"So you're afraid that you're walking toward somewhere and someone's going to say something or someone's going to push you just for, just because, just for you being you. So that was the only thing that got me scared was public, you didn't want to deal with the public, you just wanted your mom to take you there (laughs), but yea that's all." Julie (23, white, unsure, South)

HIV stigma, both general HIV stigma and stigma specific to a high viral load within transgender communities, as well as stigma related to participation in sex work, acted as additional barriers related to societal oppression and discrimination. Selena (22, black, trans woman, Northeast), explains, "So, you know, it's very difficult and once society find out you HIV positive, oh, you the monster... you're the worst of the worst of the worst." Another participant, Kay (19, American Indian, trans woman, West), stated, "I mean, when they, in my opinion when they think of like a transgender person who is gonna go get tested, they think of like an escort

TABLE 1. BARRIERS TO THE HIV CONTINUUM OF CARE (CoC) ACROSS SOCIOECOLOGICAL SYSTEM LEVELS

<i>CoC stage</i>	<i>Socioecological system levels</i>		
	<i>Sociocultural</i>	<i>Clinic/organizational</i>	<i>Interpersonal</i>
HIV testing	<ul style="list-style-type: none"> • Societal oppression and discrimination • Housing • Law and policy • Access 	<ul style="list-style-type: none"> • Confidentiality and privacy • Test site environment • Service delivery • Availability and awareness of services 	<ul style="list-style-type: none"> • Negative provider interactions • Lack of social support and social undermining • Lack of instrumental support • Disclosure of HIV status
Linkage to care	<ul style="list-style-type: none"> • Societal oppression and discrimination • Housing • Law and policy • Access 	<ul style="list-style-type: none"> • Confidentiality and privacy • Location of services • Service delivery • Availability and awareness of services • Navigating the system 	<ul style="list-style-type: none"> • Negative provider interactions • Lack of social support and social undermining • Lack of instrumental support • Disclosure of HIV status
Retention in care	<ul style="list-style-type: none"> • Societal oppression and discrimination • Housing • Law and policy • Access 	<ul style="list-style-type: none"> • Confidentiality and privacy • Location of services • Service delivery • Availability and awareness of services • Navigating the system 	<ul style="list-style-type: none"> • Negative provider interactions • Lack of social support • Lack of instrumental support • Disclosure of HIV status
Initiation of antiretroviral therapy (ART)	<ul style="list-style-type: none"> • Societal oppression and discrimination • Housing • Law and policy • Access • Black community distrust of medical system 	<ul style="list-style-type: none"> • Confidentiality and privacy • Service environment • Discontinuity of care • Availability and awareness of services • Navigating the system 	<ul style="list-style-type: none"> • Negative provider interactions • Lack of social support • Lack of instrumental support • Disclosure of HIV status
Adherence to ART	<ul style="list-style-type: none"> • Societal oppression and discrimination • Housing • Law and policy • Access • Lack of money 	<ul style="list-style-type: none"> • Confidentiality and privacy • Location of services • Discontinuity of care • Availability and awareness of services • Navigating the system 	<ul style="list-style-type: none"> • Negative provider interactions • Lack of social support • Lack of instrumental support • Disclosure of HIV status

or a prostitute, you know.” Alexis (21, black, trans woman, Northeast), described how HIV stigma can impact TGDY's experiences with testing and diagnosis:

“You just told them that they got this and the main stereotype or whatever that's out here is, you got HIV, you're gonna die. So people, if they not really not, they really don't know the real education on it then they just hear or they just take a test and they positive, you know, what's the first thing going in they head -- that they gonna die or something like that cause that just what everybody say, you know what I'm saying?”

Housing. Both homelessness and housing instability were cited by TGDY as barriers to HIV testing and care. When asked what made testing difficult, Ema (19, black, trans woman, Midwest), said, “Um, I would say, being homeless, on the street, and having nobody, I guess, to support me or encourage me to be tested, I guess...” Ema later explained how being homeless impacted her ability to regularly attend her HIV medical appointments,

“Um, yeah, homeless. Um, sitting on the street. Not being able to eat, no money, no nothing. No having nobody to, you know support you at all. Basically just being alone and figuring out everything on your own, pretty much.”

When asked what was happening in her life in the 12 months between when she was diagnosed and her first HIV medical appointment, Bianca (22, West Indian, female, Northeast) explained, “I was homeless, I was prostituting, um, just that pretty much.” Bianca went on to describe how homelessness impacted her ability to take her ART on a regular basis:

“... because even though HIV is not a death sentence, it is if you're not taking your meds. It is if you're homeless and you don't have the money or the time to go get that prescription if you don't have insurance.”

TGDY youth also discussed how housing instability makes it difficult to take their medications if they have not disclosed their HIV status:

“And then especially if you stayin' with somebody then you gotta try to hide it. Then you hidin' it, it sucks that you gotta hide it and then everybody still around, everybody still look, you don't hear. They hear your bottle shakin', it's just, you know.” Phoebe (23, black, genderqueer/gender nonconforming)

Law and policy. Participants spoke of myriad law- and policy-related barriers at all stages of the CoC, including age requirements for receiving services, incarceration, lack of health insurance, lack of an ID that represented their gender identity/name, and immigration status.

Age requirements directly affected whether or not TGDY could receive care, as in Selena's (22, black, trans woman, Northeast) case: “Well once I age out of [this adolescent clinic], it's gonna be hard. That's gonna be my hardest thing. Where I'm gonna go? Who I'm gonna see?” Age requirements also impacted whether or not TGDY attempted to receive care:

“I was also underage when I was living on my own and another thing I was on the run, you know what I'm saying, so I felt as though if I linked myself to here it'll link to something else and I'll get locked up and go to jail, you dig what I'm saying? So ... certain things they need parental consent to do ... so I just left it alone.” Alexis (21, black, trans woman, Northeast)

Incarceration also acted as a barrier to HIV testing and care. Jacobian (20, black, Male, Midwest) described how being tested while incarcerated made receiving the results difficult: “I didn't know they had tested me. They just came back and told me like this is why, you know, this is what, what, you know, was goin on or whatever. And I'm like what?” Incarceration also impacted Keisha's (23, Multi-racial, female, South) experiences with viral suppression:

“Like in the beginning this year I was [undetectable]. And then, when I went to jail and got out of jail and then ended up missing medications and missing things and then trying to get back on track, it's like I'm still fighting for that undetectable stage. But it feels like now that even though I'm trying to fight for it, seem like my medication ain't even, helping or working to even fight no more.”

Health insurance challenges presented barriers to TGDY's ability to attend appointments regularly or receive medications. Beverly (21, black, genderqueer/gender nonconforming, South) explained that she was unsure if she could attend HIV medical appointments because she “was uninformed, like, with healthcare and insurance and all that, and all this stuff, so [I] didn't know what was the proper channels were, or if [I] was able to go.” When asked what prevented her from taking her ART, Zuri (19, black, trans woman, Midwest) said,

“The situation with my insurance made me miss. I never miss purposely on my own. I miss because when I went to file my prescription for the next one, my insurance turned off. So I'm like—there's no way, he's like no, well, call this number and the process was so long like but that's—that was—that was the only reason that ever deterred me from not taking it at the end of the day, no I've always taken them.”

TGDY expressed frustration and distress at having identity documents that did not match their gender identity, gender expression, or name. Julie (23, white, unsure, South) describes her experience interacting with front desk staff:

“If it was me, I think the hardest thing was showing my ID and [the person behind the desk] saying, ‘Um what's your name?’ and you have to say not only who you actually felt like, but your real name, your government name and I think that's the number one thing, is going to the desk and saying yea, my name is [Matt], but yet you're looking like [Julie].”

Another participant, Daphne, described her experience receiving her ART prescription before legally changing her name:

“I didn't have my name changed at the time so I was kind of like pissed off that my prescription said my legal name, well my birth name, so yeah...Like I literally like, crossed it out, I literally crossed it out cause I just, when I think of when I see my name or think of my name, I just think of like that little boy that died (laughs) so I just don't wanna, you know, have nothing to do with that you know cause that's my old self. I'm my new self so this is why I don't want to see that.”

Immigration status and a lack of documentation acted as another law or policy barrier for TGDY. One participant, Jordyn (18, black, genderqueer/gender nonconforming, South), described how his immigration status impacted both his experiences disclosing his status and taking ART on a regular basis:

“Uh, immigration [is a barrier to regularly taking ART]. By me not having a permanent residency to be here, it's a lot difficult. Like when I first got here it was very, very, very, very, very difficult and it was some people say—telling me

that I couldn't get it until I actually went out and tried myself and found that there were ways around everything, but it was real hard and I up to—up to today it's still hard cause still like I have to go to a place and get my medicine, I can't just go to a regular pharmacy.”

Access. Within the theme of access to HIV testing and care, TGDY youth described barriers related to transportation, work responsibilities, and work and school schedules. Several youth spoke about the difficulties they faced attending their HIV-related services:

“Because I don't have a car and you know I stay way in [unincorporated area of the city] and the place that I go to is way in [the city] and sometimes I don't have that kind of money to be coming back and forth and that's how it made it hard.” Iliana (23, Biracial, trans woman, South)

A lack of personal transportation or money for public transportation also made it difficult for some participants to pick up their prescriptions and medication refills, or difficult to do so discretely. Isa (22, Mestizo, trans woman, West) explains, “because sometime I could not get, um, all the way to the pharmacy because I don't have enough bus tickets.” With regard to adherence to ART, lack of money was the only unique theme, which is plausible given that TGDY may not have the funds to sustain adherence to ART once they initiate therapy.

Clinic/organizational system levels

At the clinic and organizational system levels, there were fairly consistent themes across all stages of the CoC, including (i) availability and awareness of services, (ii) confidentiality and privacy, and (iii) service-related concerns. In addition, the theme of navigating the system was present for all stages of the CoC, except HIV testing.

Availability and awareness. Availability and awareness of services included a lack of sufficient HIV testing and care services in the youth's area—or a lack of awareness of services that were offered in their area. In addition, several youth were not aware that various HIV-related services existed, or expressed a concern about the lack of availability of services for TGDY.

“Um, my only experience with it was like, a gay pride parade, um, I was like 15 and just, yeah, I was sexually active so they had the free testing there, so I said why not, like, it's free, it's there, so, like that, that was like my only option for getting tested. I didn't know of any other places that I could get tested, you know.” Kay (19, American Indian, trans woman, West)

Confidentiality and privacy. Participants expressed concerns regarding their confidentiality and privacy being breached when they seek services at the various clinics and organizations connected with the HIV CoC. This included both anticipatory concerns regarding confidentiality that discouraged them from seeking services, as well as actual incidents where their confidentiality was potentially compromised, leading them to miss future appointments.

“I was afraid - - the only thing I would be afraid of, I will be honest, is waiting in the waiting room and seeing someone come that knew me or that I knew them and they'll see me there and be like, what are you doing here?” Julie (23, white, unsure, South)

“Yes, um, first time I was kinda nervous cuz when I walked into the place where I had to pick up my meds at ADAP, I seen

a bunch of people and it was like, “Oh my gosh, I wonder if they gonna yell my name out” or you know, yell my medicine out. So, it was kinda nerve-wracking and nervous at the same time when I first picked up my prescription or whatever, it was nerve-wracking.” Pru (23, black, genderqueer/gender non-conforming, South)

Service-related concerns. All CoC stages included themes that represented some form of service delivery-related concerns, including service delivery for testing, linkage, and retention; service environment for testing and initiation of ART; and service location for linkage, retention, and adherence. Barriers related to service delivery included wait time and frequency of appointments, inflexibility regarding changing appointments, non-youth-friendly services, and discontinuity of care (e.g., changes in their case worker or medical provider).

“The waiting time, you would be in there like all day and if you have a job you just can't be gone all day and it's just like it was just awful so I left...” Marceline (23, black, trans woman, South)

“I hate when they transfer me to different case managers and things like that, and that's why I don't even like come and see the case manager because you all introduce me to somebody and then next year they leave and then a couple months now, they relocate, they get fired and things like that, like it's just hard and everything...” Genevieve (24, Biracial, female, Midwest)

Service environment barriers included both the location where services were provided and the perceived culture of the organization providing services. Julie (23, white, unsure, South), described the environment of the pharmacy where she gets her prescriptions as “being a hook-up place more than a ‘let me go get help’ place.” She explains,

“You go to that pharmacy, there's a thousand other people there that you're probably going to see there that you don't want to see and then when you sit there, you - - they bother you sometimes because I guess they're going through the same process that you are so they think that you want to hook up.”

Maya, (22, Biracial, trans woman, West), described her concerns with the clinic where she first received her HIV diagnosis:

“First of all, they're very bland, like they're just non-emotional, very non-emotional. Just ... OK, we're here for you... we'll get you a doctor, like very to the point, you know. It was never, uh, um, sympathy or concern or anything like that, you know, how you feelin? It was nothin like that. It was just like OK, you're positive. We're gonna send this to the lab, get your viral load, and take it to the doctor...”

Navigating the system. The theme of navigating the system emerged for all CoC stages, except for testing. Participants detailed challenges as they enrolled (or attempted to enroll) in a variety of new programs and services, each with their own requirements, often in separate locations with different hours. When asked to describe what it was like when she received her first prescription for ART, Julie (23, white, unsure, South) explained,

“I think the number one, um, the number one thing was not understanding what was going on ... then trying to learn the whole process. ... I had no idea what I was doing, so they're just like we're going to get this done, we're going to get that

done, were going to get this done for that. And you're just like, that's so much going on right now, I don't understand what I'm doing, so when they would give you your prescription you're like, 'Ok so where do I go for this?' Ok, you go here to that address. You don't know what to expect it's completely different from [the hospital], you have to go somewhere else completely—to a pharmacy."

Another participant, Selena (22, black, trans woman, Northeast) explained how navigating the system at the pharmacy can be difficult:

"Sometimes [the pharmacy] gives me a headache and sometimes they have one [medication] and they don't have the other. Then sometimes they get all three of them and then they don't get in contact with me and then you know the prescription expires. It's just ... it depends."

When asked what made it difficult to attend their first HIV medical appointment, Angel (22, black, genderqueer/gender nonconforming, South) shared her navigation frustrations:

"You really didn't get any of the info that your supposed to first and that's frustrating from clinic to clinic and they are trying to figure out this and figure out that, so it was just it's a lot, a lot to go through where it does weigh on you. Eventually you do start to like be upset you do get pissed off because your tired of wait, so."

Interpersonal system levels

The themes that emerged in the interpersonal system were the most consistent across all five stages of the CoC, with all stages containing the following major themes: (i) negative provider interactions, (ii) lack of social support and instrumental support, and (iii) disclosure of HIV status. An additional subtheme of social undermining was revealed within the social support major theme, and only occurred within testing and linkage to care.

Negative provider interactions. Participants described a wide variety of negative interactions with providers (defined here to include all types of healthcare and social service providers). These included anticipation of, or experiences with, provider verbal interactions that demonstrated a lack of respect for the adolescent's autonomy and stated health concerns; and that were stigmatizing toward the participants' gender identity/expression, sexuality, socioeconomic status, or HIV status. In addition, there was a concern that some providers did not possess the ability to relate to TGDY, and failed to have adequate transgender health knowledge and sensitivity to HIV disclosure. Other provider concerns expressed included a lack of clear communication and explanation, as well as a lack of follow-up.

Naomi (20, Biracial, trans woman, Northeast) spoke about the judgment and dehumanization she felt when she went for an HIV test,

"Then, the second time [I got tested] I'm looked at as another person of this community that is possibly sick, ya know, and that's why this is just such an uneasy feeling because don't look at, I'm a human just like you. So don't make me feel less than no matter what you may think it is. Who are you to make me feel less than, ya know so."

Participants also described the judgmental language they heard and looks they received from providers while receiving care:

"The lady ask me why you here, why you so young, you coming get tested, what are you doing, where your parents at, are you having sex like she was real rude. She was and then she was saying oh you boys always—why you gay boys wanna be womens always having sex with men and doing all kind of other stuff." Jordyn (18, black, genderqueer/gender nonconforming, South)

Specific transphobic interactions included providers making direct antitransgender statements, providing suboptimal care, and misusing TGDY's correct name or pronouns. TGDY described the looks they received from some providers, the judgment those looks implied, and how they were spoken to in dehumanizing ways:

"Uh, I know the lady [service provider] said oh you gay and you want to be—you want to be womens or wannabes always—you always coming in with that and you know what you be—you know what you guys be doing is wrong and that's why that happens to you, I don't feel sorry for you and stuff like that." Jordyn (18, black, genderqueer/gender nonconforming, South)

"Just how they [service providers] looked and how they talked. You could tell how demeaning people are, when they're talking to you." Sasha (21, black, trans woman, Midwest)

Pru, (23, black, genderqueer/gender nonconforming, South) explained how her gender identity impacted her perception of the quality of the care she received:

"So, umm, I felt that I was bein' looked at and judged because of that, you know, 'Oh, this is just a transgender, that's, you know, not ready to change the life that I was livin'" and I feel like if, I was, you know, talked to, you know, I felt like I was given the run around here more than anything."

Lack of social support and instrumental support. TGDY youth also reported a lack of needed support from others across all stages of the CoC, both in terms of social support and instrumental support (e.g., tangible and informational support). Participants spoke of a lack of social support as both an isolating and lonely experience, as well as a barrier that prevented them from receiving care. Naomi (20, Biracial, trans woman, Northeast) explained how a lack of perceived care from her community impacted her experiences linking to HIV care: "Like no one really, again no one cared. No one cared. So it was just like, again why should I ... if no one cares about me and my life, why should I care about me and my well-being, ya know?"

Alyssa (19, black, trans woman, Midwest) describes how isolated she was after learning she was living with HIV:

"I really didn't have anyone to talk to and I didn't want to talk to just anyone who could go tell other people that I had it. I couldn't talk to my mother about it because she would have told me that it wasn't right. I basically just kept everything to myself because I didn't want people to look at me a certain way."

Liliana (20, Latina, female, Northeast) described the lack of support she felt when her "social worker of the year left and [she] got assigned a new one" because she "felt like [the new social worker] didn't have experience with trans people and the HIV thing."

Within testing and linkage to care, there was an additional subtheme of social undermining, which was characterized by a sense of competition within the transgender community at

testing and linkage to care facilities. When asked how her transgender community affected her experiences with HIV testing, Liliana (20, Latina, female, Northeast) said,

“...everyone knows each other so it - - that was the bad thing for me and, um, you know, I felt like, you know, when you go to these places like it’s a mini - - a mini competition like, you know, you have to always be on your top game and like, you know, look, you know, the best and stuff.”

Disclosure of HIV status. Finally, themes of disclosure and fear of disclosure of HIV status were present as barriers across all CoC stages. In the testing stage, participants described this barrier as an inability to tell others about their testing experiences. Cortney (21, black, genderqueer/gender nonconforming, Northeast) said, “I would never tell a soul that I’m even thinking about getting a test let alone the result too, you know, for any reason.” Phoebe (23, black, genderqueer/gender nonconforming) explained that she had to have “somebody drop [her] off like four or five blocks away ‘cuz [she] didn’t want them to know where [she] was going, so that was kind of hard to deal with, kinda hard.”

TGDY also described their fear of seeing someone they know at the clinic or in the waiting room and how that fear impacted their ability to receive care. Alyssa (19, black, trans woman, Midwest) shared,

“...it was hard too, walking through this door, and from that elevator from the first floor all the way through the lobby like this is the death walk ride, come through this waiting room. You know I am here. I might see someone that I was - just all of the emotions and it was a lot. I was worried that someone would see me and know what I am here for.”

Disclosure and fear of disclosure also affected TGDY youth’s difficulties taking their ART if those around them did not know they were living with HIV:

“Um, it was hard because I didn’t disclose it with a lot of friends. I didn’t, you know, tell everybody, um, so, I first started taking my meds at like noon time, by lunch and it was hard if I was with a group of friends or out in public to take the meds at that certain hour, so it was a little difficult.” Alley (23, black, trans woman, Northeast)

Discussion

The current study was conducted to gain insights into the experiences of TGDY across five stages of the HIV CoC—HIV testing, linkage to care, initiation of ART, retention in care, initiation of ART, and adherence to ART. Within each stage, we explored barriers to that stage along three nested socioecological environmental systems that are known to influence adolescent development and functioning^{32,33}—sociocultural, clinic/organizational, and interpersonal. Given the lack of empirical information regarding the barriers that TGDY face along the HIV CoC, this study utilized qualitative inquiry to provide a comprehensive, inductive, and youth-centered approach to understanding the lived experiences of TGDY youth.

Experiences across socioecological environmental systems

Patterns and distributions of major themes emerged across all socioecological systems. Within the sociocultural system, societal oppression and discrimination, housing, law and

policy, and access were all themes that appeared across all five stages of the CoC. Black community distrust of the medical system only appeared as a major theme for the initiation of ART. This appears to be the most relevant stage for such a phenomenon to occur since some youth may be aware of race-related injustices that have occurred in the United States public health system (such as the Tuskegee syphilis study), and thus be hesitant to initiate medication use. With regard to adherence to ART, lack of money was the only unique theme, which is also plausible given that TGDY may not have the funds to sustain adherence to ART once they initiate therapy.

At the clinic and organizational system levels, there were fairly consistent themes across all stages of the CoC. Confidentiality and privacy, and availability and awareness of services were both themes for all CoC stages. Thus, if clinics and organizational care systems and structures cannot guarantee TGDY that their personal information will be kept private and confidential, youth will not be willing to seek services there. In addition, several youth were not aware that various HIV-related services existed, or expressed a concern about the lack of availability of services for TGDY. The theme of navigating the system emerged for all CoC stages, except for testing, indicating the lack of proper guidance and navigational resources for TGDY once they receive a test confirming their HIV diagnosis.

All CoC stages included themes that represented some form of service-related concerns, including service delivery for testing, linkage and retention, service environment for initiation of ART, and service location for adherence. If clinics and organizations are able to focus on creating and providing services and service spaces that are TGDY friendly and affirming, they will likely attract and retain more TGDY.

The themes that emerged in the interpersonal system were the most consistent across all five stages of the CoC, with all stages containing the following major themes: negative provider interactions, lack of social support and instrumental support, and disclosure of HIV status. Two stages (testing and linkage to care) included the additional theme of social undermining, which was characterized by a sense of competition within the transgender community at facilities that provided testing and/or linkage to care services. The pervasive nature of interpersonal challenges across all stages of the CoC speaks to the need to provide service providers with training and support to improve their interactions with TGDY, which may include strategies for increasing gender affirmation during provider interactions.

TGDY also reported a lack of needed support from others across all stages of the CoC, both in terms of social support and instrumental support (e.g., tangible and informational support). This deficit could be addressed by providing TGDY with culturally specific and developmentally appropriate instrumental support, as well as helping youth to increase their social support networks both in the clinic and in their home environments.

Finally, disclosure of HIV status was a theme that was present across all CoC stages, addressing the need to help TGDY with disclosing their status to those individuals for whom it is most important, and critical knowledge, such as sexual partners, service providers, and potential social support persons. This suggests a need for providing culturally sensitive counseling and psychotherapy services for TGDY, and assuring that such services are easily accessible both physically and relationally.

Future research and implications of findings

This study included the perspectives of TGDY living with HIV from 14 cities across the United States. Although this was a large sample of youth from diverse geographic regions, future research should continue to explore the experiences of TGDY living with HIV in other areas of the United States and include representation of these youth in all aspects of study design and implementation. Most of the current literature on TGDY living with HIV is focused on challenges and risks faced by these youth. Although this analysis was focused on barriers to participation in the HIV CoC, it is important to also highlight the resilience exhibited by TGDY as they attempt to overcome these barriers.

As a strengths-based framework for understanding why some people remain protected and healthy despite exposure to risks, resilience is characterized as a dynamic process whereby a person can positively adapt within contexts of significant adversity and avoid negative outcomes typically associated with risk exposure.^{42–45} It has been recommended that primary and secondary HIV prevention efforts would be more efficacious if they incorporated a greater focus on a population's naturally occurring sources of resilience. Future research should explore the resilience processes exhibited by TGDY youth, and then develop interventions that promote such processes among other TGDY youth.

Social support and affirming interpersonal relationships can serve to promote the health and wellbeing of TGDY adolescents. Supportive families, acceptance from peers, friendships with other TGDY individuals, and participation in Gay–Straight Alliances (student-led, school-based clubs that aim to provide a safe place for lesbian, gay, bisexual and transgender (LGBT) students) have all been linked to positive outcomes for TGDY youth.^{46–49}

Because families of origin may be unsupportive, many TGDY youth form families of choice, such as participating in House and Ball communities, a subculture consisting primarily of young African American and Latino gay and bisexual men and transgender women. There they find support and acceptance, mitigating some of the negative effects of stigma and life stress.^{50–52} Finding ways to develop, enhance, and support health-promoting interpersonal relationships with a focus on HIV testing and care may help youth to progress more smoothly and successfully through the CoC.

Our findings also provide insights into how to improve the quality of HIV-related care for TGDY. Clinicians providing services to youth living with HIV can adopt practices to improve the quality of care provided to TGDY youth. The first is to ensure that TGDY are treated with respect in every clinic interaction, from their first call to make an appointment, to the waiting room, to interactions with clinicians, to interactions with pharmacists. TGDY encounter prejudice and discrimination throughout many areas of their lives; countering these experiences by affirming youth's gender identity is vital to establishing a good healthcare experience.

To provide such care, providers must understand the importance of social and cultural influences on TGDY's health beliefs and behaviors and how these factors affect an individual's experiences. This can be achieved by moving away from a framework of cultural competence, which falsely implies that a person can achieve the outcome of competence in another person's culture, and toward a framework of cultural humility. This is a process whereby people continuously engage in self-

reflection and self-critique as lifelong learners and reflective practitioners. It requires humility in how providers develop and maintain mutually respectful partnerships with both patients and communities, and address power imbalance that exists in the dynamics of the patient–provider relationship.⁵³

Clinicians can improve the care provided to TGDY by taking the time to learn about the multiple stressors and concerns experienced by a particular young person within their various socioecological environmental systems, and seek to understand how the youth is prioritizing and approaching their various life issues. Clinicians should understand that HIV may not be a TGDY's most pressing need. Thus, inquiring about other areas of youth's lives, such as housing and food stability, and providing needed resources will increase TGDY's ability to stay engaged in care.

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Address correspondence to:

Gary W. Harper, PhD, MPH

Department of Health Behavior and Health Education

University of Michigan School of Public Health

1415 Washington Heights

Ann Arbor, MI 48109-2029

E-mail: gwharper@umich.edu