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Ecological Barriers to HIV Service Access among Young Men who have Sex with Men and High-Risk Young Women from Low-resourced Urban Communities

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Abstract

Using an ecological perspective, we sought to elucidate the perceived barriers preventing HIV service access among two groups of U.S. youth (ages 12–24) disproportionately affected by HIV, men who have sex with men and high-risk women. We content analyzed interviews with 318 key informants to identify distinct service barriers. The 29 barriers informants named were organized into six categories (service-seeking demands, stigmas, knowledge and awareness, service quality, powerful opposition, and negative emotions). Findings suggest that barriers impacting access to HIV prevention, testing, and linkage-to-care services are remarkably similar and point to the need for comprehensive approaches to improving youth's access services that address both individual-level barriers and extra-individual barriers simultaneously. Findings can be used to guide future research, programming and interventions to reduce the disproportionate spread of HIV among US youth.

Keywords

Adolescents and young adults; HIV service access; service barriers; youth-responsive services

Introduction

HIV among Youth

In the United States (U.S.), youth, between the ages of 12 and 24, account for more than 20% of all new Human Immunodeficiency Virus (HIV) diagnoses (Centers for Disease Control and Prevention [CDC], 2017). Approximately 62,000 U.S. youth have acquired HIV (CDC, 2017). Despite continuously high rates of HIV acquisition, HIV testing rates remain low. Compared to adults, youth are much less likely to get tested and be aware of their infection (CDC, 2017). Approximately 51% of youth ages 18–24 who have acquired HIV are living with undiagnosed infections and may be unknowingly transmitting the virus

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(CDC, 2017). Young men of color who have sex with men (YMSM) are least likely to know their status and utilize HIV services (CDC, 2017; Zanoni & Mayer, 2014). Compared to other groups of youth who have acquired HIV, YMSM of color are significantly less likely to receive healthcare, be adherent to antiretroviral medication, or achieve viral suppression (CDC, 2017). Young women who live in impoverished U.S. communities with limited healthcare access are also at elevated risk of undiagnosed HIV (CDC, 2004; Prado et al., 2013). In a recent 5-year period, the estimated rate of HIV infections increased 15% among women and only 1% among men (CDC, 2014). Young women who must engage in survival sex or have unprotected sex with MSM may be at an even higher risk for HIV acquisition (Boyer et al., 2017; Montgomery, Mokotoff, Gentry & Blair, 2003). African American and Latinx youth are less likely to have HIV services available or accessible to them (Zanoni & Mayer, 2014, World Health Organization, 2014).

The prevalence of HIV among youth points to failures in both primary and secondary prevention, highlighting the need for further examination of the unique barriers youth face when accessing all types of HIV services. The National Strategy for HIV/AIDS aimed to reduce new infections, increase access to care, and promote coordinated national response to HIV (The White House, 2010). Despite national prioritization of coordinated services, the vast majority of research on HIV focuses on an individual sector of HIV (e.g., prevention, testing, or linkage-to-care). Few studies have examined similarities among barriers to prevention, testing, and linkage-to-care that may collectively contribute to our nation's failure to address the HIV epidemic among youth. This study responds to this call to action by classifying barriers that may uniquely or commonly impact prevention, testing, and linkage-to-care among youth.

Ecological Systems Framework

The disproportionate concentration of undiagnosed HIV and limited HIV service access in specific groups of U.S. youth is driven by factors across their social ecology. Mugavero and colleagues' modified ecological systems framework (Figure 1) places engagement with HIV services in the context of factors at the individual, relational, community, healthcare system, and policy levels (Mugavero et al., 2011; 2013). This framework accounts for the important developmental, psychological, social, and structural needs of U.S. youth who have increased risk of exposure (Philibin et al., 2014; DiClemente, Salazar, & Crosby, 2007).

Mugavero et al.'s (2013) ecological systems framework is especially useful for organizing factors that serve as barriers to HIV prevention, testing, and linkage-to-care service access. Individual factors deterring HIV service access among U.S. youth, particularly YMSM, include fear, shame, internalized stigma, risky behaviors and lack of readiness for care (Denno, Chandra-Mouli, & Osman, 2012; Mimiaga et al., 2009; Fortenberry, Martinez, Rude & Monte, 2013; Philbin et al., 2014; Remien et al., 2015; Kurth, et al., 2015). Relational factors among youth include fear that using services will require disclosing sexual behavior or HIV status (Catania et al., 2015) and poor interpersonal experiences with providers who are unskilled at working with youth (Philbin et al., 2014; Travers & Paoletti, 1999). Healthcare or service system barriers to youth's HIV service access include fragmented health systems and failure of services to address cultural and social aspects of

healthcare, particularly surrounding racial, ethnic, and sexual identity (Harper, 2007; Prado, Lightfoot, & Brown, 2013). Community factors such as poverty, weak transportation systems, inaccessible service locations, and negative societal beliefs about HIV and sexual health may also impede access (Kurth, et al., 2015; Kinsler, et al., 2007). Policy barriers affecting youths' access to HIV services include public policies, appropriations, and regulations such as restrictions on comprehensive sex education in schools, inability to consent for healthcare and social services, and lack of availability of public coverage of medical and ancillary services (Kohler, Manhart, & Lafferty, 2008).

Mugavero's ecological framework also highlights how various ecological factors that drive HIV service engagement among youth may have differential importance or operate in meaningfully different ways across high-risk groups. For example, at the individual level, different types of stigma are likely to impact the service use of YMSM of color compared to those of young women in underserved communities. Both groups will be impacted by the internalization of cultural reticence to discussing sexuality with adolescents (DiClemente, 1991; Glickman, 2000; Williams, Prior & Wegner, 2013) and cultural stigmatization of HIV (Ackard & Neumark-Sztainer, 2001; Darlington & Houston, 2017; Carr & Gramling, 2004). However, the way in which stigmas affect service access for young women may differ from young men. YMSM's service access may be affected by internalized homophobia (Santos, et al., 2013) and young women by sexism or gender bias (Hahm et al., 2012; Gomez & Marin, 1996) Each of these internalized stigmas is related to factors at multiple levels including the community (e.g., societal stigmas), policy (e.g., discriminatory policies), and service system level (e.g., discriminatory practices). The ecological perspective meaningfully organizes the complex set of factors driving HIV services access and highlights that their influence is likely to vary among at risk YMSM and heterosexual young women.

Current Study

Taken together, few studies have explored how multi-level barriers may impact different aspects of HIV service access. Given this, we sought to classify socioecological barriers to HIV prevention, testing, and care among two groups of U.S. youth who are disproportionately affected by HIV, YMSM of color and high-risk heterosexual women in underserved communities. To this end, we conducted inductive and deductive content analyses of interviews with youth and adult key informants from communities targeted by 14 Connect-to-Protect (C2P) coalitions to identify and address the root causes of HIV among these high-risk groups of youth. We sought to answer the following research questions:

1) What barriers affect HIV prevention, testing, and linkage-to-care service access and utilization among high-risk youth?

2) How are HIV prevention, testing, and linkage-to-care barriers distributed across levels of youth's social ecology?

3) What are the similarities and differences between HIV prevention, testing, and linkage-to-care barriers faced by YMSM of color and those faced by heterosexual young women?

Method

Context

This study was conducted within the context of C2P, a 10-year (2006–2016) community mobilization effort led by the Adolescent Medicine Trials Network for HIV/AIDS Interventions. C2P coalitions in 14 U.S. cities were charged to identify and address community-specific root causes of HIV for high-risk youth ages 12 to 24 (Ziff et al., 2006). Examples of coalition-identified root causes included: youth homelessness, sexual abuse, lack of access to mental health services, lack of HIV education in schools. Coalitions focused on enacting structural and community changes related to HIV prevention, access to HIV testing, community capacity development, and linkage-to-care for newly diagnosed youth. Seven coalitions chose to focus efforts on YMSM and seven focused on young women in underserved communities. Coalitions were coordinated by local adolescent medicine clinical trials units (see Table 1). Additional information about the C2P coalitions' processes and outcomes can be found in [deleted for blind review]. During the final 2 years of the C2P project, key informant interviews were conducted with adult and youth community leaders deemed knowledgeable about HIV issues among local youth.

Procedures

Each C2P coalition coordinator used Outcome Mapping (Earl, Carden, & Smutylo, 2001) to identify appropriate categories of key informants. Coordinators nominated 15 to 20 potential key informants for interviews based on outcome mapping results (N= 461 potential interviewees). Program evaluators who were uninvolved in coalition operations recruited informants and conducted all interviews. Initial contacts with prospective informants were made by phone and email. We reached 676 informants within seven attempts, of whom 318 agreed to participate in a telephone interview. A consent document was emailed or mailed to the informant in advance of their telephone interview. Verbal consent to participate was obtained at the time of the telephone interview. All informants were contacted by trained interviewers whose work was routinely quality checked.

The 37-item semi-structured interview protocol was crafted specifically to document perceived contributions of the coalitions to local change and evidence of their accomplishments. The interview also addressed obstacles to change and areas of unmet need (i.e., What needs to change in your community to improve efforts to prevent HIV exposure in your community?). The protocol was divided into sections addressing these issues for HIV prevention, HIV testing, and linkage-to-care. A final section asked about the strengths and weaknesses in the local coalition's functioning and sustainability. Informants received a $25 gift card for their time. Interviews lasted between 45 and 60 minutes, were audio recorded, and later transcribed. Data collection procedures were reviewed and approved by [deleted for blind review], and by each site's human subjects' research protections review board. For additional details about study procedures please see: [deleted for blind review]

Participants

Fifty youth and 268 adult informants completed key informant interviews. Youth key informants ranged between the ages of 16 and 24 (M =22.08 years old). Informants held jobs

or positions that pertained to HIV among youth such as case managers, health educators, healthcare professionals, linkage-to-care specialists, HIV test counselors, researchers, non-profit staff, and outreach workers. The majority of informants worked directly with youth and were knowledgeable about youth service access issues. Additional characteristics of the informants are displayed in Table 2.

Data Analysis

To prepare the data for analysis, final transcripts were imported into NVivo software for coding (Hrusckha et al., 2004). We analyzed transcripts in two phases using inductive and then deductive content coding (Bernard, 2002; Krippendorff, 1980). In the inductive phase, trained coders identified all barriers that limit youths' access to HIV prevention, testing or linkage-to-care services using open and axial coding. Emerging results were discussed and disputes in classification of themes were settled by the first author. For the deductive coding phase, a codebook was developed by the first author to categorize the ecological level and HIV service sector for each barrier identified in the inductive phase. The codebook was informed by Mugavero and colleagues' (2013) adapted ecological framework (Figure 1) and focused on defining the ecological levels at which barriers occurred: Individual, relationships, healthcare system (or service system), community, and policy. To ensure rigor, all transcripts were double-coded in each phase by a team of trained research assistants. When disagreements emerged, they were discussed and resulted in refinement of the codebook or coding procedures until acceptable interrater agreement was reached (> 0.9). After completing coding, we extracted quantitative information from NVivo and imported the data into SPSS. Descriptive statistics and frequencies were conducted to assess quantitative data.

Results

Results are provided for the overall sample and for whether informants focused on issues pertinent to YMSM or young women. Additionally, although informants discussed HIV prevention, testing, and linkage-to-care separately in the interview, there were no differences in the barriers they discussed pertaining to each of these sectors. As such, we describe barriers pertinent to all sectors rather than discuss HIV prevention, testing, and linkage-to-care separately.

Barriers to Youth Services

Table 3 summarizes the results of our inductive analyses. We coded an average of eight passages of text on HIV service barriers per informant (range = 0–32), for a total of 2,452 instances. We identified 29 distinct barriers, three of which—the financial cost of service seeking (14.5% of all passages), HIV stigma (10.8%), and inadequate sexual health education (10%)—accounted for a third of the passages. The next most frequently discussed barriers—unsupportive provider interactions (5.5%), opposition from schools (4.6%), inadequate services (4.3%), competing priorities (4.2%), inaccessible service locations (4.1%), limited service focus on YMSM or young women (4.1%), transportation problems (3.9%) and difficulty navigating healthcare systems (3.9%)—accounted for another third of the discussions. We further classified the 29 service barriers we identified into six types:

demands of service seeking (32.7%), stigmas (19.6%), knowledge and awareness (17.2%), service quality (15.0%), powerful opposition (11.5%), and negative emotions (4.1%).

Service-seeking demands.—Barriers related to the demands of seeking HIV services accounted for 36% of passages describing service barriers by YMSM-focused informants and for 30% by those focused on young women. Informants emphasized how service-seeking demands acted jointly to prevent access. For example, one adult informant described the relationships among cost, transportation problems, and competing demands:

> "… [the] *different barriers they may be facing, whether that's transportation. If they're low socioeconomic status, they may be working after school to help out the family. Young moms in our community don't have access to child care. HIV just doesn't fall high on their priority list.*
>
> –Adult Informant: Young Women-focused Site

With one exception, barriers classified as demands were discussed at similar rates across informants who spoke about YMSM and young women. Inaccessible locations, which was the fifth most discussed barrier among YMSM-focused informants (6.6%), was far less frequently discussed by those informants who worked with young women (2.2%).

Stigmas.—One fifth of the passages focused on societal stigmas related to HIV, sexuality, and sexual orientation. These stigmas were said to leave youth fearful of, reluctant to, or unable to access services. HIV stigma was discussed most frequently (9.4% of YMSM passages and 11.8% of young women passages). Informants reported widespread discrimination against those living with HIV, exceptionalism of HIV compared to other chronic diseases, and societal perceptions of HIV as a "*gay disease*" and "*death sentence.*" These stigmas were said to influence youth's perceptions of how welcome and well-treated they would be in diverse service settings. The comments of one informant illustrated the manner in which stigma was perceived to relate to service access:

> "Just being infected. There's a stigma about that. There's a stigma about actually taking the test. People don't want to go in and take the test that is known for treatment, because they think that their friends are going to say, 'Oh, you must have that.'"
>
> –Adult Informant: Young Women-focused Site

Informants also discussed barriers stemming from negative attitudes and beliefs about sex among youth. Informants described how adults who interact with youth (e.g. parents, teachers, providers, religious leaders) often viewed sex a "*taboo subject*", "*uncomfortable,*" or "*inappropriate*". Informants from young women-focused sites noted "slut-shaming" between female youth and staff as a common occurrence. Discomfort with sex and disbelief that youth are sexually active was said to leave few adult mentors with whom youth could openly talk about sex:

> A lot of youth identify as not having a safe person to talk to about sex with… Parents, teachers, and even people who work in healthcare have been telling them

> [youth] 'you can't talk to me about anything'…it creates an environment where there are consequences for talking about sex openly with an adult.
>
> –Adult Informant: YMSM-focused Site

Informants from all coalitions described how homophobic and heteronormative views in their communities and in the institutions that serve youth (e.g., schools) adversely affected youth's comfort and willingness to access services. Sexual minority stigmas were discussed more frequently by informants from YMSM-focused coalitions (4.1% of instances, eighth in frequency) than by their counterparts who focused on young women (1.2%, >20th frequency). For example, one informant said:

> I think I would still say shame and stigma. Addressing those issues would greatly benefit linkage-to-care activity. We need to deal with people's internal shame and homophobia, as well as external homophobia in the community.
>
> –Adult Informant: YMSM-focused Site

Knowledge and awareness.—Just under one-fifth of barrier passages focused on a lack of sexual health education in communities, youth's lack of awareness of where and how to seek out services, and youth's inaccurate perceptions of HIV acquisition risk. Informants described how absent or inaccurate sexual education in schools, homes, and communities adversely affected youths' use of HIV services. For example, one informant described how without comprehensive sexual health education in schools, youth receive inaccurate information:

> "My experience with adolescents lets me know that a lot of information they receive, if it does not come from home, if they are fortunate in the few instances where it does come from home, it comes from their peers. It comes from acquaintances on the street and often that is misinformation."
>
> –Adult Informant: YMSM-focused Site

Informants noted that youths' inaccurate perceptions about their risk of contracting HIV, which they often saw as related to youth's lack of exposure to accurate information, could lead youth to feel "*untouchable*". Informants described how these inaccurate perceptions of risk impacted perceptions of HIV services as relevant for youth and the general community. Informants also pointed to youth's and adult's lack of awareness of where and how to seek out HIV services.

Service quality.—Fifteen percent of the passages described how the poor quality and inappropriateness of HIV services hindered access and utilization. Informants described how unsupportive interactions with service providers, especially among YMSM and youth of color, led to their reduced service use. Informants also described how a lack of staff, resources, and formal regulations limited the reach and scope of services available to youth, in turn reducing the possibility of their use of services. For example, several informants described how some linkage-to-care providers might not have the knowledge and resources to retain a homeless youth in medical care. Informants also described youth — especially female youth — as less likely to engage with HIV services that they perceived as catering to

adult, gay white men. One informant described how lack of intentional focus on young women hinders HIV prevention:

> "It can be an obstacle into care…The young ladies thinking, 'Well, they're not targeting me, so I must not be at risk'… They are at higher risk."
>
> –Adult Informant: Young Women-focused Site

Powerful opposition.—Youth's lack of autonomy to make their own decisions and limits on their agency prescribed in law and regulations inhibited their resource access, according to multiple key informants (11% of passages). Compared to informants from YMSM-focused sites, informants from young women-focused sites discussed youth's lack of power and opposition to their agency more frequently (7% vs 15.1% of discussions). Most of these passages focused on opposition from schools surrounding sexuality education as a prime influence on service access, which was the third most common barrier identified by informants working with young women and the 13th among informants working with YMSM (5.9% and 3.1%, respectively). In the following quote, a youth informant described the influence of schools:

> The curriculum has to be abstinence based…but you can talk about other preventive methods. You can talk about condoms. You cannot talk about homosexuality. You cannot talk about abortion. You cannot pass out condoms and you cannot do testing in schools unless you're a health care professional in a school clinic.
>
> –Youth Informant: Young Women-focused Site

Opposition to supportive programs and endorsement of restrictive policies from legislators was the sixth most commonly identified barrier among young women-focused informants and the 20th among YMSM-focused informants (5% vs 1.7%). For instance, informants noted that access is prevented when legislation requires parental consent for services. The comments of the following informant are illustrative:

> "You know, some of these kids are having a hard time getting into or to be seen into clinics because they have to have parental permission. And, the way the structure of the HIV services are here, you had to have parental permission to get covered for health care."
>
> –Adult Informant: Young Women-focused Site

Politicians—via their influence on legislation—were also seen as influencing access (e.g., "**…** *our governor shoots down anything that would benefit the youth"*). Religious institutions were among the other powerful institutions named as negatively affecting access to HIV services through their influence on local attitudes and social mores.

Negative emotions.—The least frequently discussed barriers concerned emotional needs and feelings including fear, discomfort, mistrust, denial and other emotional and psychological states. For instance, informants discussed fear of needles and of going to get tested as a barrier to accessing services. Barriers in this category were discussed at similar rates across YMSM- and young women-focused informants.

Ecological Classifications of Barriers

Table 4 summarizes the ecological classification of the six categories of barriers according to Mugavero's and colleagues' ecological framework (2013). As we show, about 30% of barriers focused on the characteristics of youth (individual-level barriers) and the remaining 70% of barriers focused on extra-individual issues (11% relational, 31% service system, 20% community-level, and 9% policy). Across participants, most of the individual-level barriers pertained to the demands of services seeking, such as economic difficulties and the need to prioritize basic survival over health concerns. Extra-individual barriers were most likely to be described at the service-system level. Informants primarily described qualities of organizational, medical, and educational environments that were ill-suited to attend to the needs of youth and difficult to navigate. Across ecological levels, informants from YMSM- and young women-focused coalitions spoke about barriers across levels with similar frequency, except that informants from young women-focused coalitions were twice as likely to discuss social policy (5.5% vs. 11.1%). Barriers were often discussed as occurring at multiple levels. This was particularly the case for barriers such as economic difficulties, lacking sexual health education, and lacking service awareness. One informant's comments are illustrative:

> I think a lot of that is about transportation issues. It's about poverty. It's these much larger structural issues that are really barriers to people being engaged and taking action around these issues. And, as agencies I think we often sort of at a loss, like particularly when you don't have enough funding. I think it's really hard to get traction on that conversation. But, the ability for folks to get around the region and have access to medical care and prevention services, I think that's a huge barrier.
>
> –Adult Informant: YMSM focused site

Similarities and Differences among YMSM and Young Women

We examined similarities and differences in barriers identified by informants at C2P sites focused on YMSM (1,354 barriers) and young women (1,098 barriers). Overall, there was significant overlap in the types of barriers discussed by informants, with few notable differences. Prominent barriers discussed at YMSM-focused sites more often centered on lack of cultural competency with YMSM or YMSM of color, while prominent barriers at young women-focused sites often concerned sex negative interactions and HIV stigma. Informants at YMSM and young-women focused sites perceived poverty, lack of job opportunities, and homelessness to be significant barriers to service access, but with informants from young women-focused sites pointing out the additional economic burden to women of securing childcare in order to access health services. Finally, informants who worked with young women were more likely to note inadequate funding for female-focused HIV initiatives. Informants working with males were more likely to identify lack of access to basic resources such as stable housing as barriers to services.

Discussion

Given the disproportionate effect of the HIV epidemic on youth in the U.S., addressing barriers that restrict youths' access and use HIV prevention, testing, and linkage-to-care

services is crucial to improving health outcomes. The current study sought to identify the barriers preventing HIV service access and utilization among two groups of U.S. youth disproportionately affected by HIV, YMSM and heterosexual young women in underserved urban communities. Our findings confirm the presence of multi-systemic barriers affecting youth service access. We expand on the current HIV service access literature by gaining insight on these challenges from a large, diverse pool of youth and adult service providers from multiple cities, allowing us to link barriers to the social systems and settings influencing service access among youth.

Barriers across Youths' Social Ecology

Overall, our findings suggest that accessing HIV services as a youth is tremendously difficult, as youth face unique barriers at every level of their social ecology. Consistent with other studies (Ayala et al., 2013; Philibin et al., 2013; Kurth, et al., 2015; Denno, et al., 2012; Mashburn, et al., 2004), we find that at the individual level, youth are challenged by economic difficulties, competing priorities, internalized stigmas and knowledge gaps. Similarly, at the relational level, pervasive discomfort with youth sexuality contribute to unsupportive relationships for youth. At the systems level, youth face complex system navigation and providers who are ill-trained in dealing with groups of diverse youth. At the policy level, societal ambivalence about youth's sexuality and agency pervade public policies. These findings underscore the importance of addressing barriers across all levels of youth's social ecology.

Three types of barriers— knowledge and awareness, and stigmas, demands service seeking — accounted for the majority identified barriers, and were most likely to be discussed at several ecological levels and equally for YMSM and young women. Lack of knowledge and awareness about sexual health and the respective services available to youth emerged as a dire need in all communities. Informants remarked that parents, providers, schools, and legislators consistently took steps to restrict youth access to sexual health education on the basis that it equates to a permission to engage in sexual activity, depriving youth of opportunities to learn about their health.

HIV-stigma, sexual stigma, and negative attitudes about sex contributed to a culture in which youth were said to feel embarrassed and unsafe accessing services. They anticipated ridicule and shaming from parents, providers, and peers. Although the impact of HIV-stigma on service seeking is well-known among youth populations (Brown, Macintyre, & Trujillo, 2003; Rao et al., 2007; Earnshaw & Chaudoir, 2009; Gamarel, et al., 2017), we found that sexual stigma and negative attitudes about sex additionally contributed to an environment in which youth felt unsafe and ashamed. Although normalizing HIV testing remains an important objective for youth (Mashburn et al., 2004; Dorell et al., 2011; Ayala et al., 2013), our findings suggest other forms of stigma pose obstacles to accessing other HIV-related services. Efforts to educate and normalize discussions about sex and sexuality might be effective at reducing stigma as a barrier to all HIV services. Large scale stigma interventions addressing several types of stigmas (e.g., HIV, sexuality, sexual orientation) should be considered to improve at risk youth's utilization to HIV-related services.

The demands of service seeking were widely perceived to overwhelm youth's capacity. Services were described as costly, stigmatizing, inaccessible, and unnavigable, creating conditions that are unreasonable for anyone in need to face and especially youth, who may not have the skills in self-advocacy and systems navigation typical of an adult. The demands of service seeking might be mitigated by holistic centralized care that intentionally integrates peripheral support services and medical care in a common location (Davila et al., 2013) and creates close collaboration between service providers and youth serving organizations (Li, Que, & Power, 2017). Integrated programs that provide linkage to medical services, social services, and assistance with growing skills for everyday living are well-structured to assist youth's connection with the health care system and may lead to enhanced social and behavioral health outcomes.

Informants questioned how youth could prioritize HIV prevention, testing, and care services when they lacked the means to meet their needs for basic survival. Economic issues were particularly salient themes. Informants described youth as facing poverty, scarce employment opportunities, and limited access to resources to meet the most basic needs of living. For youth alienated from their families due to lack of acceptance of sexual activity, sexual identity, gender identity or HIV status, these conditions may be especially severe (Zanoni & Mayer, 2014). Although the Affordable Care Act and other social service benefits are available to youth, due to their more limited skills in navigating complex systems, youth may depend more heavily on the healthcare system to access these entitlements, to facilitate their service entry. Too few HIV service agencies are adequately funded to assist youth overcome these barriers (Doshi, Malebranche, Bowleg, and Sangaramoorthy, 2013). Moreover, a dearth of interventions target the economic factors that can impact youth's access to HIV services (Prado et al., 2013).

Similarities and Differences among YMSM and Young Women

In these data, the barriers to service access for YMSM and young women were similar, with two prominent exceptions. Informants who were knowledgeable of the issues affecting young women spoke more frequently about the impact of conservative and sex-phobic social policies on young women and about sexual minority stigma on YMSM. Although these are not surprising, they point to the importance of efforts to normalize understanding of sexual orientation diversity and female sexuality. Given this finding may be a product of the geographic location of the young women-focused sites (see Table 1), future research should strongly consider incorporating local political and social climate in research and intervention efforts. Another prominent difference between the YMSM and young women sites concerned inadequate focus on services for young women and YMSM of color was often mentioned. These data suggest continued efforts to increase the number and responsiveness of services to the needs of minority young women and MSM remain a priority.

Limitations

The original intent of our key informant interviews was to assess the contributions of the C2P coalitions to local improvements, not to assess barriers to ongoing services per se. Barriers were discussed extensively, however, in the context of informants' considering what work remained in their communities. It is not clear, had barriers been the primary focus,

whether each of the barriers we identified would have been discussed at a similar frequency. Moreover, because we explored barriers in the context of cities with coalitions seeking to address these kinds of barriers, it is unclear how our findings might apply to cities without coalitions working over long periods to address these issues. Our approach rendered important insights into youth HIV services in fourteen specific and geographically diverse communities, however the degree to which findings transfer to any other community is uncertain and an important direction for future research. Moreover, we were not able to meaningfully examine regional differences in these data as the target populations of the coalition sites were not equitably distributed across regions. Future research should consider exploring the impact of geographic location on barriers to accessing HIV services and resources.

Our reliance on quantitative content analytic techniques to describe informants' views also has limitations. Greater frequency does not necessarily imply greater importance, as was best illustrated by our findings on the role of stigma. Although stigma was discussed less often than other barriers, informants described it as a root cause of other barriers, suggesting its importance is far greater than can be represented by tallying how often it is mentioned. Finally, although the perceptions of informed community members offer novel insight into the HIV epidemic in these communities, future research should consider complementing community member perceptions with those of youth at-risk or living with HIV to provide a more comprehensive picture of service access barriers facing youth.

Conclusions

Our work meaningfully advances research in an area of important public health need: the study of HIV prevention, testing and linkage-to-care service accessibility among YMSM and young women in economically challenged communities. We identified 29 distinct service barriers and fit these to a typology that can be used to organize them. Findings suggest that barriers impacting each of these three HIV service sectors are remarkably similar, highlighting the continuing need for coordinated service delivery and universal intervention strategies to assist youth in accessing diverse forms of care. Our findings point to the need for comprehensive approaches to improving youth's access to HIV prevention, testing, and healthcare services that address both individual-level barriers and extra-individual barriers simultaneously. Findings underscore the importance of attending to specific barriers to services faced by YMSM and young women in underserved communities.

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References

Ackard DM, & Neumark-Sztainer D (2001). Health care information sources for adolescents: age and gender differences on use, concerns, and needs. Journal of Adolescent Health, 29(3), 170–176. [PubMed: 11524215]

Ayala G, et al. (2013). Access to basic HIV-related services and PrEP acceptability among men who have sex with men worldwide: barriers, facilitators, and implications for combination prevention. Journal of Sexually Transmitted Diseases, 2013.

Bernard H (2017). Research methods in anthropology: Qualitative and quantitative approaches Rowman & Littlefield.

Brown L, Macintyre K, & Trujillo L (2003). Interventions to reduce HIV/AIDS stigma: what have we learned? AIDS Education and Prevention, 15(1), 49–69. [PubMed: 12627743]

Boyer CB, Greenberg L, Chutuape K, Walker B, Monte D, Kirk J, … & Adolescent Medicine Trials Network. (2017). Exchange of sex for drugs or money in adolescents and young adults: an examination of sociodemographic factors, HIV-related risk, and community context. Journal of community health, 42(1), 90–100. [PubMed: 27498094]

Carr R, & Gramling L (2004). Stigma: a health barrier for women with HIV/AIDS. Journal of the Association of Nurses in AIDS Care, 15(5), 30–39.

U.S. Centers for Disease Control and Prevention, HIV/AIDS Surveillance Report, 2014:13

U.S. Centers for Disease Control and Prevention, HIV/AIDS Surveillance Report, 2003 2004:15.

U.S. Centers for Disease Control and Prevention. Diagnoses of HIV infection in the United States and dependent areas, 2016. HIV Surveillance Report 2017; 27.

Darlington CK, & Hutson SP (2017). Understanding HIV-related stigma among women in the Southern United States: A literature review. AIDS and Behavior, 21(1), 12–26. [PubMed: 27492025]

Davila J, Miertschin N, Sansgiry S, Schwarzwald H, Henley C, & Giordano T (2013). Centralization of HIV services in HIV-positive African-American and Hispanic youth improves retention in care. AIDS care, 25(2), 202–206. [PubMed: 22708510]

Denno D, Chandra-Mouli V, & Osman M (2012). Reaching youth with out-of-facility hiv and reproductive health services: A systematic review. Journal of Adolescent Health, 51(2), 106–121. [PubMed: 22824440]

Denning P, & DiNenno E (2010, 7). Communities in crisis: is there a generalized HIV epidemic in impoverished urban areas of the United States. *In* XVIII international AIDS conference.

DiClemente R, 1991 Predictors of HIV-Preventive Sexual Behavior in High-Risk Adolescent Population: The influence of Perceived Peer Norms and Sexual Communication on Incarcerated Adolescents Consistent Use of Condoms. Journal of Adolescent Health, 12(385–390). [PubMed: 1751507]

DiClemente R, Salazaar LF, & Crosby R. a. (2007). A review of STD/HIV preventative interventions for adolescents: Sustaining effects using an ecological approach. Journal of Pediatric Psychology, 32(8), 888–906. [PubMed: 17726032]

Dorell C et al. (2011). Missed opportunities for HIV testing in health care settings among young African American men who have sex with men: implications for the HIV epidemic. AIDS Patient Care and STDs, 25(11), 657–664. [PubMed: 21923415]

Doshi R, Malebranche D, Bowleg L, & Sangaramoorthy T (2013). Health care and HIV testing experiences among Black men in the South: implications for "Seek, Test, Treat, and Retain" HIV prevention strategies. AIDS Patient Care and STDs, 27(2), 123–133. [PubMed: 23268586]

Earl S, Carden F, & Smutylo T (2001). Outcome mapping: Building learning and reflection into development programs Ottawa, ON: International Development Research Centre.

Earnshaw VA, & Chaudoir SR (2009). From conceptualizing to measuring HIV stigma: a review of HIV stigma mechanism measures. AIDS and Behavior, 13(6), 1160. [PubMed: 19636699]

Fortenberry J, & Martinez J, Rudy B, Monte D (2013). Linkage to care for HIV-positive adolescents: A multi-site study of Adolescent Medicine Trials Unit of the Adolescent Trials Network, 51(6), 551–556.

Gamarel KE, Nelson KM, Stephenson R, Rivera OJS, Chiaramonte D, Miller RL, & Adolescent Medicine Trials Network for HIV/AIDS Interventions. (2017). Anticipated HIV Stigma and Delays in Regular HIV Testing Behaviors Among Sexually-Active Young Gay, Bisexual, and Other Men Who Have Sex with Men and Transgender Women. AIDS and Behavior, 1–9.

Glickman C (2000). The language of sex positivity. Electronic Journal of Human Sexuality, 3.

Gomez CA, & Marin BV (1996). Barriers to HIV prevention strategies for women. The Journal of Sex Research, 33, 355–362.

Hahm H, Lee J, Rough K, et al. (2012). Gender power control, sexual experiences, safer sex practices, and potential HIV risk behaviors among young Asian-American women. AIDS and Behavior, 16 179–188. [PubMed: 21259042]

Harper G (2007). Sex isn't that simple: culture and context in HIV prevention interventions for gay and bisexual male adolescents. The American Psychologist, 62(8), 803–19. [PubMed: 18020756]

Hruschka D, Schwartz D, John D, Picone-Decaro E, Jenkins R, & Carey J (2004). Reliability in coding open-ended data: Lessons learned from HIV behavioral research. Field Methods, 16(3), 307–331.

Kinsler J, Wong M, Sayles J, Davis C, & Cunningham W (2007). The effect of perceived stigma from a health care provider on access to care among a low-income HIV-positive population. AIDS patient care and STDs, 21(8), 584–592. [PubMed: 17711383]

Kohler P, Manhart L, & Lafferty W (2008). Abstinence-only and comprehensive sex education and the initiation of sexual activity and teen pregnancy. Journal of Adolescent Health, 42(4), 344–351. [PubMed: 18346659]

Kurth A, Lally M, Choko A, Inwani I, & Fortenberry J (2015). HIV testing and linkage to services for youth. Journal of the International AIDS Society, 18(2).

Krippendorff K, 1980 Content Analysis. An Introduction to its Methodology Sage Publications Ltd., London.

Li X, Que H, & Power K (2017). Welcome to "the Rock": Service Providers' Views on Newcomer Youth Integration in Newfoundland and Labrador. Journal of International Migration and Integration, 1–18.

Mashburn A, Peterson J, Bakeman R, Miller R, & Clark L (2004). Influences on HIV testing among young African-American men who have sex with men and the moderating effect of the geographic setting. Journal of Community Psychology, 32(1), 45–60.

Mimiaga M, et al. (2009). Health system and personal barriers resulting in decreased utilization of HIV and STD testing services among at-risk black men who have sex with men in Massachusetts. AIDS Patient Care and STDs, 23(10), 825–35. [PubMed: 19803696]

Montgomery JP, Mokotoff ED, Gentry AC, & Blair JM (2003). The extent of bisexual behaviour in HIV-infected men and implications for transmission to their female sex partners. AIDS Care, 15(6), 829–837. [PubMed: 14617504]

Mugavero M, Amico K, Horn T, & Thompson M (2013). The state of engagement in HIV care in the United States: from cascade to continuum to control. Clinical Infectious Diseases, 57(8), 1164–1171. [PubMed: 23797289]

Mugavero M, Norton W, & Saag M (2011). Health care system and policy factors influencing engagement in HIV medical care: piecing together the fragments of a fractured health care delivery system. Clinical infectious diseases, 52(suppl_2), S238–S246. [PubMed: 21342913]

Philbin M, Tanner A, Duval A, Ellen J, Kapogiannis B, & Fortenberry JD (2014). Linking HIV-positive adolescents to care in 15 different clinics across the United States: creating solutions to address structural barriers for linkage to care. AIDS Care, 26(1), 12–9. [PubMed: 23777542]

Prado G, Lightfoot M, & Brown CH (2013). Macro-level approaches to HIV prevention among ethnic minority youth: state of the science, opportunities, and challenges. The American Psychologist, 68(4), 286–99. [PubMed: 23688095]

Rao D, Kekwaletswe T, Hosek S, Martinez J, & Rodriguez F (2007). Stigma and social barriers to medication adherence with urban youth living with HIV. AIDS care, 19(1), 28–33. [PubMed: 17129855]

Remien R, et al. (2015). Barriers and facilitators to engagement of vulnerable populations in HIV primary care in New York City. Journal of Acquired Immune Deficiency Syndromes, 69, 16–24.

Santos G, et al. (2013). Homophobia as a barrier to HIV prevention service access for young men who have sex with men. Journal of Acquired Immune Deficiency Syndromes, 63(5), e167–e170. [PubMed: 24135782]

Travers R, & Paoletti D (1999). Responding to the support needs of HIV positive lesbian, gay and bisexual youth. Canadian Journal of Human Sexuality, 8(4), 271–283.

Williams D, Prior E, & Wegner J (2013). Resolving social problems associated with sexuality: can “Sex-Positive” approach help?. Social work, 58(3), 273–276. [PubMed: 24032308]

Zanoni B, & Mayer K (2014). The adolescent and young adult HIV cascade of care in the United States: exaggerated health disparities. AIDS Patient Care and STDs, 28(3), 128–135. [PubMed: 24601734]

Ziff MA, Harper GW, Chutuape KS, Deeds BG, Futterman D, Francisco VT, … & Adolescent Medicine Trials Network for HIV/AIDS Intervention (2006). Laying the foundation for Connect to Protect: A multi-site community mobilization intervention to reduce HIV/AIDS incidence and prevalence among urban youth. Journal of Urban Health, 83, 506–522. [PubMed: 16739051]

World Health Organization. (2014). Consolidated guidelines on HIV prevention, diagnosis, treatment and care for key populations

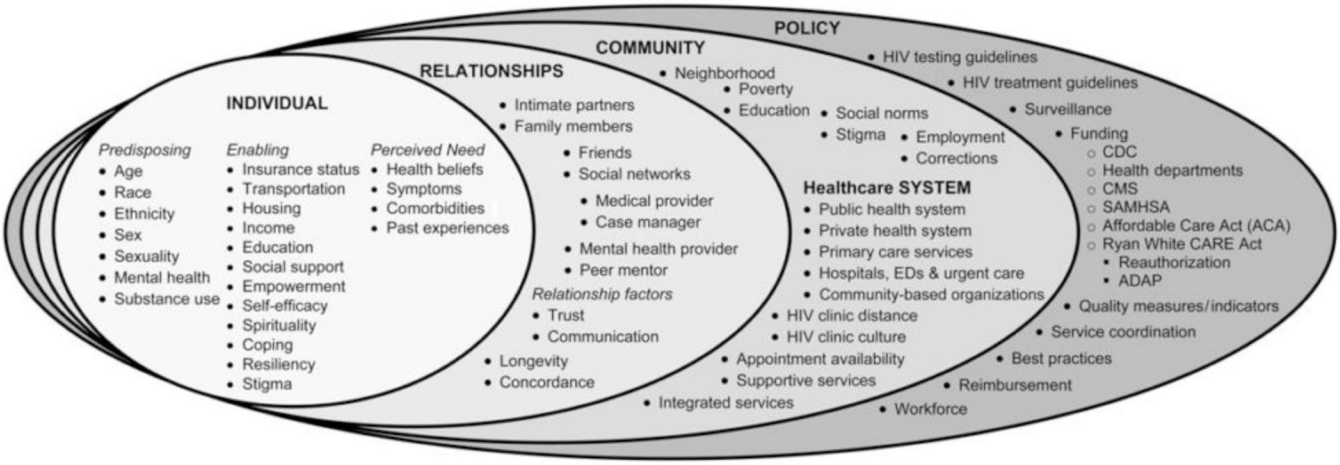

Figure 1.
Adapted socioecological framework (Mugavero et al. 2013)

Table 1.

C2P Coalitions and Focus

Location	Convening Institution	Coalition Focus
Baltimore, MD	Johns Hopkins University	YMSM
Boston, MA	Fenway Health	YMSM
Bronx, NY	Montefiore Medical Center	Young Women
Chicago, IL	John H. Stroger Jr. Cook County Hospital	Young Women
Denver, CO	University of Colorado Children's Hospital of Denver	YMSM
Detroit, MI	Wayne State University Medical Center	YMSM
Houston, TX	Baylor College of Medicine/Texas Children's Hospital	Young Women
Los Angeles, CA	Children's Hospital of Los Angeles	YMSM
Memphis, TN	St. Jude's Research Hospital	Young Women
Miami, FL	University of Miami School of Medicine	Young Women
New Orleans, LA	Tulane University Health Sciences Center	Young Women
Philadelphia, PA	Children's Hospital of Philadelphia	YMSM
Tampa, FL	University of South Florida	Young Women
Washington, DC	Children's National Medical Center	YMSM

Table 2.

Characteristics of Key Informants (N=318)

		N (%)
Employment Sector		
	Community-based or non-government organization	111 (35%)
	Healthcare/medicine	55 (17%)
	Government	54 (17%)
	Education	46 (14%)
	Business	7 (2%)
	Other	45 (14%)
Relationship to Local C2P Coalition		
	Member	235 (74%)
	Former Member	16 (5%)
	Never Member	63 (20%)
	Unspecified	4 (1%)
		M (Range)
Time in Current Position		6.6 years (2 months-31 years)

Table 3.

Frequencies and Percentages of Identified Barriers to Accessing Services

Barrier Type	YMSM		Young Women		TOTAL	
	Freq	%	Freq	%	Freq	%
Number of Barrier Passages	*1098*	*100*	*1354*	*100*	*2452*	*100*
Service seeking demands	**394**	**35.9**	**408**	**30.1**	**802**	**32.7**
Financial Costs	168	15.3	187	13.8	355	14.5
Other competing health and social priorities	43	3.9	60	4.4	103	4.2
Inaccessible locations	72	6.6	30	2.2	102	4.1
Transportation problems	37	3.4	59	4.4	96	3.9
Difficulties navigating healthcare system	51	4.6	45	3.3	96	3.9
Service hours	23	2.1	27	2.0	50	2.0
Stigmas	**210**	**19.1**	**270**	**19.9**	**480**	**19.6**
HIV stigma	104	9.4	161	11.8	265	10.8
Negative attitudes about sex	25	2.3	51	3.8	76	3.1
General or other stigmas	36	3.3	41	3.0	77	3.1
Sexual minority stigma	45	4.1	17	1.2	62	2.5
Knowledge and awareness	**179**	**16.3**	**242**	**17.9**	**421**	**17.2**
Inadequate sexual health education	106	9.6	139	10.3	245	10
Lack of awareness of services	43	2.7	50	3.7	93	3.8
Low perception of HIV risk	30	3.9	53	3.9	83	3.4
Service quality	**178**	**16.2**	**190**	**14.0**	**368**	**15**
Incompetent and unsupportive interactions	76	6.9	59	4.3	135	5.5
Poor service provision and capacity	58	5.3	48	3.5	106	4.3
Limited target population focus	23	2.1	78	5.7	101	4.1
Lack of representative or qualified staff	21	1.9	5	0.4	26	1
Powerful opposition	**77**	**7.0**	**204**	**15.1**	**281**	**11.5**
Schools (administration, teachers, board)	34	3.1	80	5.9	114	4.6
Legislation (state, local, national)	19	1.7	67	5.0	86	3.5
Parents	10	0.9	19	1.4	29	1.2
Politicians	2	0.2	14	1.0	16	0.6
Faith-based institutions	1	0.09	9	0.7	10	0.4
Juvenile justice system	2	0.2	7	0.5	9	0.4
Other	7	0.6	2	0.15	9	0.4
Partners	2	0.2	6	0.4	8	0.3
Negative emotions	**60**	**5.5**	**40**	**3.0**	**100**	**4.1**

Barrier Type	YMSM		Young Women		TOTAL	
	Freq	%	Freq	%	Freq	%
Fear	23	2.1	18	1.35	41	1.7
Diagnosis	12	1.1	14	1.05	26	1.1
Discomfort	18	1.6	6	0.45	24	1
Trust	7	.06	2	0.15	9	.4

Table 4.

Analytic Barrier Category by Ecological Level for YMSM and Young Women

Ecological level	Proportion of Instances by Sample		
Analytic Barrier Category	YMSM	Young Women	Overall
Individual	**30.9**	**28.7**	***29.7***
Knowledge and Awareness	6.1	6.3	*6.2*
Powerful Opposition	0.0	0.0	*0.0*
Negative Emotions	4.1	2.4	*3.2*
Stigmas	5.0	5.3	*5.1*
Service Quality	0.6	0.2	*0.4*
Service-seeking Demands	15.0	14.5	*14.8*
Relationship	**11.1**	**11.2**	***11.1***
Knowledge and Awareness	0.8	1.5	*1.2*
Powerful Opposition	1.5	2.1	*1.8*
Negative Emotions	0.5	0.3	*0.4*
Stigmas	3.0	4.8	*4.0*
Service Quality	4.3	1.8	*2.9*
Service-seeking Demands	1.0	0.7	*0.9*
Service System	**33.2**	**29.8**	***31.3***
Knowledge and Awareness	5.6	4.7	*5.1*
Powerful Opposition	2.7	5.8	*4.4*
Negative Emotions	0.5	0.1	*0.3*
Stigmas	1.6	1.5	*1.5*
Service Quality	10.0	9.3	*9.6*
Service-seeking Demands	12.8	8.5	*10.4*
Community	**19.4**	**19.2**	***19.3***
Knowledge and Awareness	3.3	4.2	*3.8*
Powerful Opposition	0.4	1.1	*0.8*
Negative Emotions	0.3	0.2	*0.2*
Stigmas	9.4	8.0	*8.6*
Service Quality	0.5	1.8	*1.3*
Service-seeking Demands	5.5	3.8	*4.6*
Policy	**5.5**	**11.1**	***8.6***
Knowledge and Awareness	0.6	1.2	*0.9*
Powerful Opposition	2.5	6.1	*4.5*
Negative Emotions	0.1	0.0	*0.0*
Stigmas	0.1	0.4	*0.2*
Service Quality	0.7	0.9	*0.8*
Service-seeking Demands	1.6	2.5	*2.1*