Risk Factors for HIV Transmission and Barriers to HIV Disclosure: Metropolitan Atlanta Youth Perspectives

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Abstract

Youth carry the highest incidence of HIV infection in the United States. Understanding adolescent and young adult (AYA) perspectives on HIV transmission risk is important for targeted HIV prevention. We conducted a mixed methods study with HIV-infected and uninfected youth, ages 18–24 years, from Atlanta, GA. We provided self-administered surveys to HIV-infected and HIV-uninfected AYAs to identify risk factors for HIV acquisition. By means of computer-assisted thematic analyses, we examined transcribed focus group responses on HIV education, contributors to HIV transmission, and pre-sex HIV status disclosure. The 68 participants had the following characteristics: mean age 21.5 years (standard deviation: 1.8 years), 85% male, 90% black, 68% HIV-infected. HIV risk behaviors included the perception of condomless sex (Likert scale mean: 8.0) and transactional sex (88% of participants); no differences were noted by HIV status. Qualitative analyses revealed two main themes: (1) HIV risk factors among AYAs, and (2) barriers to discussing HIV status before sex. Participants felt the use of social media, need for immediate gratification, and lack of concern about HIV disease were risk factors for AYAs. Discussing HIV status with sex partners was uncommon. Key reasons included: fear of rejection, lack of confidentiality, discussion was unnecessary in temporary relationships, and disclosure negatively affecting the mood. HIV prevention strategies for AYAs should include improving condom use frequency and HIV disclosure skills, responsible utilization of social media, and education addressing HIV prevention including the risks of transactional sex.

Introduction

NEWLY REPORTED HIV DIAGNOSES rates in the United States (US) have decreased by 30% in the past decade.¹ However, the Centers for Disease Control and Prevention (CDC) recently reported a marked increase (38.4%) between 2002–2011 in the estimated annual percentage change in new HIV diagnoses among adolescents and young adults (AYAs) aged 13–24 years, with black males who have sex with males (MSM) experiencing the largest increases (132.5%).¹

The state of Georgia is ranked fourth highest in the nation for total number of new HIV diagnoses, with the HIV in-

fection rate in 2011 being 12.1 per 100,000 among AYAs 13–19 years of age and 72.7 per 100,000 among those 20–24 years of age.² Recent epidemiological data from the Atlanta Metropolitan Statistical Area (MSA) show that young black gay males have an HIV incidence of approximately 12.1% and that by age 39 years, up to 60% of black MSM will have acquired HIV.³ Despite this high infection rate, data on behavioral risk factors for HIV acquisition among AYAs is lacking. Georgia participates in the Youth Risk Behavior Survey (YRBS); however since it is at the states and local agencies discretion to add or delete questions based on policy or programmatic need, the state of Georgia does not include

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the questions regarding sexual behavior, and there is no other available systematic data collection system. Understanding risk factors in AYAs and behaviors leading to HIV infection is essential to improving prevention efforts.

This alarming rise in infection rates among AYAs likely reflects several challenges in healthcare access and delivery. First, AYAs historically have poor utilization of healthcare and prevention services, which affects individual outcomes and decreases the effectiveness of HIV treatment as prevention.^{4,5} Black HIV-infected AYAs have the lowest rates of viral suppression (18.3%) among all groups,⁶ and recent estimates of AYAs HIV care cascade in the US show that only 6% of HIV infected youth between 13–29 remain virally suppressed.⁷ Second, adolescence is a period characterized by psychosocial and physical developmental changes, often leading to sexual exploration associated with high-risk behaviors.⁸ According to the 2013 YRBS, 46.8% of American teens in grades 9–12 have had sex at least once, with 15% having had four or more sex partners, and only 59% having used a condom during their most recent intercourse. Yet only 13% of teens had ever been tested for HIV.⁹ Furthermore, sexual minority AYAs engage in these risk behaviors more often than their heterosexual counterparts.^{10,11}

Third, unidentified HIV-infected AYAs are a significant source of secondary HIV transmission, with higher transmissibility during the acute phase of infection.^{12–15} Although national data shows improvement in awareness of disease among HIV-infected individuals older than 18 years of age, black MSM report the lowest awareness percentage.^{16,17} In addition, there is a lack of data in populations younger than 18 years of age. In Atlanta, broad gaps along the HIV care continuum among youth are evidenced by extremely low rates of testing, linkage to care, and viral suppression.^{9,18,19} Only 57% of HIV-positive youth from Atlanta are linked to care, and only 34% achieve viral suppression.⁷ In 2011, 29% of AYAs age 13–24 were identified in stage 2 HIV (CD4 count 200–499 cells/mm³) and 12% in stage 3 (CD4 count <200 cells/mm³) at the time of diagnosis, highlighting the need for increased testing and earlier detection.⁷ This combination of poor medical access and follow-up and high-risk behaviors may have led to high rates of HIV infection in AYAs from disproportionately-affected communities.

The Metropolitan Atlanta Community Adolescent Rapid Testing Initiative (MACARTI) with Linkage into Care and Counseling Trial is an outreach initiative in the Atlanta MSA that aims to increase identification of HIV infection and linkage to care among AYAs. As part of this trial, we conducted age-specific focus groups and provided self-administered surveys to HIV-infected and HIV-uninfected AYAs ages 18–24 regardless of sex and race to identify risk behaviors for HIV acquisition and barriers to discussing HIV status prior to establishing a sexual relationship. Our goals were to understand perspectives from AYAs to inform targeted HIV prevention strategies.

Methods

In 2012–2013, researchers from the MACARTI team recruited HIV-infected and uninfected youth, ages 18–24 years, from the Atlanta MSA. Recruitment tools included flyers and presentations to community partners (AIDS Healthcare

Foundation, AID Atlanta, The Evolution Project, Positive Impact, and Atlanta Police Department) and to the Young Adult Network group within the Ponce Family and Youth Clinic (PFYC) of the Grady Infectious Diseases Program. The PFYC is a large pediatric, adolescent and young adult clinic serving the medical and psychosocial needs of over 600 HIV-infected children and AYAs (0–24 years of age).

Interested youth were screened to complete a survey and participate in a focus group. Inclusion criteria for participation in the survey and focus groups were ages 18–24 years and residency in Atlanta MSA. A mixed method methodology was selected for this phase because the study team wanted to not only quantify specific behaviors and patterns, but also be able to expand on some of them and identify new and important topics that would foster the development of an HIV testing intervention in a non-clinical setting that was specific for AYAs.

After providing written informed consent, enrolled youth completed Audio Computer-Assisted Self-Interviewing (ACASI) surveys that gauged opinions on dating, sexual behavior, and HIV testing preferences of AYAs using categorical and Likert scale (LS) responses (scales were either from 1–5 or 1–10, with one being “*never*” and five or ten being “*always*”).

Surveys were created by the study team with the input of different experts in the field. Variables collected included, demographic data such as age, gender, race, living situation, and education level. We also collected participants’ opinions regarding potential risk behaviors for HIV acquisition. These included inquiry on transactional sex to pay for food, drugs, or living expenses; the frequency and reasons for unprotected sexual encounters; and attendance and sexual engagement at sex parties.

Transactional sex was defined as exchanging sex for money or material goods including food, drugs, or living expenses.²⁰ Lastly, we inquired about local places where AYAs like to meet and addressed acceptability and ways to approach AYAs for HIV testing in non-traditional venues. The ACASI surveys took 15 min to complete.

All enrolled youth attended exploratory qualitative focus group sessions to identify target venues for HIV testing, ways to approach at-risk AYAs for testing, opinions on testing methodologies, barriers to testing, reasons for delaying entry to HIV care (if applicable), and social aspects of the HIV epidemic. Two members of the research team led the focus groups using a semi-structured guide (Table 1). The focus group discussions lasted 90–120 min. Participants were compensated \$25 for their participation. The Emory University Institutional Review Board and the Grady Research Oversight Committee approved this research study.

Quantitative data analysis

Quantitative analyses were performed using SAS 9.3 (Cary, NC); statistical significance was assessed at the 0.05 significance level. Participant characteristics were summarized using means and standard deviations for continuous variables and frequencies and percent for discrete variables. In situations of non-normality, means and standard deviations were replaced with medians and interquartile ranges. Statistical comparisons between the HIV-infected and uninfected subgroups were made using *t*-tests for continuous

TABLE 1. FOCUS GROUP MODERATOR GUIDE, MACARTI TRIAL, 2012–2013

Question number	Question
1	What do you know about HIV? Where did you learn about HIV and other STDS? /Where do you think most people in your community learn about HIV?
2	What do you think are the main factors contributing to the increase in transmission of HIV in the adolescent and young adult population?
3	Think about what's common in your circle of friends. Before they are going to have sex, is HIV part of the discussion? Why or why not?
4	What could be done to make HIV more acceptable to discuss?
5	Think about the most common places you, your friends, or other people your age go to meet people. What do you think are the most popular places? Specifically, where do you think people in your age group are meeting people to have sex?
6	If you were to go out and test, where do you think would be the ideal place to go? Why?
7	What types of things would make you want to get tested out in the community? / What types of things would make you not want to get tested?
8	What do you think is the best way to approach someone out in the community to get tested?
9	Think about what you were told when you were diagnosed. What was said that was helpful and what was said that was not? Is there anything you wish you had been told?
10	Do you think some of your friends are infected and don't know it? Do you think they will allow us to test them?
11	What motivates you/people to stay in treatment? / Why don't people your age seek out treatment
12	Think about treatment and healthcare options in your community. What is available to you? Where do your friends, family, or neighbors go? Why do they go there?

variables and Chi-square tests of independence for discrete variables. In situations of non-normality, the *t*-test was replaced by a nonparametric equivalent (Mann-Whitney U or Kolmogorov-Smirnov test); likewise, an exact form of the Pearson's Chi-square test was implemented when expected counts were low (<5).

Qualitative data analysis

One focus group moderator transcribed the group audio recordings verbatim (AW). The research team then reviewed the transcriptions for accuracy and made edits as necessary. Although the discussion guide covered several topics (Table 1), this article focuses on responses to questions on HIV education, perceptions about HIV transmission, discussion of HIV prior to sexual activity, and ways to facilitate these discussions (Questions 1–4).

A qualitative data analyst (LT) uploaded transcripts into NVivo (QSR International Pty Ltd. Version 8, 2008) and applied structural codes to the data to label each question and participants' responses.²¹ Two qualitative data analysts (AM, LT) thoroughly read each transcript. The analysts reviewed five transcripts by structural code to create an emergent, data-driven code list.²² The analysts then compared their code lists, discussed discrepancies, and created a preliminary content codebook. To ensure coding consistency, analysts independently coded two transcripts and assessed intercoder agreement using Kappa scores. The analysts reviewed and discussed codes with a Kappa score less than 0.80 until a consensus was reached. Text segments were recoded as necessary and the codebook was finalized. Each analyst then coded five of the remaining ten transcripts. Salient and co-occurring concepts were identified and organized into thematic categories.

Results

Quantitative ACASI surveys

We enrolled 68 participants: 85% male; 90% black; mean age of 21.5 years (standard deviation, SD: 1.8 years). Sixty-eight percent were HIV-infected, and 72% reported sexual activity with other males at least once during their lifetime. 50% lived with their parents or guardians, and 50% had received a high school education or less (Table 2).

Eighty-three percent of AYAs used social media to meet individuals specifically for sexual relationships; 33% met individuals through school or college. A Likert scale (1–5) on how often social media mobile applications were used to meet other people for sexual encounters, showed a mean score of 4.6 and 4.7 for HIV-infected and non-infected groups, respectively. The amount of time spent on dating mobile applications was greater than 5 h daily among 71% of HIV-infected

TABLE 2. BASELINE DEMOGRAPHIC CHARACTERISTICS OF PARTICIPANTS, MACARTI TRIAL, 2012–2013 (N=68)

Characteristic	Level	N (%)
Gender	Male	58 (85.3%)
	Female	10 (14.7%)
Race	American Indian	1 (1.5%)
	African American	61 (89.7%)
	White	3 (4.4%)
	Hispanic or Latino	3 (4.4%)
Age (mean ± SD ^a)	–	21.5 ± 1.8
HIV positive ^b	Yes	46 (67.7%)
	No	22 (32.4%)
Living situation	Parents/guardian/other family	34 (50.0%)
	Partner/friends/college	18 (26.5%)
	Group home/homeless	2 (2.9%)
	Alone	11 (16.2%)
	Other	3 (4.4%)
Education	High school or less	34 (50.0%)
	College	26 (38.2%)
	Graduate school	3 (4.4%)
	Other	5 (7.4%)

^aStandard deviation; ^bself report.

participants versus 53% of non-infected participants ($p=0.079$). The preferred place to have sex was at home (81%) or hotels (46%); however, 28% and 27% considered having sex at bathhouses and public places, respectively.

Participants believed that having transactional sex in exchange for food (78%), living expenses (88%), or drugs (84%) was a frequent practice among their peers. Using Likert Scale responses (1–10), participants were asked about perceptions on the extent to which sex without condoms occurred; a mean score of 8.0 (SD: 1.9) was reported, with participants citing personal preference (65%) and fear of rejection (58%) as the main reasons for lack of condom use. When stratified by HIV status, no significant differences were observed in any of the demographic or socio-behavioral variables, reflecting the homogeneity of both groups.

Focus group discussion results

We conducted 17 focus group discussions, 11 with HIV-infected AYAs, two with HIV-uninfected AYAs, and four with a mixed group of HIV-infected and -uninfected AYAs. All participants completing an ACASI survey also participated in a focus group discussion. Focus groups had an average of 6–7 participants and discussions centered around two main themes: (1) HIV risk behaviors among AYAs, and (2) barriers to discussing HIV status before sex. A comparison of emerging themes across focus group types identified no major differences.

HIV risk factors among AYAs. Participants attributed widespread use of social media, frequent sexual encounters, the need for “immediate gratification”, and the lack of concern about HIV acquisition and transmission as significant contributors to HIV spread. Participants noted that web- and mobile phone-based social media applications, such as Jack’d, Grinder, Adam4Adam, and Facebook, facilitated sexual encounters (especially among MSM) by identifying potential sexual partners who were nearby and available to meet. Participants attributed increased rates of HIV transmission in their age group to having multiple sex partners and having sex soon after meeting a potential partner. Participants emphasized the desire for immediate gratification, or “to get what they can at the moment,” the role of drug and alcohol use in sexual encounters, and a lack of concern for acquiring HIV as factors leading to infrequent condom use. Participants also characterized their HIV education as insufficient, completely absent, or not applicable to their lives.

The following discussions between groups of HIV-infected/-uninfected participants illustrate some of these themes. Participants in an HIV-infected group shared:

Male: My opinion is the internet makes meeting new people so convenient and I think alcohol and drug usage is another contributing factor as to why people don't take proper precaution and are kind of careless in the activities they engage into...All of our phones are internet capable. We are constantly on our phones. Text messaging allow[s] us to connect with people a lot quicker...You're kind of just meeting people for hook ups just because it's quick and easy.

Female 2: I just think a lot of people just don't care about who they meetin' nowadays or what they can get or what they can catch. People just want to get what they can at the

moment and once they get what they can at the moment they finally realize that it is spreading, that's why most people our age is spreading more rapidly than other people younger or older than us...

In another focus group with HIV-infected participants a male stated:

Male: Because nobody is using protection. They don't care about it. They're young and stupid. I know from experience when I tell people about my status, they don't care, they still want to go ahead.

Regarding HIV education, a male from an HIV-uninfected focus group shared:

Male 1: Actually they did, they did um teach some of this in school in biology. It was just a one day thing we watched a video on it, it wasn't taken as serious. Especially, students don't care, it wasn't, 'this is real, your age group is getting HIV,' it was just like, 'Today we are learning about HIV, this is what it looks like, this is what happens, you'll get a quiz.' Yeah, because when I watched the video, when a lot of people watched the video, it was just class work, it's not serious, [it's just] we gotta' do this today, I gotta' get a grade.

An HIV-infected participant stated the following when asked about HIV education:

Male 2: I found out when I came to the clinic. In school they didn't teach about it. The only thing they ever talked about was pregnancy.

Barriers to discussing HIV status before sex. Participants shared that discussing HIV status prior to sexual engagement with partners was an uncommon practice. Key themes for nondisclosure of HIV status included issues with disclosure interfering with the ability to have sex or establish a relationship due to fear of rejection or lack of confidentiality, negatively affecting the mood at the time of sex, and not being necessary unless a real relationship was established. Some HIV-infected participants shared that a feeling of personal responsibility provided motivation to discuss their HIV status before engaging in sexual activity.

An HIV-uninfected participant shared:

Male: I know it's a conversation to have as far as relationship-wise, but as far as sex I just figure as long as I wear a condom when they are giving me head or while we are [having sex], [we don't have to talk about HIV].

The following illustrates nondisclosure of HIV status due to a real relationship not being established:

Male: That's something you discuss when you married, we ain't married. You know me, I don't just go out and screw everybody and I don't feel the need to tell people. I'm not going to lie, I would not tell the person before I have sex with them, I would wrap it up because I am a chicken...it comes back to rejection. Obviously, if I was to have sex with you, I find you so attractive, so I don't want to be rejected when I tell you.

Another participant explained how discussing HIV could affect the mood at the time of sex:

Male: It's all about the heat of the moment. If you're horny and you want to do it, you not going to be like, 'Oh hold on let

me ask you a couple of questions, let me look at your medical records' and stuff like that, I mean it's just wham bam see ya later...Some people just not comfortable talking about stuff like that like even if they not positive, they not going to bring it up.

The following illustrates the personal responsibility that some HIV-infected participants shared:

Male: For me, I have to discuss it with people before I have sex with them. That would weigh very heavy on my heart; I couldn't [not tell them]. I am not going to have sex with someone on a first date. Once I get to the sex part I would tell them... People nowadays would just wrap it up [instead of disclose their status], but for me I couldn't do that. Condoms can break.

Discussion

HIV prevention strategies for AYAs in Atlanta MSA requires HIV education that includes everybody regardless of their gender or sexual orientation, and that is focused on increased condom use, responsible utilization of social media, and an understanding of the reasons behind transactional sex. The MACARTI focus group participants were mostly young black gay males and represent the population at highest risk of HIV acquisition in Atlanta MSA.^{3,7}

The need for immediate gratification and easy accessibility to peers through social media allows for the expansion and diversification of sexual partners. A study by Whiteley et al. examining the frequency of cell phone and social media use by black adolescents between 13–18 years of age, revealed that over 90% used cell phones and 60% used social networking sites daily.¹⁷ In addition, a greater frequency of cell phone and internet use was associated with sexual sensation seeking, riskier peer sexual norms and a history of oral/vaginal/anal sex.²³ Data from the Kaiser Family Foundation indicate that black and Hispanic youth spend 4.5 h more each day with electronic media than white youth.²⁴ Others studies have also documented an increase in risk behaviors that could lead to HIV and other sexually transmitted infections (STIs) among youth seeking sex partners through online technologies.^{25,26} Important next steps may include the development of HIV/STI prevention tools for AYAs through social networking approaches and other innovative tools.^{27–30}

The easy accessibility of sexual partners, irregular condom use, and absence of discussions about HIV status also place AYAs at higher risk of HIV acquisition and transmission. In the focus groups, participants indicated that lack of condom use was most often due to personal preference. Rates of sex with and without condoms have been noted in other studies. The American College Health Association-National College Health Assessment (ACHA-NCHA-II) in 2013 showed that consistent condom use among sexually active college students was low, with only 3.1%, 26.2%, and 9.7% of the participants who engaged in oral, vaginal, and anal intercourse, respectively, reporting using a condom every time they had sex.³¹

El Bcheraoui et al.³² investigated patterns of condom use among students of Historical Black Colleges and Universities (HBLO) and noted that 46% did not use a condom during their last sexual intercourse, and those who perceived themselves at average/high risk of acquiring STIs were less likely to use a condom during their last sexual intercourse (Adjusted OR: 0.6; 95% CI: 0.4–0.8). Reasons for not using condoms

included unwillingness to spoil the moment, having unplanned sex, not feeling at risk, showing commitment to a partner by not using a condom, worrying about a partner's perception of lack of trust toward him or her, being in a monogamous relationship and trusting the partner.³² Although HBCU students may differ from participants in our focus group, these results highlight the lack of condom use among a wide variety of adolescents. Addressing sex without condoms among AYAs requires urgent and novel interventions that are youth friendly, promote healthy sexual relationships, emphasize the continuity of sex-associated risks and provides tools to confront personal insecurities.

Eighty-eight percent of participants recognized that their peers had transactional sex to obtain food, housing, or living expenses. Economically motivated relationships may be common among certain groups of AYAs and influence the level of risk-taking behaviors and negotiations regarding condom use. Studies have shown that black MSM are more likely to need transactional sex for survival.^{33–35} Walls et al. examined correlates of survival sex among homeless AYAs, and documented the prevalence of transactional sex to be 9.4%.²⁸ Blacks were 2.2 times as likely to have engaged in survival sex when compared to whites. When stratified by sexual orientations, homeless MSM, lesbian, and bisexual youth were also more likely to participate in survival sex.³⁶ However, other studies have found no racial or gender differences but much higher prevalence rates of transactional sex among youth.³⁷ Further studies are required to better understand the extent of this practice and its associated risk factors among youth.

Finally, a lack of HIV education in schools may contribute to HIV acquisition among AYAs. Predefined boundaries (attitudes) towards HIV and sex education and/or HIV-related stigma by school authorities may have contributed to the lack of HIV awareness among youth. Participants observed that when education was offered, it was directed towards male–female relationships and promotion of abstinence, overlooking youth who did not self-identify as heterosexual.

The 2012 School Health Profile that is designed to measure school health policies and practices, including policies related to HIV infection and AIDS prevention as well as safe and supportive environments for sexual minority students, showed that only 1% of schools in Georgia provided curricula that engaged all five practices (identify safe spaces; prohibit harassment; encourage staff to attend professional development on safe and supportive environments; facilitate access to providers not on school property for health services; facilitate access to providers not on school property for social and psychological services) involving lesbian, gay, bisexual, transgender or questioning youth.^{9,38}

A study by Ahmed and colleagues showed that a majority of teachers supported the promotion of abstinence, and were uncomfortable teaching sexual risk-reduction strategies.³⁹ Our results indicate that expanding teachers' knowledge and increasing their comfort level towards implementation of a more comprehensive all-inclusive sexual education curriculum is of critical importance in Georgia to limit HIV transmission.

There were limitations to this study. First, we used a convenience sample of HIV-infected and -uninfected youth in Atlanta MSA that may not be representative of HIV-infected

and -uninfected AYAs in other areas of the US. Second, our convenience sample included AYAs who were willing to participate in focus groups and this requirement may have introduced unmeasured selection bias resulting in a study population with more favorable opinions of research than AYAs who declined to participate. However, having used a mixed-methods approach allowed us to obtain both individual level data as well as a collective perspective on our topics of interest. Individual level data highlighted certain areas of interest, for example, social media utilization and lack of condom use which we were able to expand on through the focus group discussions.

In summary, reducing the high HIV incidence among AYAs in Atlanta MSA calls for all-inclusive HIV education tools, strategies for increased condom use, responsible utilization of social media, and a better understanding of transactional sex practices. Empowering AYAs by improving their knowledge of sexual risk reduction, HIV acquisition, and supporting them to confront their HIV-related fears are necessary for developing healthier sexual relationships, reducing HIV incidence and ultimately reducing HIV-related health disparities.

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