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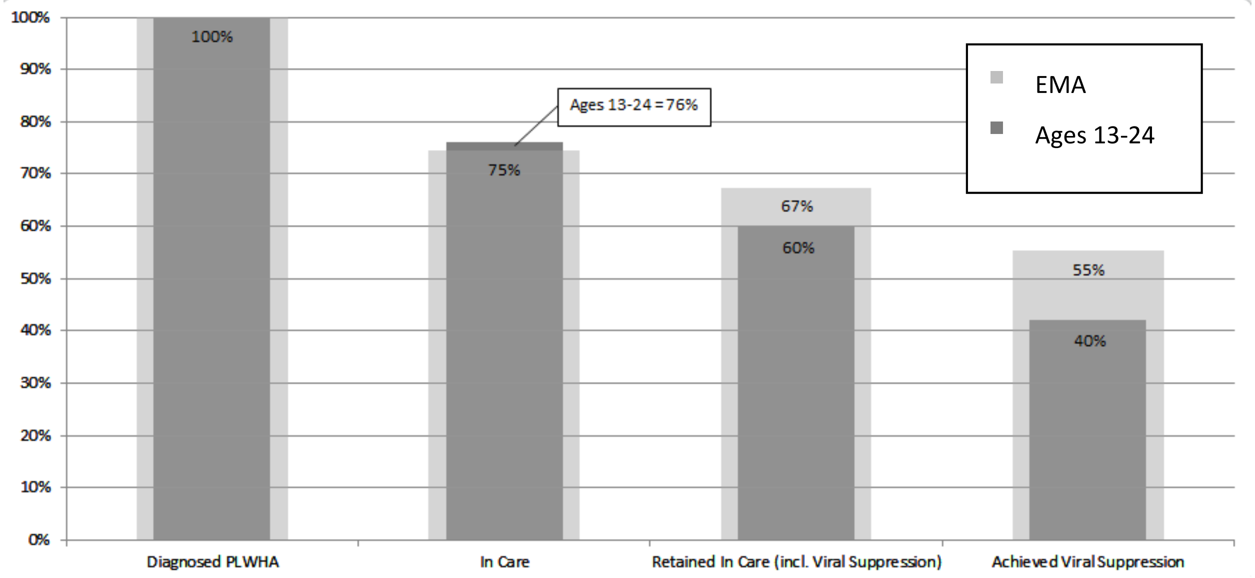
Available Data on 2012 Comprehensive Plan Special Populations

Adolescents (Aged 13 to 17)

Epidemiologic Summary (age range is 13-24):

- 2014 Prevalence (EMA): 1,364, or 5% of all diagnosed cases
- 2014 New Diagnoses (EMA): 360, or 26% of all new diagnoses
- 2014 Linkage - New Diagnoses (EMA): 239, or 74% linked w/in 3 mos.
- 2013 Late/Concurrent Diagnosis (EMA)[1]: 164, or 2% of all late diagnosis cases
- 2014 HIV Care Continuum (EMA):



From 2013 Epidemiologic Profile: "[As of 2011] a total of 125 adolescents (people age 13 to 17) [were] living with HIV in the Houston EMA. Almost all (92.8%) [were] African American or Hispanic/Latino. The majority were also perinatally infected (79.2%). However, small percentages also reported MSM (12.1%) and heterosexual contact (12.2%) as their primary risk factor. This is divergent from new HIV diagnoses in this age group in the EMA, for which the majority were either MSM or heterosexual (88.8%)."

Service Utilization (age range is 13-24):

- In 2014, the RW program served 815 youth (ages 13-24) were served, or 6.6% of all program clients

Needs Assessment & Special Studies:

- 2014 Needs Assessment: Adolescents (13-17) comprised 1.2% of the total sample surveyed.[2] Compared to the sample as a whole, adolescents experienced more barriers accessing Health Insurance Assistance and Local HIV Medication Assistance. Adolescents also reported difficulty accessing Housing Services.

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[1] Late diagnosis cases reflect the diagnosed population, not new diagnoses.

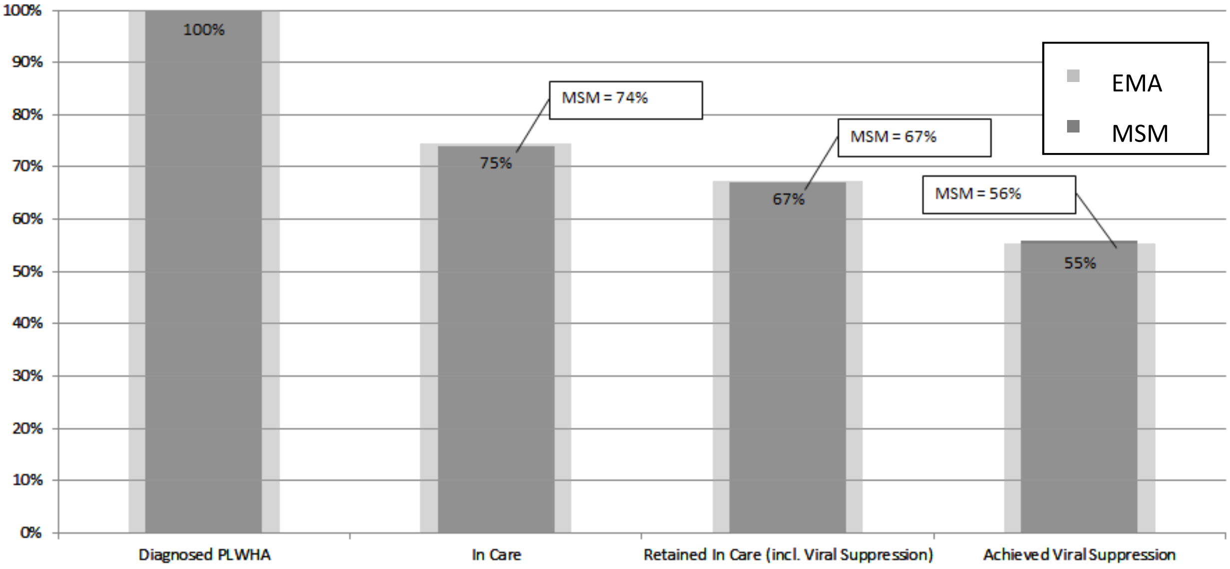
[2] Surveys completed by care takers; 8 surveys completed.

Men who Have Sex with Men (MSM)

(Men who engage in male-to-male sexual practices and identify as gay or bisexual, those who engage in male-to-male sexual practices and do not identify as gay or bisexual, and those who engage in gay or bisexual male culture regardless of gender identity (i.e., male-to-female transgender))

Epidemiologic Summary:[3]

- 2014 Prevalence (EMA): 13,759, or 55% of all diagnosed cases
- 2014 New Diagnoses (EMA): 930, or 67% of all new diagnoses
- 2014 Linkage - New Diagnoses (EMA): 706, or 78% linked w/in 3 mos.
- 2013 Late/Concurrent Diagnosis (EMA)[4]: 4,261, or 56% of all late diagnosis cases
- 2014 HIV Care Continuum (EMA):



From 2013 Epidemiologic Profile: “[From 2002 to 2011], an average of 489 MSM of color (MSMOC) [were] diagnosed with HIV in Houston/Harris County each year compared to an average of 164 White MSM annually. This breaks down to 259 African American MSM and 214 Hispanic/Latino MSM diagnosed each year on average. In addition, the number of African American MSM diagnosed with HIV has increased each year of this ten year period as did the number of Hispanic MSM diagnosed with HIV each year.”

“When analyzed by age, the numbers of newly diagnosed MSM in Houston/Harris County in each age range have remained relatively stable over a ten year period, with the exception of young MSM (MSM age 13 to 24) and MSM age 35 to 44. In the case of the former, the numbers of new HIV cases in young MSM have increased each year (from 2003 to 2010) while, in the case of MSM age 35 to 44, the numbers of new HIV cases have declined.”

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[3] Does not include MSM/IDU risk factor

[4] Late diagnosis cases reflect the diagnosed population, not new diagnoses.

Service Utilization:

- In 2014, males comprised 74% of all RW program clients served, and 75% of new clients served.

Needs Assessment & Special Studies:

- 2014 Needs Assessment: MSM (gay, bisexual, or pansexual self-identified) comprised 37.4% of the total sample surveyed. Fifty percent of out-of-care participants identified as MSM. Compared to the sample as a whole, MSM experienced more barriers accessing Early Intervention Services, Health Insurance Assistance, Housing, Legal Services, Local HIV Medication Assistance, Medical Nutrition Therapy, Oral/Dental Care, and Substance Abuse Services. MSM also reported difficulty accessing Case Management Services, Day Treatment, Food Pantry, Mental Health Services, HIV Primary Care, and Transportation.

Transgender[5]

(Individuals who cross or transcend culturally-defined categories of gender)

Epidemiologic Summary:
Gender identity for transgender and gender non-conforming individuals is generally not reflected in most epidemiologic and surveillance data. This is one of the primary shortcomings of using solely epidemiologic data to identify populations with disproportionate burden. Often transgender and gender non-conforming individuals are categorized by sex at birth, which does not accurately and adequately demonstrate current risks, needs, and barriers.

Service Utilization:

- In 2014, 93 transgender unduplicated clients were served in the RW program. or 0.8% of all clients served. Ninety-one were identified as male-to-female transgender, while two were identified as female-to-male transgender.

Needs Assessment & Special Studies:

- 2014 Needs Assessment: Transgender and gender non-conforming individuals (reporting discordant sex at birth + gender identity or expression today) comprised 3.5% of the total sample surveyed. Transgender individuals reported universal condom use (using condoms every time) in higher proportions than both cisgender men and cisgender women (63% versus 40% and 44%, respectively). Compared to the sample as a whole, transgender individuals experienced more barriers accessing Case Management Services, Food Pantry, Health Insurance Assistance, Local HIV Medication Assistance, and HIV Primary Care. Transgender also reported difficulty accessing Day Treatment, Early Intervention Services, Housing, Medical Nutrition Therapy, Mental Health Services, Oral/Dental Care, and Transportation.\
- 2013 Access to HIV Care among Transgender and Gender Non-Conforming People in Houston: Seventy-six percent of transgender individuals in the study were linked to care within three months of their HIV diagnosis. Those reporting delayed entry most often cited denial about their positive status. When asked what barriers, if any, respondents had encountered since their diagnosis, the most commonly-cited barriers were lack of transportation (44%) poor treatment from staff due to gender variance (29%), lack of funds to pay for services (28%), and denial about being HIV-positive (24%). In addition, 19% of respondents reported lack of provider familiarity with transgender needs as a barrier to care. The five most commonly reported additional needs included housing, including rental assistance and shelters for transgender individuals; transportation services; assistance with basic needs such as food and clothing; support groups for transgender individuals; and employment assistance for individuals. Eighty-four percent of respondents reported being treated differently in public due to gender variance, including 16% who reported being asked to leave a public place. In addition, 60% of respondents reported being harassed or taunted due to their gender variant status, 36% reported being threatened with violence, and 30%, 23%, and 16% reported being the victims of physical assault, sexual assault, and rape, respectively, at some time in their lives.

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[5] Here refers to both transgender and gender non-conforming individuals.

POWER Report Back
2014 and 2015 Data
Houston Specific Frequencies

Sample of All BMSM from Houston:
Total N Year 1=382
Total N Year 2= 234
Total N= 616*
*25 duplicates
Analytic Sample: 591 Participants

Table 1: Demographics for total sample of BMSM in Houston

	N=591* *% (n)*
Education	
Less than high school	6.3 (39)
High School diploma	30.6 (127)
Some college	39.8 (245)
College diploma or more	33.3 (205)
Age mean (standard deviation)	29.2 (9.6)
Health care	
Presence of health coverage	78.1 (481)
Unable to access care	22.5 (135)
US Born	98.4 (606)
Ethnicity (select all the apply)	
African American	78.3 (482)
Caribbean American	2.9 (18)
African Immigrant	1.5 (9)
Other	3.1 (19)
HIV Seroprevalence	39.7 (212)

Table 2: Seroprevalence by Age Group in Houston

Age Group	**% of Age Group HIV+**
18-19	5.0
20-24	34.1
25-29	38.0
30-34	38.3
35-39	58.6
≥ 40	65.0

Table 3: Care Continuum among BMSM in Houston

	N=591* *% (n)*
HIV Positive	31.6 (212)
Aware of Status	55.6 (118)
Linked to Care	52.4 (111)
Retained in Care	50.0 (106)
Prescribed ARVs	43.9 (93)
Undetectable Viral Load	40.0 (72)

*Includes all self-reported positives and self-reported negatives who received an HIV test

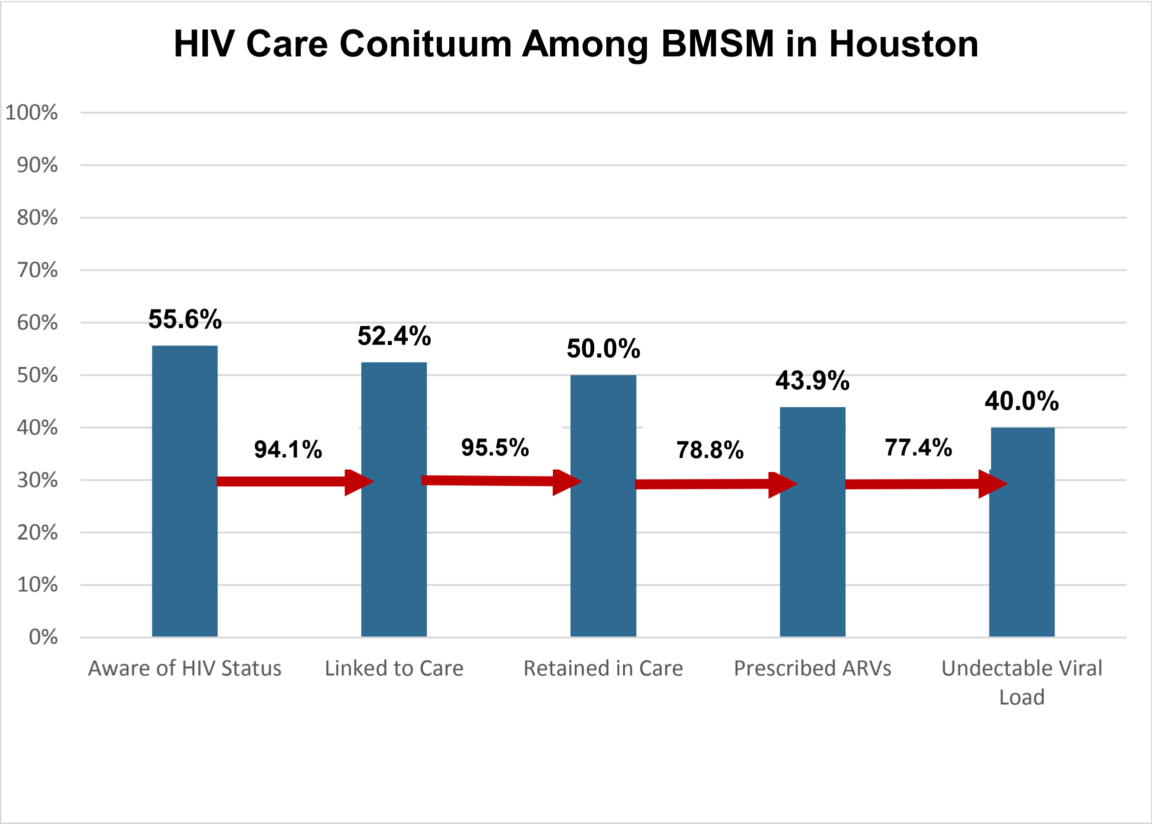


Table 3: HIV Testing in Houston

	N=591 % (n)
Received an HIV test through POWER	88.0 (520)
Tested With POWER	51.5 (268)
Tested with CBO	48.5 (252)
Never Received HIV Test	6.8 (42)
Never Received HIV test, tested with study	83.3 (35)
Tested with POWER	34.3 (12)
Tested with CBO	65.7 (23)
Received an HIV test, past 6-month	69.2 (426)
Did not receive HIV test, past 6-month	30.8 (190)
No past 6-month test, tested with study	90.5 (170)
Tested with POWER	44.7 (76)
Tested with CBO	55.3 (96)

Those who got a prior HIV test in the last X months (based on the date of last HIV test and date of survey)

Sample size	**6 months?**	**12 months?**	**24 months?**
539	353 (65.87%)	406 (75.69%)	465 (86.37%)

Table 4: Syndemic Variables in Houston

	N=591* *% (n)*
Depression	25.0 (153)
Alcohol	
Alcohol Consumption (past year)	78.9 (485)
Problematic Alcohol Consumption	118 (19.2)

Drug Use	
Poly-Substance Use	5.0 (31)
Problematic Substance Use	6.5 (40)
Marijuana	22.1 (136)
Poppers	8.3 (46)
Crack	5.6 (30)
Cocaine	9.5 (53)
Methamphetamines	3.8 (20)
Heroin	2.3 (12)
Prescription Opiates	4.2 (22)
Erectile Dysfunction Drugs	3.3 (20)
Party Drugs	5.1 (27)
Violence	
Intimate Partner Violence	19.8 (122)
Physical Assault	16.4 (101)
Childhood Sexual Abuse	25.2 (155)
Perceived Discrimination	
Race	19.3 (119)
Sexuality	21.8 (134)
HIV Status	9.4 (58)
Incarceration (past 2-years)	12.3 (80)
Homeless (past-year)	12.0 (74)

Any questions? Contact Leigh Bukowski at lab108@pitt.edu.

National HIV Behavioral Surveillance (NHBS) - MSM *Risk Behaviors*

NHBS is a surveillance system of the HIV risk behaviors of adults in the United States. Risk behaviors of men who have sex with men (MSM) are explored in the NHBS. To participate in the NHBS-MSM study a screening interview will be used to assess whether each respondent meets inclusion criteria. Respondents are eligible to complete the NHBS-MSM interview if they:

- Have not previously participated in the current NHBS-MSM cycle
- Live in the participating MSA or Division
- Are 18 years of age or older
- Were born male and self-identify as male
- Have ever had oral or anal sex with another man
- Are able to complete the interview in English or Spanish

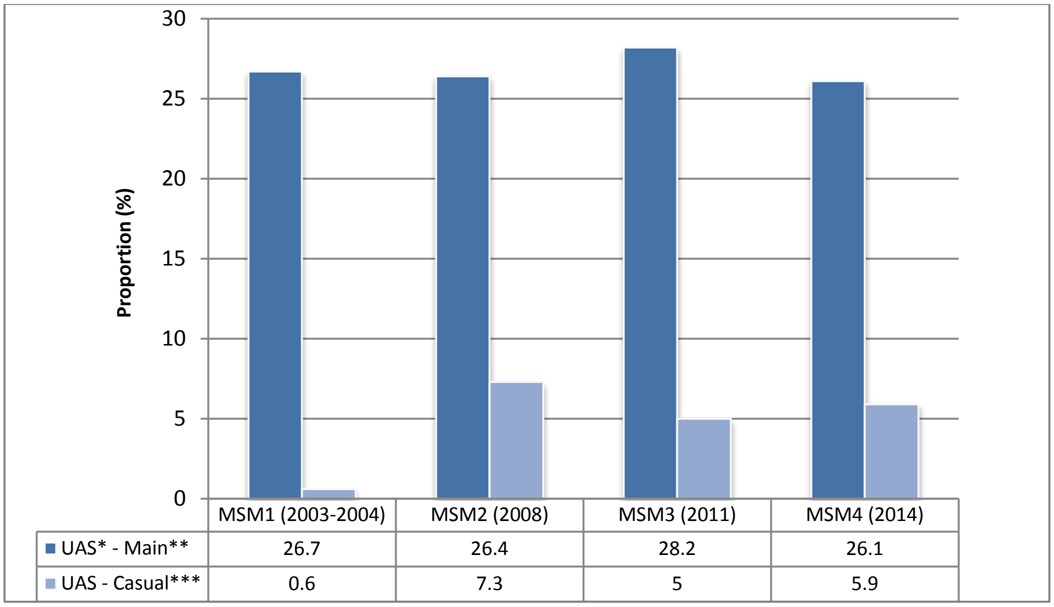
Only those participants meeting the participant inclusion eligibility criteria who also report having had sex with another man in the past 12 months count toward the required NHBS-MSM sample size of 500 current MSM. So far, four cycles of NHBS-MSM have been completed (MSM1 in 2003-2004, MSM2 in 2008, MSM3 in 2011 and MSM4 in 2014) and the MSM5 cycle is anticipated to occur in 2017.

The following risk behavior data reported by MSM during the four cycle periods of NHBS-MSM in Houston was analyzed:

- Unprotected anal sex (UAS) or sex without a condom with a main partner
- Unprotected anal sex (UAS) or sex without a condom with a casual partner
- Condom use during insertive anal sex (IAS) at last sex
- Condom use during receptive anal sex (IAS) at last sex
- Alcohol and/or drugs use at last sex
- Know partner HIV status at last sex
- Ever tested for HIV

A main partner was defined to the participants as a person you have sex with and who you feel committed to above anyone else (girl/boyfriend, wife/husband, significant other, or life partner). A casual partner was defined to the participants as a person you have sex with but do not feel committed to or don't know very well. Other terms explained to the participant were insertive anal sex (IAS) where the participant put his penis in his partners' anus and receptive anal sex (RAS) where the partner put his penis in the participants' anus.

The data showed that more than 25% of MSM had unprotected anal sex with their main partner in the past 12 months in all cycles (Fig. 1). MSM participants showed higher rates of unprotected sex when they engaged in insertive sex when compared to receptive sex (Fig. 2). In general, nearly 30% of MSM were unaware of the HIV status of their last sex partner. Nearly half of the time, the use of alcohol and or drugs occurred during the last sexual encounter in all MSM cycles (Fig. 3). Consistently throughout the years very high rates of ever being tested for HIV have been reported among MSM participants (Fig. 4).



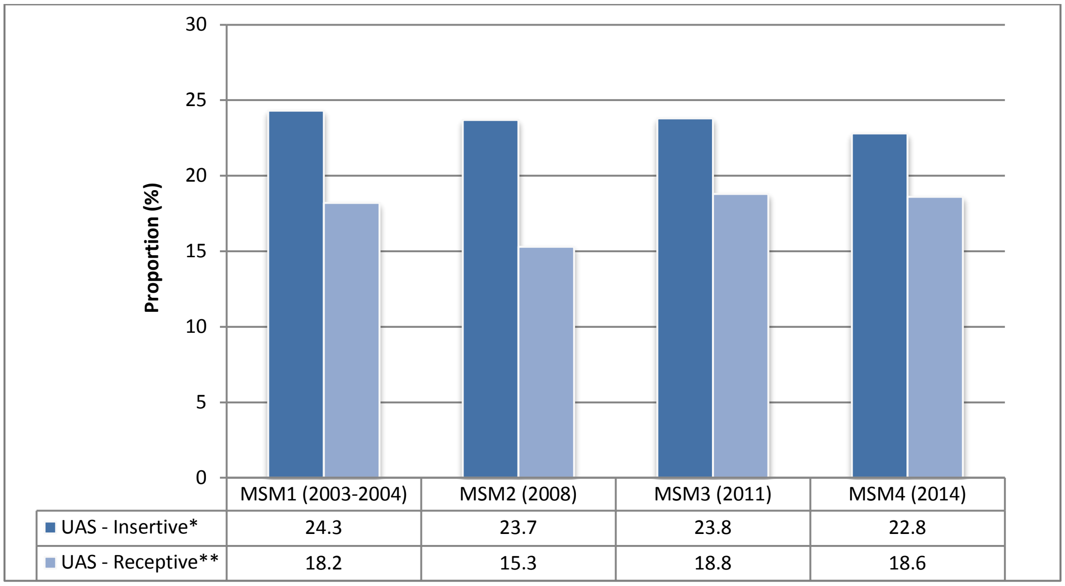
	MSM1 (2003-2004)	MSM2 (2008)	MSM3 (2011)	MSM4 (2014)
■ UAS* - Main**	26.7	26.4	28.2	26.1
■ UAS - Casual***	0.6	7.3	5	5.9

**UAS*: Unprotected anal sex*

***Main partner* - a person you have sex with and who you feel committed to above anyone else (girl/boyfriend, wife/husband, significant other, or life partner).*

****Casual partner* - a person you have sex with but do not feel committed to or don't know very well.*

Figure 1: MSM unprotected anal sex by main or casual partner

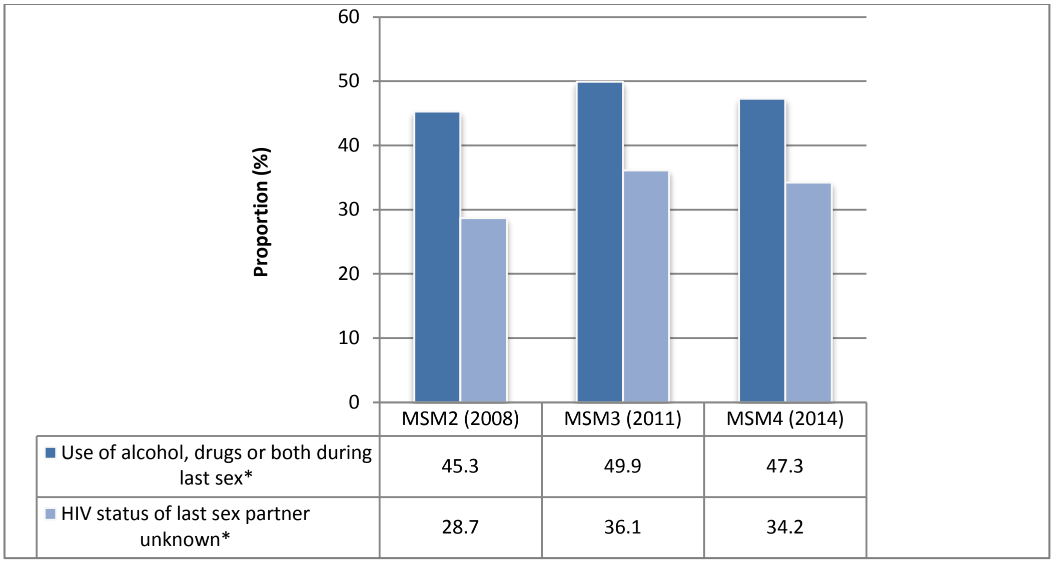


	MSM1 (2003-2004)	MSM2 (2008)	MSM3 (2011)	MSM4 (2014)
■ UAS - Insertive*	24.3	23.7	23.8	22.8
■ UAS - Receptive**	18.2	15.3	18.8	18.6

***Insertive –** anal sex where participant put his penis in his partners' anus.*

*****Receptive -** anal sex where partner put his penis in the participants' anus.*

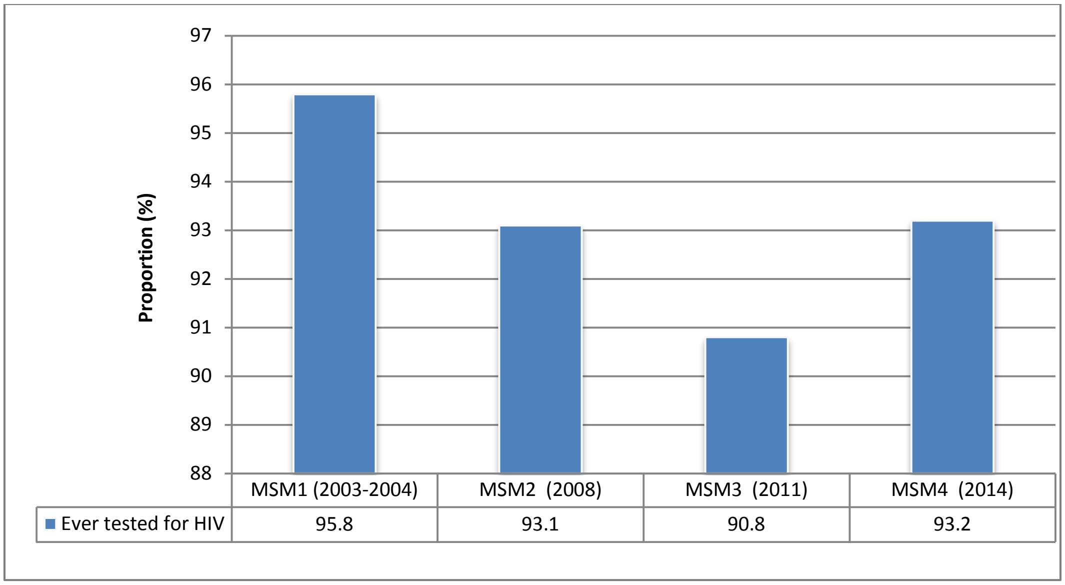
Figure 2: MSM unprotected anal sex, insertive vs receptive



	MSM2 (2008)	MSM3 (2011)	MSM4 (2014)
■ Use of alcohol, drugs or both during last sex*	45.3	49.9	47.3
■ HIV status of last sex partner unknown*	28.7	36.1	34.2

** **MSM1** data was not included because the variables do not exist for last sex or last sex partner in general.*

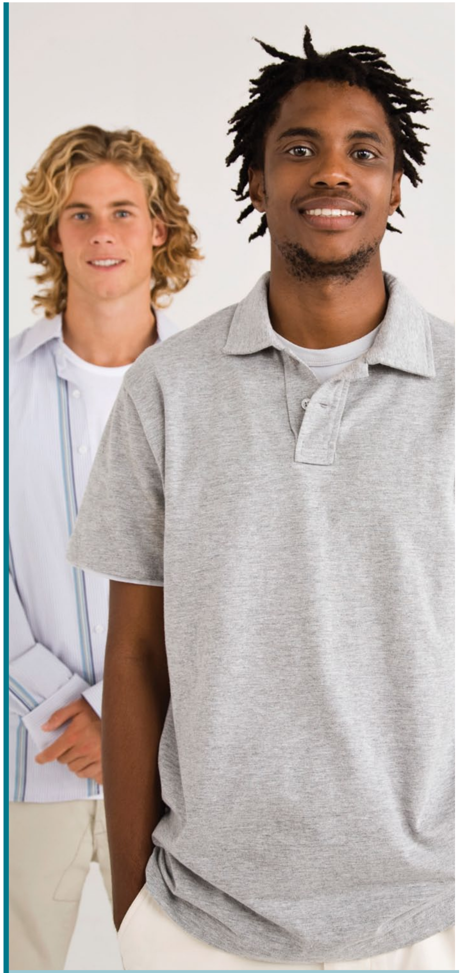
Figure 3: MSM high risk behaviors during last sex



	MSM1 (2003-2004)	MSM2 (2008)	MSM3 (2011)	MSM4 (2014)
■ Ever tested for HIV	95.8	93.1	90.8	93.2

Figure 4: MSM who had ever tested for HIV

HIV and Young Men Who Have Sex with Men



Many young people in the United States remain at risk for HIV infection. An estimated 47,500 Americans were newly infected with HIV[1] in 2010. Of these, 26%—about 12,200—were adolescents or young adults aged 13–24 years.[1] Young men who have sex with men (YMSM),[a] especially black/African American[b] YMSM, are at highest risk. The ongoing risk for HIV infection among YMSM underscores the need to reach each new generation with effective HIV prevention messages and services. Schools and education agencies are important partners in this effort.

Fast Facts

HIV disproportionately affects young men who have sex with men (YMSM).

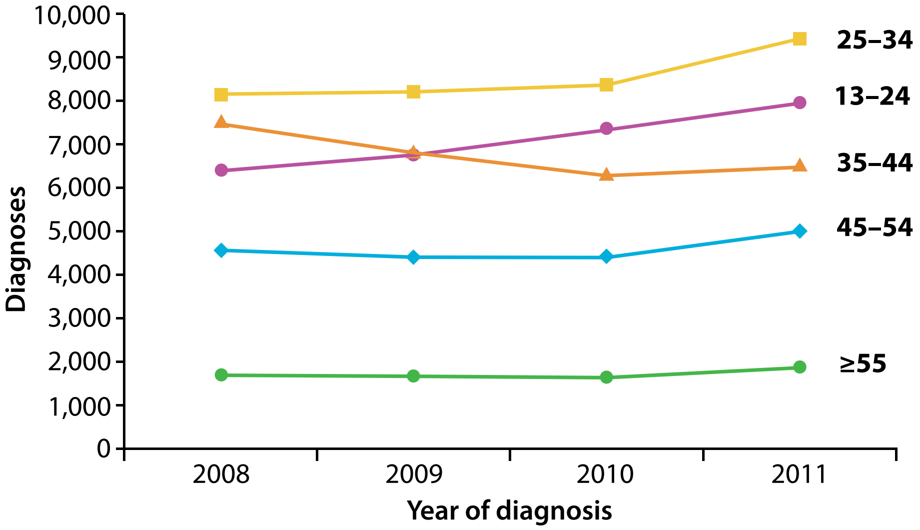
YMSM:

- In 2011, among adolescent males aged 13–19 years, approximately 93% of all diagnosed HIV infections were from male-to-male sexual contact.[2]
- From 2008–2011, YMSM aged 13–24 years had the greatest percentage increase (26%) in diagnosed HIV infections.[3] (Figure 1)

Black and Hispanic/Latino[c] YMSM:

- In 2011, among all YMSM aged 13–24 years with HIV infection, an estimated 58% were black; 20% were Hispanic/Latino.[3]
- Black YMSM also experienced the largest increase of all racial/ethnic groups in diagnosed HIV infections—from 3,762 diagnoses in 2008 to 4,619 diagnoses in 2011.[3] (Figure 2)

Figure 1. Diagnoses of HIV Infection among Men Who Have Sex with Men, by Age Group, 2008–2011—United States and 6 Dependent Areas



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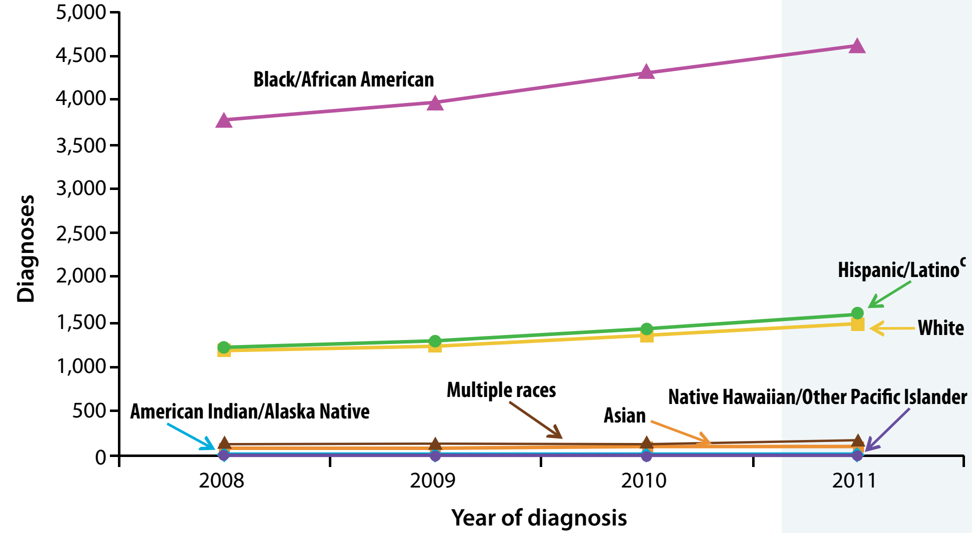
[a] CDC uses the term men who have sex with men (MSM) in its surveillance systems. MSM indicates the behaviors that transmit HIV infection, rather than how individuals self-identify in terms of their sexuality.

[b] Black/African American: Referred to as black in this fact sheet.

[c] Hispanics/Latinos can be of any race.

Figure 2. **Diagnoses of HIV Infection Among Men Who Have Sex with Men Aged 13–24 Years, by Race/Ethnicity, 2008–2011—United States and 6 Dependent Areas**

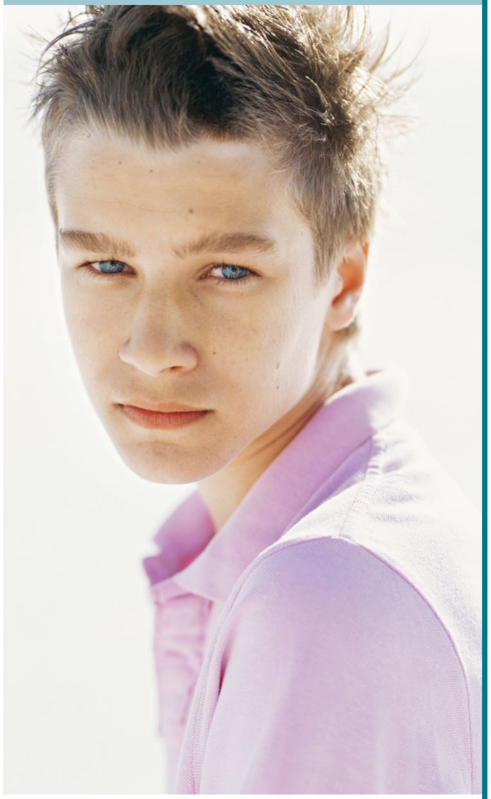


[c] Hispanics/Latinos can be of any race.

HIV Prevention Challenges

The reasons for disparities in HIV infection are varied and not well understood. These disparities do not appear to reflect individual racial or ethnic differences in risk behaviors.[4] Possible factors to explain these disparities may include the following:

- **Inadequate HIV prevention education and interventions.** Sex education programs that are not sensitive and appropriate to the needs of YMSM might not be effective in reducing sexual risk behaviors among those students.[5]
- **Limited awareness of infection.** Some HIV-infected men who have sex with men (MSM) may not know they are infected, especially MSM of color and YMSM.[6] Those who do not know they are infected might be less likely to take measures to keep from spreading the virus to others. Getting tested for HIV is an important part of prevention.
- **Low perception of risk.** Improved treatment for HIV has helped many people with HIV infection live longer and healthier lives. YMSM, who did not witness the toll of AIDS in the early years of the epidemic, might view HIV as less dangerous and disregard risks and important prevention practices.[7]
- **Alcohol and illegal drug use.** Alcohol, methamphetamine (commonly known as "meth" or "crystal meth"), and other "party drug" use is common among some YMSM. Alcohol and drug use can lead to risky sexual behavior.[7]
- **Feelings of rejection and isolation.** Bullying, harassment, family disapproval, social isolation, and sexual violence are experienced frequently by YMSM and other sexual minority youth.[d] These experiences can cause poor self-esteem and feelings of shame and can lead to more emotional distress, suicide attempts, substance use, and risky sexual behavior.[8-10]



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[d] Those who identify as gay, lesbian, or bisexual or who have sexual contact with persons of the same or both sexes.

School-Based Strategies for Addressing HIV Among YMSM

CDC funds state and local education and health agencies to help schools implement policies and practices to reduce health risks among sexual minority youth, including YMSM. Because black and Hispanic/Latino YMSM are at especially high risk of HIV infection, CDC collaborates with local education agencies and national nongovernmental organizations to reduce HIV and other sexually transmitted diseases (STDs) among this population. These partners are collaborating with local community-based organizations, health departments, and other health care organizations to collect data, promote safe and supportive environments, increase HIV/STD testing and treatment in schools and school-based health centers, refer students to youth-friendly health services, and implement evidence-based HIV/STD education and prevention activities.

Collect and use health risk behavior data.

Many states and large urban school districts use CDC's Youth Risk Behavior Survey (YRBS) data to monitor health risk behaviors and selected health outcomes among sexual minority students. In addition, starting in 2015, the national YRBS questionnaire and the state/local standard questionnaire will include questions about sexual identity and sex of sexual contacts. By documenting that some youth do engage in same-sex sexual activity and various health risk behaviors, YRBS data can help confirm the value of addressing the health needs of sexual minority youth in schools, adjust intervention priorities, and monitor health outcomes.

More information is available at www.cdc.gov/yrbs.

Establish safe and supportive school environments.

HIV prevention activities are more likely to have an impact if they address the challenges YMSM face at school, especially verbal harassment related to their sexual orientation.[11] For lesbian, gay, bisexual, or transgender students, having a safe and supportive school environment has been associated with decreases in depression, suicidal feelings, substance use, and unexcused school absences.[12,13] To help establish supportive school environments for YMSM, schools can address bullying and sexual harassment, help students feel cared for and valued, and foster parent engagement.

Provide key sexual health services.

Linking YMSM to HIV testing and treatment is key to preventing the spread of HIV and AIDS. Confidential clinical services can help prevent new cases of HIV by increasing testing and treating HIV and other STDs. Schools can help youth access key preventive sexual health services such as HIV and STD testing, counseling, and referral, either by providing these services at schools or connecting students with community providers.[14]

Implement exemplary sexual health education.[e]

Because sexual health education programs that ignore issues in the lives of YMSM might not work effectively, schools and education agencies should ensure that health education curricula include evidence-based prevention information relevant to this population. Professional development training can help school staff understand the health needs of YMSM and shape health messages accordingly.

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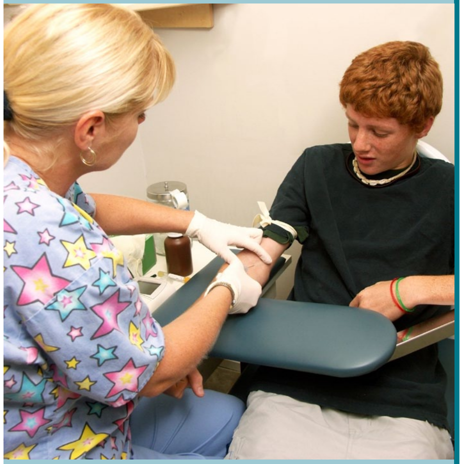
[e] Sexual health education programs that are medically accurate, consistent with scientific evidence, and tailored to students' contexts; and that use effective classroom instructional methods.

HIV and YMSM Resources

- Evidence-based HIV prevention interventions:
  www.cdc.gov/healthyyouth/adolescenthealth/registries.htm
- Specific CDC-funded YMSM program activities:
  www.cdc.gov/healthyyouth/disparities/ymsm/
- CDC resources on school connectedness and parent engagement in school health:
  www.cdc.gov/healthyyouth/adolescenthealth/protective.htm
- Parental influence on sexual minority youth:
  www.cdc.gov/healthyyouth/protective/positiveparenting/parents_influence.htm



Getting tested for HIV is a critical part of prevention.

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HIV Among Youth

July 2015

Fast Facts

- Youth aged 13 to 24 accounted for an estimated 26% of all new HIV infections in the United States in 2010.
- Most new HIV infections among youth occur among gay and bisexual males; there was a 22% increase in estimated new infections in this group from 2008 to 2010.
- Over 50% of youth with HIV in the United States do not know they are infected.

Youth in the United States account for a substantial number of HIV infections. Gay, bisexual, and other men who have sex with men* account for most new infections in the age group 13 to 24; black/African American** or Hispanic/Latino[a] gay and bisexual men are especially affected. Continual HIV prevention outreach and education efforts, including programs on abstinence, delaying the initiation of sex, and negotiating safer sex for the spectrum of sexuality among youth—homosexual, bisexual, heterosexual, and transgender—are urgently needed for a new generation at risk.

** Referred to as gay and bisexual in this fact sheet. ** Referred to as black in this fact sheet.*

The Numbers

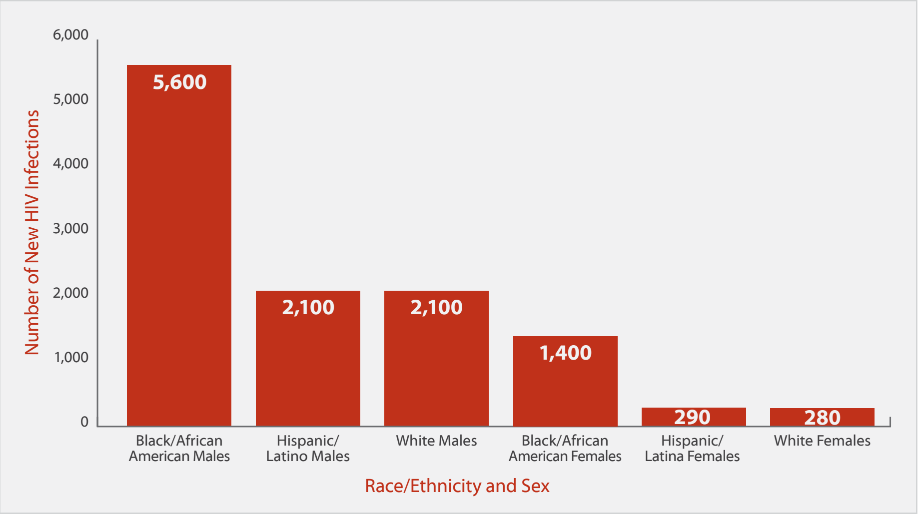
New HIV Infections[b] Among Youth (Aged 13-24)

- In 2010, youth made up 17% of the US population, but accounted for an estimated 26% (12,200) of all new HIV infections (47,500) in the United States.
- In 2010, young gay and bisexual men accounted for an estimated 19% (8,800) of all new HIV infections in the United States and 72% of new HIV infections among youth. These young men were the only age group that showed a significant increase in estimated new infections—22% from 2008 (7,200) through 2010 (8,800).
- In 2010, black youth accounted for an estimated 57% (7,000) of all new HIV infections among youth in the United States, followed by Hispanic/Latino (20%, 2,390) and white (20%, 2,380) youth.

HIV and AIDS Diagnoses[c] and Deaths Among Youth (Aged 13-24)

- An estimated 9,961 youth were diagnosed with HIV infection in the United States in 2013, representing 21% of an estimated 47,352 people diagnosed during that year. Eighty-one percent (8,053) of these diagnoses occurred in those aged 20 to 24, the highest number of HIV diagnoses of any age group.
- At the end of 2012, there were an estimated 62,400 youth living with HIV in the United States. Of these, 32,000 were living with undiagnosed HIV infection.
- In 2013, an estimated 2,704 youth were diagnosed with AIDS, representing 10% of the 26,688 people diagnosed with AIDS that year.
- In 2012, an estimated 156 youth with AIDS died, representing 1% of the13,712 people with AIDS who died that year.

Estimates of New Infections Among Youth Aged 13-24 Years, by Race/Ethnicity and Sex, United States, 2010



Source: CDC. Estimated HIV incidence among adults and adolescents in the United States, 2007–2010. *HIV Surveillance Supplemental Report* 2012;17(4).

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[a] Hispanics/Latinos can be of any race.

[b] New HIV infections refer to HIV incidence, or the number of people who are newly infected with HIV within a given time frame (for example, 1 year), whether or not they are diagnosed.

[c] HIV and AIDS diagnoses indicate when a person is diagnosed with HIV infection or AIDS, but do not indicate when the person was infected.

Prevention Challenges

Low perception of risk. A majority of 15- to 24-year-olds in the United States responding to a Kaiser Family Foundation survey said they were not concerned about becoming infected with HIV, which means they may not take measures to protect their health.

Declining health education. The prevalence of having been taught in school about HIV infection or AIDS decreased from 92% in 1997 to 85% in 2013.

Low rates of testing. It is estimated that in 2010, about 50% of youth aged 13 to 24 with HIV in the United States were unaware of their infection, compared to 12.8% overall. In a 2013 survey, only 13% of high school students (22% of those who had ever had sexual intercourse), and in a 2010 survey, only 35% of adults aged 18 to 24 had been tested for HIV.

Low rates of condom use. In a 2013 survey in the United States, of the 34% of high school students reporting sexual intercourse in the previous 3 months, 41% did not use a condom.

High rates of sexually transmitted diseases (STDs). Some of the highest STD rates in the United States are among youth aged 20 to 24, especially those of minority races and ethnicities. The presence of an STD greatly increases a person's likelihood of acquiring or transmitting HIV.

Older partners. Young gay and bisexual men are more likely to choose older sex partners than those of their own age, and older partners are more likely to be infected with HIV.

Substance use. Nearly half (47%) of youth aged 12 to 20 reported current alcohol use in 2011, and 10% of youth aged 12 to 17 said they were current users of illicit drugs. Among the 34% of currently sexually active students nationwide, 22% had drunk alcohol or used drugs before last sexual intercourse. Substance use has been linked to HIV infection because both casual and chronic substance users are more likely to engage in high-risk behaviors, such as sex without a condom, when they are under the influence of drugs or alcohol.

Homelessness. Runaways, homeless youth, and youth who have become dependent on drugs are at high risk for HIV infection if they exchange sex for drugs, money, or shelter.

Inadequate HIV prevention education. Young people are not always reached by effective HIV interventions or prevention education—especially young gay and bisexual men, because some sex education programs exclude information about sexual orientation.

Feelings of isolation. Gay and bisexual high school students may engage in risky sexual behaviors and substance abuse because they feel isolated and lack support.

What CDC Is Doing

CDC uses a multifaceted approach to meet the goals of the National HIV/AIDS Strategy:

- In 2011, CDC awarded $55 million over 5 years to 34 community-based organizations (CBOs) to expand HIV prevention services for young gay, bisexual, and transgender youth of color.
- CDC funds health departments and CBOs to deliver effective behavioral interventions (www.effectiveinterventions.org).
- CDC's **Division of Adolescent and School Health** collects and reports data on youth health risk behaviors and supports many other projects (www.cdc.gov/yrbs). For example:
    - Funding 19 state and 17 local education agencies helps districts and schools deliver exemplary sexual health education emphasizing HIV and other STD prevention, increase adolescent access to key sexual health services, and establish safe and supportive environments for students and staff.
    - To meet the HIV/STD prevention needs of young men who have sex with men (YMSM), Advocates for Youth assists local education agencies with implementing multiple program activities and developing strategic partnerships and collaborations between schools and community-based, mental health, and social services organizations.
    - The National Coalition of STD Directors works with state education agencies and CAI works with local education agencies to increase adolescent access to key preventive sexual health services.
    - The American Psychological Association works with state education agencies and the Gay-Straight Alliance Network works with local education agencies to establish safe and supportive learning environments for students and staff.
- Through its *Act Against AIDS* campaigns (www.cdc.gov/actagainstaids), CDC aims to provide effective messages about HIV prevention and to reduce stigma, especially for high-risk groups. *Let's Stop HIV Together*, for example, fights stigma by showing that people with HIV are real people —including young people.

View the bibliography at www.cdc.gov/hiv/risk/age/youth.

Additional Resources

CDC-INFO
1-800-CDC-INFO (232-4636)
www.cdc.gov/info

CDC HIV Website
www.cdc.gov/hiv

CDC Act Against AIDS Campaign
www.cdc.gov/actagainstaids

U.S. Department of Health and Human Services
HRSA
Health Resources and Services Administration

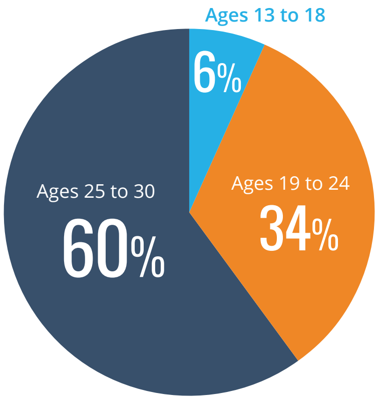
Youth and Young Adults and the Ryan White HIV/AIDS Program

September 2015

To address the burden of HIV among young people and prevent further transmission of the virus, it is critical to strategically target prevention messages and to increase engagement of young people in HIV medical care. Youth represent a medically underserved population in the United States,[1] and successfully connecting with and caring for this population requires tailored approaches. Of the approximately 525,000 clients served by the Ryan White HIV/AIDS Program during 2013,[2] 15% were youth and young adults (hereafter referred to as "youth") aged 13–30 years (Figure 1). Consistent with national surveillance data and trends,[3] these youth, particularly those aged 19–30 years, were most likely to be black men who have sex with men (BMSM). Among female youth clients, 86% were racial or ethnic minorities.[2]

This report outlines the Health Resources and Services Administration's (HRSA) longstanding history serving youth, the health disparities that exist among this population, barriers youth face in engaging in care, data trends among Ryan White HIV/AIDS Program clients aged 13–30, and the ways in which grantees are overcoming challenges to successfully develop youth-centered programs.

Figure 1. Youth Served by the Ryan White HIV/AIDS Program, 2013
Ages 13–30, *N=79,050*



Source: Ryan White Services Report data, 2013

History of Youth-Focused Initiatives

The Ryan White HIV/AIDS Program has made a concerted effort throughout the years to focus attention on youth affected by HIV. In 1993, the Pediatric AIDS Service Demonstration Grants, administered by the HRSA for HIV-positive children and their families, were incorporated into the Ryan White HIV/AIDS Program, specifically the Part D program for women, infants, children, youth, and their families. Also beginning in 1993, the Special Projects of National Significance (SPNS) program funded 10 models of adolescent HIV care though the Adolescent Care Demonstration and Evaluation Initiative.[4] This multiyear project evaluated four categories of interventions:

- youth involvement
- outreach to bring youth into services
- case management and linkage to services
- a comprehensive continuum of care

Did You Know?

National statistics on youth and HIV

- According to national HIV incidence surveillance data from 2007 to 2010, individuals aged 13 to 24 accounted for 26% of new HIV infections.
- In 2012, nearly 45% of youth with HIV in the United States were unaware of their infection.

Sources:

CDC. Estimated HIV incidence in the United States, 2007–2010. HIV Surveillance Supplemental Report 2012;17(No. 4). http://www.cdc.gov/hiv/library/reports/surveillance/

CDC. Monitoring selected national HIV prevention and care objectives by using HIV surveillance data—United States and 6 dependent areas—2013. HIV Surveillance Supplemental Report 2015;20(No. 2). http://www.cdc.gov/hiv/library/reports/surveillance/

SPNS has also funded engagement and retention in care initiatives for high-risk youth populations. Specifically, the Outreach, Care, & Prevention to Engage HIV Seropositive Young Men who have Sex with Men (MSM) of Color Initiative focused on developing and evaluating innovative service models targeting HIV-infected men who have sex with men aged 13–24.[5] Other recent HRSA initiatives targeting young MSM (YMSM) include:

- UCare4Life: a mobile texting program that helps patients with HIV infection better adhere to medication regimens
- The Resource and Technical Assistance Center for HIV Prevention and Care for Black Men who have Sex with Men: a cooperative agreement that seeks to identify and disseminate best practices and models, particularly for BMSM aged 13–24.

HRSA publications focusing on youth in addition to this report include: newsletters focusing on the delivery of culturally competent care to young adult patients and transitioning adolescents from pediatric to adult care settings; and a population fact sheet on HIV and youth, detailing the critical issues faced by this population and featuring highlights of the Ryan White HIV/AIDS Program's response.

HRSA Data:

Where do they come from and how are they used?

The Ryan White HIV/AIDS Program Services Report (RSR) is the HRSA HIV/AIDS Bureau's (HAB) primary source of annual, client-level data collected from its nearly 2,000 funded grantees and providers.

These data are used to assess the number and type of non-AIDS Drug Assistance Program clients receiving services, as well as the quality of HIV care. Client-level RSR data collection has been in effect since 2010. Agencies that provide any Ryan White HIV/AIDS Program clinical or supportive services are required to submit data to HAB each year in a specified format. Those data contain an encrypted, unique identifier for each client and, depending on the type of agency reporting, additional demographic, service, and clinical data. Demographic data include the client's gender, race/ethnicity, health care coverage, poverty level, and housing status. Service data include the number and date of outpatient ambulatory medical care visits as well as visit counts for other core medical services, including mental health, substance abuse, and oral health. Providers of outpatient ambulatory medical care also report all viral load and CD4 test results and dates, as well as information concerning receipt of screening tests for hepatitis B, hepatitis C, and syphilis.

This array of data enables HAB to calculate important measures of performance, including viral load suppression and retention in HIV care—two central components of the National HIV/AIDS Strategy.

Health Disparities among Youth

Stigma and disclosure are two barriers to HIV care for clients, regardless of age. These issues, however, may be particularly acute among youth because adolescence and young adulthood are marked with self-identity exploration and sexual awakening.[6-8]

Adolescence is a psychologically complex time characterized by lowered inhibitions, increased risk-taking behavior, and decreased parental support and oversight.[9] Meanwhile, the establishment of romantic relationships, feelings of invulnerability, and choices regarding drug and alcohol use are distinct characteristics of this period.[9]

The U.S. Centers for Disease Control and Prevention (CDC) Youth Risk Behavior Survey found that 47% of high school students were sexually active and only 59% used a condom during their last sexual encounter. Of sexually active students, only 13% had been tested for HIV.[10] These factors, individually and in combination, place youth at increased risk for sexually transmitted infections (STIs), including HIV.

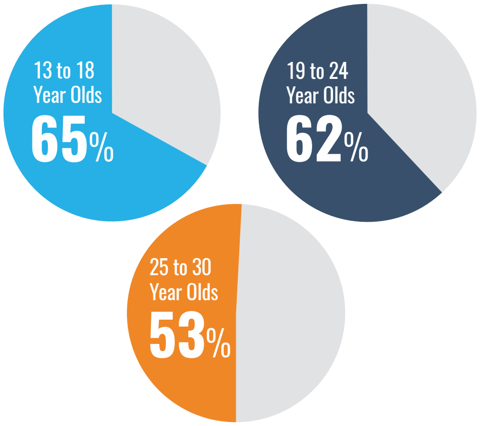
Fear of violence, rejection, discrimination, and confidentiality related to HIV status and sexual orientation are among the leading causes of delayed initiation into care and treatment by youth.[6-8] Compounding these factors are the structural challenges youth face when accessing and navigating the health care and insurance landscapes, regardless of whether they were perinatally or behaviorally infected. These barriers range from cost for care or co-pays, lack of transportation, low health literacy, competing priorities, and limited educational attainment.[6] In fact, among Ryan White HIV/AIDS Program clients, only 40% of youth aged 13–18 utilized outpatient/ambulatory medical care during 2013, compared to 56–63% among clients in other age groups.[2]

Disparities among Racial/Ethnic Minority Youth

HIV infection is inextricably linked to a host of health, social, and structural issues that are more pronounced within communities of color. These include poverty, psychological comorbidities, substance use, sexual victimization, stigmatization, and discrimination, all of which undermine the health and well-being of infected persons, including youth. Vulnerabilities such as these are cumulative and support the notion of a *syndemic,* or set of mutually reinforcing epidemics driven by cultural marginalization, that heightens the risk for acquiring HIV.[11-14] In the United States, communities of color, particularly black, non-Hispanic communities of color, are most severely affected by HIV infection; the highest rate of new infections is among young, black, non-Hispanics,[15] which underscores a need to strategically reach a new generation of people.

Figure 2. Black, Non-Hispanic Youth Served by the Ryan White HIV/AIDS Program

by Age Group, 2013



Source: Ryan White Services Report data, 2013

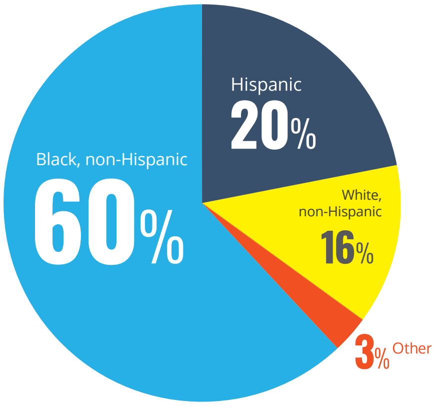
Consistent with the burden of HIV among youth in the United States, black, non-Hispanic youth represent the largest racial/ethnic group among Ryan White HIV/AIDS Program clients aged 13–30. As Figure 2 illustrates, black, non-Hispanics represent the majority of young clients served by the Ryan White HIV/AIDS Program across all age cohorts of young people.

Young Women

Young women of color are also disproportionately affected by HIV and are well represented in the Ryan White HIV/AIDS Program: during 2013, approximately 86% of female Ryan White HIV/AIDS Program clients aged 13–30 were women of color.

Figure 3. Young Women of Color Served by the Ryan White HIV/AIDS Program

Ages 13–30, by Race/Ethnicity, 2013



Source: Ryan White Services Report data, 2013

Heterosexual contact was the leading cause of transmission among young women and accounted for 26% of all infections among Ryan White HIV/AIDS Program clients aged 13–30. Figure 3 illustrates the distribution by race and ethnicity of young women aged 13–30 who received Ryan White HIV/AIDS Program services during 2013.

Young women have several risk factors for HIV infection. Male-to-female transmission of HIV is approximately 2 to 4 times more efficient than female-to-male transmission, due to the permeable mucous membranes of female reproductive organs.[16] In addition to anatomical risk factors, beliefs about gender roles, knowledge of sex and sexuality, and gender inequality in relationships all play important roles in determining girls' risk factors and risk behavior.[17-19] Trauma and intimate partner violence (IPV), as well as associated post-traumatic stress disorder (PTSD), are also significantly higher among HIV-positive women and girls, than among the general population of women. Risk associated with IPV and HIV is two-sided: Women and girls are at increased risk for violence because of their HIV status, and those who experience violence are at increased risk for being infected with HIV.[20,21] Among women and girls who have experienced IPV in the United States, 69% experienced this violence at age 25 or younger, and 22% experienced IPV for the first time between the ages of 11 and 17 years old.[22]

Trauma and IPV are linked to poorer health outcomes along the HIV Care Continuum.[21] For many women and girls, engagement in care and medication adherence cannot be separated from painful reminders of violence or betrayal. As "Tammy," a Ryan White HIV/AIDS Program Part D client, says, "I know I need to take my meds. It's just so hard some days. I thought we were in love. I thought he was monogamous. Now, every day from here until forever I have to live with a reminder of what he's done. I can never escape it."

Young MSM

Gay, bisexual, and other men who have sex with men have particularly high rates of HIV infection and face their own unique set of challenges. For example, social networking sites for sex-seeking are particularly popular among YMSM and contribute to an increased number of sex partners and increased risk for STIs.[23] As one Ryan White HIV/AIDS Program YMSM client states, "It's easier to find a hook-up online now than it is to order Chinese takeout." He adds, "It's the reverse order of a relationship. We hook up first and then if there is chemistry and real connection, then maybe you'll date. Quite honestly, we only see heterosexual relationships in the media. I don't know what a healthy, black, gay relationship looks like. I've never seen it."

Among Ryan White HIV/AIDS Program clients aged 13–30, MSM was the transmission category for 60% of infections. The racial/ethnic distribution among YMSM in 2013 was 54% black, non-Hispanic; 22% Hispanic; 20% white, non-Hispanic; and 4% other races.

Black, non-Hispanics were particularly overrepresented among YMSM aged 13–24.* This is consistent with national trends: from 2009 to 2013, young, black MSM aged 13–24 had the largest increase in diagnoses of HIV infection compared to other racial/ethnic groups of YMSM —from 3,895 diagnoses in 2009 to 4,643 diagnoses in 2013.[24]

MSM of color, including YMSM of color, tend to select sexual partners who are of the same race/ethnicity. Higher HIV prevalence, coupled with a smaller dating community, place these individuals at increased risk.[25-27] MSM, especially YMSM, may also underestimate their risk or make inaccurate assumptions about their partner's HIV status. For example, the National HIV Behavioral Surveillance System conducted HIV testing in 20 cities and found that only 49% of HIV-positive YMSM aged 18–24 knew of their infection.[28] For black YMSM, partnering with older black men (among whom HIV prevalence is high) may also lead to increased risk, particularly as HIV prevalence is found to increase with age among the MSM population.[27]

*Among RSR clients, approximately 68% of YMSM aged 13–18 were black, non-Hispanic, and 62% of YMSM aged 19–24 were black, non-Hispanic

Transitioning into Adulthood: Behaviorally Infected Youth and Perinatally Infected Youth

The efficacy of HIV antiretroviral therapy (ART) has greatly improved life expectancy for HIV-positive individuals and, as a result, many adolescents are making the transition into adult care systems. By the age of 21, HIV-positive young adults should make a planned, purposeful switch from child-centered to adult care.[29] The differences between these care models are well-documented, and the primary difference is fragmentation of services. While child-centered care facilities utilize multidisciplinary teams of pediatricians, nurses, social workers, psychologists, child life therapists, and other dedicated caregivers, adult-oriented care often fails to include both medical and psychosocial services.[29] These services are especially important as HIV-infected young people have higher rates of mental health issues like anxiety, depression, and PTSD than their HIV-negative peers.[7]

Perinatally infected youth account for 9% of Ryan White HIV/AIDS Program clients aged 13–30, compared to 87% of behaviorally infected youth, and 4% other transmission modes. Perinatally infected youth often experience drug resistance after many years of ART therapy and, in some cases, inconsistent treatment adherence. Because of this, they are more likely to have complex, intolerable medication regimens and to be in advanced stages of HIV disease compared to behaviorally infected youth.[30] The most common barriers to care experienced by both groups are forgetting to take medication and consciously deciding to take a break. A higher number of identified barriers is also associated with poorer medication adherence.[31]

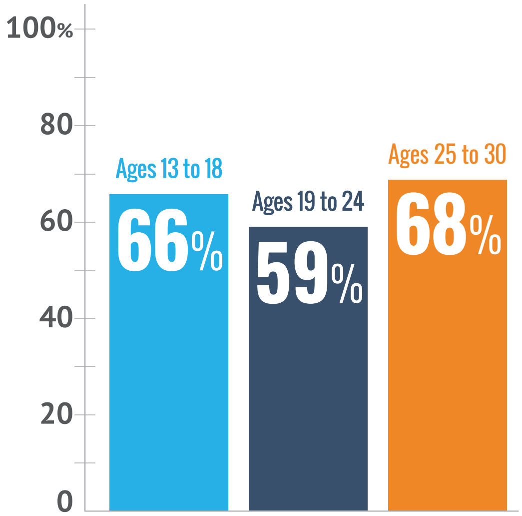
Many youth, particularly those perinatally infected, establish strong emotional attachments to their pediatric health care providers and are reluctant to break these bonds. Consequently, transitions can be very challenging, and 50% of perinatally infected youth report adherence difficulties post-transition.[32] As "Luisa," a perinatally infected Ryan White HIV/AIDS Program client explains of the transition, "I'm not scared of leaving [pediatric care], and I know I can come back and visit. But it'll be different. I can't open up to everybody and have them walk out of my life," she says. "I've had that my whole life going in and out of foster homes. I've finally found people I trust and I don't want to start over."

While Luisa's story is unique, her concerns are not. Creating a supportive environment for youth transitioning to adult care requires understanding the circumstances surrounding where these clients are coming from and who they are. The vast majority of Ryan White HIV/AIDS Program clients are racial and ethnic minorities, and almost all are dealing with the effects of poverty and lack of private insurance. For most of these clients, life has been filled with uncertainty and has been anything but easy. Many youth received little or no medical care or access to information about their health prior to becoming HIV-positive and entering care at a Ryan White HIV/AIDS Program-funded facility. For youth facing developmental, security-related, and mental and physical health-related challenges, these challenges do not necessarily disappear when clients enter adult care and, thus, providers need to create a welcoming environment where youth feel safe and supported.

Viral Suppression and Retention in Care

Knowledge of HIV infection, retention in HIV care, and viral suppression are key pieces of the HIV Care Continuum and carry both individual and public health benefits.[33] Having access to caring and culturally competent staff within a welcoming environment can mean the difference between youth engaging in services and moving along the HIV Care Continuum or walking out the door. "Why would I go across town to have a receptionist give me attitude and then sit in some cold, sterile waiting room for 30 minutes just to be seen for 10?" asks "DaShawn," a Ryan White HIV/AIDS Program youth client. "It's got to be a place I'd want to hang out. Even better if the people working there look like me."

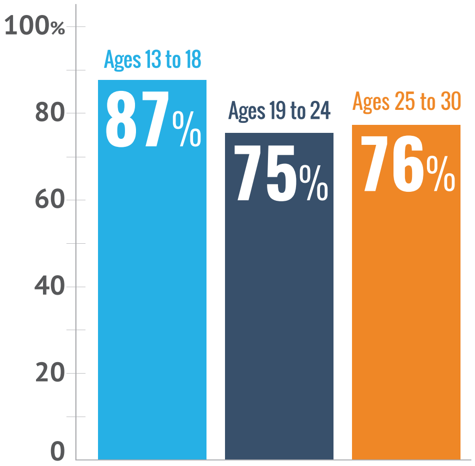
Figure 4. Viral Suppression among Youth Served by the Ryan White HIV/AIDS Program
by Age Group, 2013



Source: Ryan White Services Report data, 2013

Ryan White HIV/AIDS Program grantees and providers have found ways to successfully connect with youth, and better viral suppression outcomes have been seen among youth in Ryan White HIV/AIDS Program settings compared to national estimates.[34] But there is room for improvement: for example, among Ryan White HIV/AIDS Program clients of all ages, approximately 79% were virally suppressed in 2013; youth clients, however, had lower percentages of viral suppression than the average, as illustrated in Figure 4.

Figure 5. Retention in HIV Care among Youth Served by the Ryan White HIV/AIDS Program
by Age Group, 2013

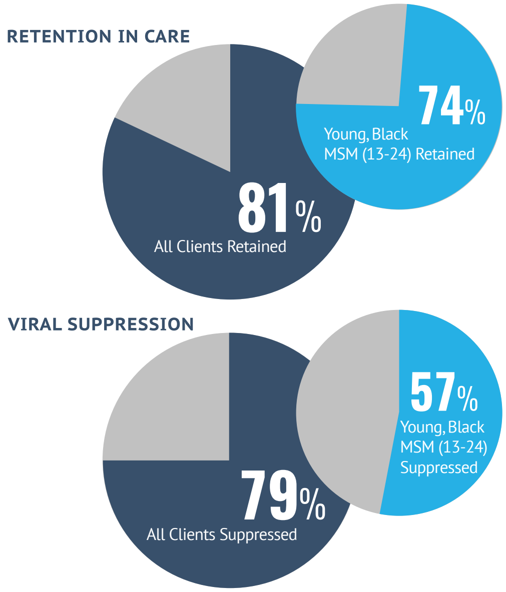


Source: Ryan White Services Report data, 2013

Lack of viral suppression among HIV-positive youth—a sexually active population with inconsistent condom use—may lead to increased HIV transmission.[35,36] Black, non-Hispanic clients are the least likely of any racial/ethnic group to be virally suppressed. This is particularly noteworthy given high rates of HIV infection among black, non-Hispanic YMSM and black, non-Hispanic young women.

Retention in care is a critical component supporting viral suppression. Youth served through the Ryan White HIV/AIDS Program in 2013 achieved significantly better retention in care than national estimates,[34] although gaps continue to exist between percentages of youth retained in care and those who achieve viral suppression. Figure 5 shows the percentages of retention in care among youth in the different age groups; these percentages are particularly higher than the viral suppression percentages in Figure 4.

Figure 6. Retention in Care and Viral Suppression among Young, Black MSM Served by the Ryan White HIV/AIDS Program, 2013



Source: Ryan White Services Report data, 2013

When examining young, black MSM aged 13–24—the most at-risk youth population—retention and viral suppression are both lower than Ryan White HIV/AIDS Program clients overall (Figure 6) and lower than the averages among youth clients. Continued efforts to better reach this population and deliver the services and adherence information they need remains critical to curtailing new infections and moving closer to an AIDS-free generation.

Examples of Successful Interventions

Grantee sites are using a variety of innovative methods to successfully facilitate engagement in care and leadership development among youth and young adults with HIV. Although each operating model is unique, successful programs are striving to be as youth-friendly and accommodating as possible while encouraging youth to take an active role in the HIV community.

Howard Brown Health Center

Mary Brewster and Beto Soberanis of Howard Brown Health Center in Chicago, IL, believe it is critical to engage youth in overall health care, not just HIV care. To facilitate this, all case managers at Howard Brown are certified Affordable Care Act enrollment counselors, allowing them to help clients obtain insurance and learn how to utilize it. "We try to break down any of those barriers you see in more traditional medical settings and make it as accessible to our youth as possible," says Brewster, the youth program director.

At Howard Brown, a lesbian, gay, bisexual, transgender, and queer-friendly facility, this may entail combining hormonal therapy and HIV treatment into one appointment, absorbing the cost of HIV treatment for youth who are unable to access insurance, or meeting youth off-site. Case managers working specifically with the youth population strive to make their facility a one-stop health center where patients can access all of the medical services they need in one location. If needed, appointments are provided on a walk-in basis, especially for those who are transient or street-based, to make HIV care as simple and accessible as possible.

New York State AIDS Institute

To encourage leadership among youth with HIV, the AIDS Institute in New York has formed a Young Adults Consumer Advisory Committee (YACAC). Youth aged 13–24 meet periodically to discuss relevant and timely issues, including pre-exposure prophylaxis (PrEP), stigma, discrimination, and emotional attachment to pediatric providers. They have the opportunity to provide feedback and recommendations to AIDS Institute staff, as well as to speak directly with clinical providers to voice any concerns. Participants are often paired with older mentors from the AIDS Institute's adult advisory committee to support their engagement in YACAC, and both encourage and facilitate the subsequent transition to the adult consumer advisory board.

Dan Tietz, the AIDS program manager for consumer affairs, stresses the importance of meeting youth at their level. Logistically, this entails flexible scheduling to accommodate school and other activities, communicating with youth informally through social media and text messages, and hiring dedicated staff that are as young or peer-like as possible. "These youth understand that when they give recommendations, they see tangible results. One of the keys is to let it be their process and respect that process." Youth seeing their recommendations readily implemented within the clinic has a two-fold result: a more youth-friendly clinic overall, and development of the next generation of HIV leaders. Youth are additionally provided with opportunities to be involved in their care, with the goal of promoting improved self-management and an easier transition into the adult care system.

Children's Hospital & Research Center Oakland

Because the transition from child-centered to adult care systems is often difficult for HIV-infected youth, patients at the Oakland Children's Hospital begin preparing early. From ages 17–21, young adults are led through a transition program to ensure they have a full understanding of the HIV disease process, their own medical history, and the importance of medication adherence and engagement in care. "A successful youth program incorporates a pediatric program that has a dedicated HIV youth program for the kids to transition through," says Stephanie Montgomery at Oakland Children's Hospital.

Youth at Oakland Children's Hospital are also encouraged to attend the One Love Conference, a 3-day youth-created, youth-led conference held at a local California college campus. It gives adolescents and young adults an opportunity to engage in discussions and workshops on issues such as finances, relationships, and medication adherence, as well as providing an opportunity to develop leadership skills. The hospital-affiliated Downtown Youth Clinic also focuses on the transition from pediatric to adult systems of care by employing peer advocates to work with youth to identify key goals for not only their health but also for school and careers, thereby critically thinking about their futures and setting themselves up for success.

Characteristics of a Successful Youth Program

While programs vary, certain shared characteristics across sites can help providers refine their work to better reach—and engage—HIV-positive youth. These include:

- An LGBTQ-friendly environment
- One-stop shops with health, hormone therapy, and social support services in one location (if not feasible, active referrals to youth-friendly social support settings)
- Employment of youth-dedicated, youth-friendly staff
- Accessible location with walk-in appointments and flexible scheduling
- Uses informal modes of communication, like texting and social media
- Creates a warm, welcoming environment with social interaction and entertainment in waiting areas
- Active communication with youth
- Opportunity for youth to give feedback and have opinions heard
- Creation of leadership opportunities for youth
- Access to youth peer support groups
- Incentives, where possible, such as bus tokens to alleviate the financial burden of transportation
- Navigators to help youth understand the health care system and enroll them into Affordable Care Act coverage (if applicable)
- Development of individualized transition plans
- Early transition planning for adult care
- Health education
- Goal-setting (for health, school, career)
- Connection to youth-friendly activities and conferences to support social networking and skills building

Conclusion

HRSA focuses efforts on youth in a myriad of ways and equips providers with best practices for reaching this population. Through the Integrating HIV Innovative Practices (IHIP) Project, SPNS has created training manuals and curricula around hard-to-reach populations, including youth. Other ways SPNS is evaluating and addressing the needs of HIV-positive youth include a BMSM initiative focused on youth:

> The Ryan White HIV/AIDS Program Part B-funded Resource and Technical Assistance Center for HIV Prevention and Care for Black Men who have Sex with Men Cooperative Agreement has a special focus on YMSM youth aged 13–24. This project is working to synthesize strategies for reaching and engaging this population and creating technical assistance materials to help the broader Ryan White HIV/AIDS Community.

Additionally, publications such as this report underscore issues among youth as well as strategies for reaching them. Similarly, a forthcoming HRSA CAREAction newsletter on social media includes tips on reaching youth via various online platforms and how to literally meet youth "where they are."

HRSA encourages grantees to increase their communication and collaboration with one another to create an even stronger safety net for high-risk populations such as youth. For example, the National Quality Center, in conjunction with HRSA's Division of Community HIV/AIDS Programs, created a Part C and D Collaborative to establish sustainable clinical quality management programs, share best practices across Part C- and D-funded sites, and ultimately improve health outcomes. The Ryan White HIV/AIDS Program has a rich history and a depth of knowledge to share with the broader health care community, just as grantees have much to share with one another.

Ultimately, effectively addressing challenges requires knowing where a need exists, understanding how to address it, and staying the course to see it through. For HRSA, the RSR data highlight client needs and challenges. As the HRSA Living History website essay on youth[37] illustrates, the Bureau has a longstanding and unwavering commitment to addressing HIV among young people in the United States. HRSA remains committed to proactively tackling barriers to care to bring HIV-positive youth into care, provide them a seat at the table, and ensure that they have a bright future.

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Topline

The Kaiser Family Foundation Survey of Gay and Bisexual Men on HIV

September 2014

METHODOLOGY

The Kaiser Family Foundation *Survey of Gay and Bisexual Men on HIV* was designed and analyzed by researchers at the Kaiser Family Foundation (KFF), and was conducted July 17-August 3, 2014, among a nationally representative sample of 431 men ages 18 and older who self-identified as gay or bisexual. The survey was funded by M·A·C AIDS Fund. Interviews were conducted in English and Spanish using GfK's KnowledgePanel, an online research panel. KnowledgePanel members are recruited through probability sampling methods and include both those with internet access and those without (KnowledgePanel provides internet access for those who do not have it and, if needed, a device to access the internet when they join the panel). A combination of random digit dialing (RDD) and address-based sampling (ABS) methodologies have been used to recruit panel members (in 2009 KnowledgePanel switched its sampling methodology for recruiting panel members from RDD to ABS). The panel comprises households with landlines and cellular phones, including those with only cell phones, and those without a phone. Both the RDD and ABS samples were provided by Marketing Systems Group (MSG). KnowledgePanel continually recruits new panel members throughout the year to offset panel attrition as people leave the panel.

Panel members complete an annual profile survey that includes a range of demographic, attitudinal and behavioral questions, including questions about sexual orientation. Men who identified as gay or bisexual on the profile survey were eligible for the KFF survey sample and were sent an invitation to complete the survey. Respondents were asked to reconfirm their sexual orientation using the following question: Do you consider yourself to be 1) Heterosexual or straight, 2) Gay, 3) Bisexual, 4) Other? Men who had previously identified as gay or bisexual but selected something other than one of these options in the screening interview were asked: In an earlier survey, you identified as gay/bisexual. Do you still consider yourself to be gay/bisexual, or not? The vast majority of respondents in the final sample (97 percent) re-confirmed their identity as gay or bisexual on the first question, and 3 percent reconfirmed on the second question. Respondents who did not reconfirm as gay or bisexual on either question were thanked for their time and told that the interview was over.

The survey data were weighted to be representative of gay and bisexual men nationwide. Weighting took place in several stages. First, all members of the panel carry a weight designed to produce a nationally representative sample of the U.S. adult population. This weight matches gender, age, race/ethnicity, education, region, household income, homeownership status, metropolitan area, and Internet access to parameters from the March 2013 Supplement of the Census Bureau's Current Population Survey (CPS).[1]

In the second stage, the sample of gay and bisexual men was weighted to match known national parameters where available, and to match the full sample of panel members who identify as gay and bisexual men on characteristics for which no national parameters are available. The sample was weighted using an iterative technique to match age, race/ethnicity, region, and education to parameters for gay and bisexual men from the 2013 National Health Interview Survey (NHIS), and to match primary language, Internet access, metropolitan area, and household income to targets derived from the weighted sample of all gay and bisexual men in the panel.

Margins of sampling error and tests of statistical significance take into account the effect of weighting at each of these stages. The margin of sampling error including the design effect for the full sample of 431 gay and bisexual men is plus or minus 7 percentage points. Numbers of respondents and margin of sampling error for key subgroups are shown in the table below. For results based on other subgroups, the margin of sampling error may be higher. Sample sizes and margin of sampling errors for other subgroups are available by request. Note that sampling error is only one of many potential sources of error in this or any other public opinion poll.

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[1] Details about KnowledgePanel sampling, recruitment, and weighting methodology, including details about how design weights are calculated, is available at http://www.knowledgenetworks.com/knpanel/docs/knowledgepanel(R)-design-summary-description.pdf

Group	N (unweighted)	M.O.S.E.
Total gay and bisexual men	431	±7 percentage points
Gay	299	±8 percentage points
Bisexual	132	±12 percentage points
Racial/ethnic minorities	142	±12 percentage points
Whites	289	±8 percentage points
Ages 18-34	101	±12 percentage points
Ages 35 and over	330	±8 percentage points

Some of the same questions that were asked on the *Survey of Gay and Bisexual Men on HIV* were also asked of the general public as part of the July 2014 Kaiser Health Tracking Poll, a nationally representative telephone survey. More detail on that survey's methodology, along with the full question wording and results, are available at http://kaiserfamilyfoundation.files.wordpress.com/2014/08/8618-t.pdf.

TOPLINE RESULTS:

Q1. Do you consider yourself to be: heterosexual or straight, gay, bisexual, other?
(If Respondent picked an option other than “gay” or “bisexual”, Q2 was shown)
Q2. In an earlier survey, you identified as [gay/bisexual]. Do you still consider yourself to be [gay/bisexual] or not?

Summary of Q1/Q2

	Total
Gay	70
Bisexual	30

This survey is about topics related to men who consider themselves to be gay or bisexual. For purposes of keeping the questions succinct, we will sometimes use the more general term “gay men” to refer to this group.

Q3. What do you think is the **most important** issue facing gay and bisexual men today?/ [asked if Q3 response was anything other than “refused”] Q3a. Is there another issue facing gay and bisexual men you think is almost as important? (OPEN-END)

	Total
Discrimination/Stigma/Lack of acceptance	43
Equal rights (general)	26
Marriage equality	24
HIV/AIDS	20
Employment/Discrimination in the workplace	8
Health (general)	7
Violence/Hate crimes/Bullying	7
Sexually transmitted diseases (other than HIV)	5
Health care/insurance	5
Dating/Relationships/Finding a partner	4
Self-acceptance	3
Mental health	2
Stereotypes	2
Drug use	2
Aging	1
Religion	1
Conservatives	1
Nothing/Nothing in particular	1
Adoption	1
Other	11
Don’t know	2
Did not answer	3

Percentages will add to more than 100 due to multiple responses.

Q4. Thinking specifically about health and health care, what do you think is the **most important HEALTH issue** facing gay and bisexual men today?/ [asked if Q4 response was anything other than "refused"] Q4a. Is there another health issue facing gay and bisexual men you think is almost as important? (OPEN-END)

	Total
HIV/AIDS	52
Sexually transmitted diseases (other than HIV)	28
Safe sex	9
Mental health	8
Drug use	8
Health insurance issues/Benefits for spouses/kids	6
Access to health insurance/care	6
Cost/Affordability	4
Finding an accepting doctor/provider	3
Smoking	2
Cancer	2
Health/Diseases (general)	2
Hepatitis	2
Diabetes	1
Aging	1
Eating well/Nutrition	1
Affordable Care Act/Obamacare	*
Fitness	*
Violence	*
Other	6
Nothing/Nothing in particular	4
Don't know	3
Did not answer	4

Percentages will add to more than 100 due to multiple responses.

Q5. Thinking about some policy issues affecting gay and bisexual men, how much of a priority do you think each of the following should be? (items randomized; response options rotated 1-4/4-1)

	Top priority	Very important but not top priority	Somewhat important priority	Not a priority at all	Did not answer
a. Equal employment rights for LGBT people	47	36	14	2	*
b. Legally sanctioned marriages for same-sex couples	40	34	20	6	*
c. Adoption rights for same-sex couples	29	39	24	7	1
d. More efforts aimed at prevention and treatment of HIV	54	33	10	2	*
e. Efforts to combat bullying and violence directed at LGBT youth	51	33	13	2	1

Q6. How concerned are you, personally, about becoming infected with HIV?

	Total
Very concerned	16
Somewhat concerned	19
Not too concerned	31
Not at all concerned	25
Already have HIV	8
Did not answer	*

Q7. How concerned are you, personally, about each of the following? (items randomized; response options rotated 1-4/4-1, anchor 5)

	Very concerned	Somewhat concerned	Not too concerned	Not at all concerned	Already have	Did not answer
a. Becoming infected with a sexually transmitted disease other than HIV	20	23	31	23	4	*
b. Developing cancer	27	34	29	8	2	*
c. Having a heart attack	23	35	29	12	1	*
d. Developing diabetes	15	29	31	14	10	*

Q8. Thinking about the impact of HIV/AIDS in the United States today, which comes closer to your view?

	Total
The U.S. is making progress	64
The U.S. is losing ground	12
The problem is about the same as it has been	24
Did not answer	*

Q9. And thinking more specifically about the impact of HIV/AIDS **on gay and bisexual men** in the U.S. today, which comes closer to your view?

	Total
The U.S. is making progress	58
The U.S. is losing ground	13
The problem is about the same as it has been	28
Did not answer	1

Q10. For each of the following people and groups, please indicate if you think they are doing enough to address the problem of HIV/AIDS in the U.S., are not doing enough, or if they should not be involved at all in this issue. (items randomized)

	Doing enough	Not doing enough	Should not be involved	Did not answer
a. President Obama and his administration	36	55	8	1
b. Congress	15	74	10	1
c. Pharmaceutical companies	33	62	4	1
d. Public schools	17	68	14	*
e. Religious leaders and institutions	13	52	34	1
f. LGBT organizations	71	27	1	*
g. The media	29	59	12	*
h. Businesses that target gay consumers	33	51	16	*

Q11. Compared with other issues, do you think leaders in the gay community currently pay **[**too much**]** attention, **[**too little**]** attention, or about the right amount of attention to the issue of HIV? (items in brackets rotated)

	Total
Too much	9
Too little	34
About the right amount	56
Did not answer	*

Q12. How significant an issue is HIV/AIDS for you personally?

	Total
Very significant	25
Somewhat significant	24
Not too significant	31
Not a significant issue in your life	20
Did not answer	*

Q13. How often would you say the subject of HIV/AIDS comes up in discussions with each of the following? (items randomized; response options rotated 1-4/4-1, anchor 5)

	Often	Sometimes	Rarely	Never	Not applicable	Did not answer
a. Your family	5	9	35	44	7	*
b. Your friends	6	25	40	25	4	*
c. Your casual sexual partners	14	20	20	13	33	*
d. Your long-term sexual partners	9	22	28	20	21	*

Q13 Results based on those who did not select “Not applicable” for each category

	Often	Sometimes	Rarely	Never	Did not answer	*n*
a. Your family	5	10	37	47	*	*394*
b. Your friends	6	26	42	26	*	*414*
c. Your casual sexual partners	20	30	30	20	*	*263*
d. Your long-term sexual partners	12	28	35	25	*	*330*

Q14. In the past 12 months, how much information have you gotten about HIV from each of the following sources? (items randomized; response options rotated 1-4/4-1)

	A lot of information	Some information	Not much information	No information at all	Did not answer
a. Mainstream media, such as radio, television, and newspapers	2	20	37	40	*
b. Media targeted at LGBT audiences	6	29	22	43	*
c. The Internet	13	32	21	34	*
d. Your friends and family	2	11	30	57	*
e. Doctors and other health professionals	10	19	29	43	*
f. Gay/LGBT community organizations	6	24	27	41	1
g. HIV/AIDS organizations	9	24	26	40	*

Q15. And which of these would you say is your MAIN source of information on HIV/AIDS?

Summary Q14/Q15 based on total, includes those who said they got “a lot of information” from only one source

	Total
The Internet	8
Doctors and other health professionals	7
HIV/AIDS organizations	3
Gay community/LGBT organizations	2
Media targeted at LGBT audiences	1
Your friends and family	1
Mainstream media, such as radio, television, and newspapers	*
Other	*
Did not get a lot of information from any of these sources	78

Q16. As far as you know, is the number of new HIV infections each year among gay and bisexual men [increasing] [decreasing], or staying about the same? (items in brackets rotated)

	Total
Increasing	32
Decreasing	22
Staying about the same	26
Don't know	20
Did not answer	*

Q17. Here is a list of some things that may or may not be reasons why it has been difficult to reduce the spread of HIV among gay men. For each, please say whether you think it is a major reason, a minor reason, or not a reason. (items randomized)

	Major reason	Minor reason	Not a reason	Did not answer
a. The stigma[2] that surrounds HIV	56	32	12	*
b. Complacency[3] about HIV in the gay community	62	28	9	1
c. Lack of understanding about how to prevent HIV transmission	31	41	27	*
d. Too many gay men not knowing their status	75	20	4	1
e. Not enough focus on HIV by LGBT organizations	17	53	29	1

Q18. Given what you know about antiretroviral medications[4] for HIV available to people in the United States, how effective do you think the current treatment options are in terms of each of the following? (items randomized; response options rotated 1-4/4-1)

	Very effective	Somewhat effective	Not too effective	Not at all effective	Not sure	Did not answer
a. Helping people with HIV live longer	57	25	4	2	13	*
b. Improving the health of people with HIV	44	33	8	1	13	1
c. Preventing the spread of HIV to sexual partners	14	22	21	20	23	1

Q19. As far as you know, if someone who is HIV-positive is taking consistent antiretroviral treatment, does this significantly reduce the risk of passing HIV on to their sexual partners, or not?

	Total
Yes, significantly reduces risk of passing HIV on	25
No, does not significantly reduce risk	39
Don't know	36
Did not answer	*

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[2] Survey respondents were able to click on certain words in the survey to obtain a definition. The definition provided for stigma was: "Stigma is a set of negative and often unfair beliefs that a society or group of people have about something"

[3] The definition provided for complacency was: "Complacency is the feeling of being satisfied with how things are and not wanting to try to make them better"

[4] The definition provided for antiretroviral medications/Antiretroviral treatment was: "A combination of three or more antiretroviral medications (sometimes referred to as antiretroviral therapy, or ART) is currently the standard treatment for HIV infection."

Q20. In your opinion how effective are condoms, if used consistently and correctly, at preventing HIV transmission between gay men?

	Total
Very effective	60
Somewhat effective	36
Not too effective	2
Not at all effective	2
Did not answer	*

Q21. As far as you know, is there a prescription medication that people who are HIV-negative can take to lower their risk of getting HIV, or not?

	Total
Yes	26
No	31
Don't know	43
Did not answer	*

Q22. As far as you know, what is the current recommendation for HIV testing for gay and bisexual men? Is it recommended they get tested:

	Total
Every month	8
Once every 3-6 months	55
Once a year	15
Less often than once a year	1
Don't know	20
Did not answer	*

Q23. As far as you know, when someone is diagnosed with HIV, when is it recommended that they begin antiretroviral treatment? (items randomized, anchor 4-5)

	Total
As soon as they are diagnosed	46
When their CD4 count falls below a certain level	17
When they begin to feel sick	1
Other	*
Don't know	35
Did not answer	*

Q24. [Do you personally feel you have all the information you need about each of the following, or would you like to have more information?/ Do you personally feel you would like to have more information about each of the following, or do you feel like you have all the information you need?] (items randomized; response options rotated 1-2/2-1)

	Have all the information you need	Would like to have more information	Did not answer
a. Where to go to get tested for HIV	72	28	*
b. How to bring up the topic of getting an HIV test with your partner	69	31	*
c. How often you should get tested for HIV	60	39	*
d. How to talk with a health care provider about HIV/AIDS	68	31	1
e. How effective condoms are in preventing HIV	70	30	*
f. Medication to prevent the transmission of HIV among HIV negative persons	39	60	*
g. When to begin treatment if HIV positive	50	50	*
h. How risky different sexual behaviors are in terms of HIV transmission	60	40	*

The next part of the survey asks questions about HIV and sexual behavior, including questions that some people may find embarrassing or uncomfortable. We would like to remind you that your responses are confidential and that you have the ability to skip any questions that you do not wish to answer. Your responses will be combined with the responses of others and no identifying information about you will be released with your answers.

Q25. In general, how comfortable would you be, personally, with each of the following? How comfortable would you be… (items randomized; response options rotated 1-4/4-1)

	Very comfortable	Somewhat comfortable	Somewhat uncomfortable	Very uncomfortable	Did not answer
a. having a roommate who is HIV-positive	46	26	18	10	*
b. having casual sex with someone who is HIV-positive	11	11	16	61	*
c. being in a long-term sexual relationship with someone who is HIV-positive	18	15	25	41	*
d. being in a non-sexual relationship with someone who is HIV-positive	50	26	13	11	*

Q26. Do you personally know anyone, including yourself, who is currently living with HIV, or not?

	Total
Yes	49
No	43
Not sure	7
Did not answer	1

Q27. Who do you know that is currently living with HIV?

Based on those who report that they personally know someone currently living with HIV (n= 238)

	Yes	No	Did not answer
a. Yourself	21	76	3
b. A current sexual partner	14	80	6
c. A past sexual partner	43	52	6
d. A family member	9	83	8
e. A close friend	55	42	3
f. An acquaintance	75	21	4
g. Someone else	8	61	31

Summary Q26/Q27 based on total

	Total
Yes, know someone living with HIV	49
Yourself	10
A current sexual partner	7
A past sexual partner	21
A family member	4
A close friend	27
An acquaintance	37
Someone else	4
No, do not know anyone living with HIV	43
Not sure	7
Did not answer	1

Q28. Has anyone close to you ever died from HIV/AIDS, or not?

	Total
Yes	32
No	62
Not sure	*
Did not answer	

Q29. How often do you ask a person's HIV status before having sex with them for the first time?

	Total
Always	27
Most of the time	18
Just some of the time	12
Never	16
Not applicable	26
Did not answer	1

Q29 Results based on those who did not select "Not applicable" *(n=303)*

	Total
Always	37
Most of the time	24
Just some of the time	16
Never	22
Did not answer	1

Q30. Have you ever been in a sexual relationship with someone who is HIV-positive, or not?

	Total
Yes	25
No	63
Not sure	12
Did not answer	*

Q31. Have you ever decided NOT to pursue a sexual relationship with someone specifically because they were HIV-positive, or not?

	Total
Yes	35
No	65
Did not answer	*

Q32. How accepting do you think each of the following groups are towards people living with HIV? (items randomized; response options rotated 1-4/4-1)

	Very accepting	Somewhat accepting	Somewhat unaccepting	Very unaccepting	Did not answer
a. The general public	3	19	53	24	1
b. Gay men	34	46	16	3	1
c. Your social circle	32	42	16	8	1
d. Your family	16	39	28	17	1
e. The medical community	33	51	12	3	1

Q33. There are many reasons why people living with HIV might be reluctant to tell others about their status. In your opinion, is each of the following a major reason, minor reason, or not a reason why some gay men living with HIV don't tell others they are HIV-positive? (items randomized)

	Major reason	Minor reason	Not a reason	Did not answer
a. Fear of discrimination in housing, jobs or other situations	76	18	6	*
b. Fear of rejection by intimate partners	76	18	6	*
c. Fear of rejection by family and friends	79	16	4	1
d. A general desire for privacy	62	30	7	*

Q34. As you may know, there is a new prescription medication that people who are HIV-negative can take to lower their risk of getting HIV, sometimes called pre-exposure prophylaxis (PrEP), or by the brand name Truvada. How much have you heard about this new medication?

	Total
A lot	9
A fair amount	11
Only a little	25
Nothing at all	55
Did not answer	*

Q35. Have you, yourself, ever taken this new prescription medication (known as PrEP or Truvada) for HIV prevention, or not?

Based on those who say they have heard at least a little about PrEP or Truvada (n=199)

	Total
Yes	11
No	88
Did not answer	1

Summary Q34/Q35 based on total

	Total
Have heard at least a little about PrEP	45
Yes, have ever taken PrEP	5
No, have not taken PrEP	40
Did not answer	*
Have heard nothing at all about PrEP	55
Did not answer	*

Q36. Do you personally know anyone else who has ever taken this new prescription medication (known as PrEP or Truvada) for HIV prevention, or not?

Based on those who say they have heard about PrEP or Truvada (n= 199)

	Total
Yes	19
No	67
Not sure	14
Did not answer	--

Summary of Q34/Q36 based on total

	Total
Have heard at least a little about PrEP	45
Yes, know someone who has ever taken PrEP	9
No, do not know anyone who has ever taken PrEP	30
Not sure if know anyone who has ever taken PrEP	6
Have heard nothing at all about PrEP	55
Did not answer	*

Summary of Q34/Q35/Q36 based on those who say they have heard about PrEP or Truvada (n=199)

	Total
Yes, know someone who has ever taken PrEP (including self)	10
No, do not know anyone who has ever taken PrEP (including self)	90

Q37. Still thinking about the new prescription medication that people who are HIV-negative can take to lower their risk of getting HIV (also known as PrEP or Truvada), which comes closer to your view of how widely this medication should be used?

	Total
It should be used as widely as possible among gay men because every available prevention tool should be used to limit the spread of HIV in communities at risk	56
It should be used on a more limited basis among gay men because people using it may be less likely to use condoms consistently, putting them at risk for other sexually transmitted diseases	43
Did not answer	1

Q38. Now thinking about your own medical care, is there a place that you usually go to when you are sick or need advice about your health, or not?

	Total
Yes	78
No	22
Did not answer	*

Q39. What kind of place is it that you usually go?

Based on those who report that there is a place that they usually go when they are sick (n= 361)

	Total
A doctor's office or HMO	70
A general clinic or health center	18
An HIV clinic	5
A hospital outpatient department	2
A clinic or health center that serves the LGBT community	1
A hospital emergency room	1
An urgent care center	1
Some other place	2

Summary Q38/Q39 based on total

	Total
Yes, have a place you usually go when sick/need health advice	78
A doctor's office or HMO	54
A general clinic or health center	14
An HIV clinic	4
A clinic or health center that serves the LGBT community	1
A hospital emergency room	1
An urgent care center	1
A hospital outpatient department	1
Some other place	1
No, do not have a usual place to go when sick/need health advice	22
Did not answer	*

Q40. Do you have a regular personal doctor that you see at the place you usually go for health care, or not?

Based on those who report that there is a place that they usually go when they are sick (n= 361)

	Total
Yes, have a regular doctor	89
No, do not	11
Did not answer	*

Summary Q38/Q40 based on total

	Total
Yes, have a place you usually go when sick/need health advice	78
Yes, have a regular doctor	69
No, do not	9
Did not answer	*
No, do not have a usual place to go when sick/need health advice	22
Did not answer	*

Q41. Have you ever discussed your sexual orientation with **[**your regular doctor**/**a doctor or other health professional**]**, or not? (If Q40=”yes” insert “your regular doctor”; if Q38=”no” or Q40=”no” insert “a doctor or other health professional”)

	Total
Yes	52
No	47
Did not answer	1

Q42. Which of the following is the main reason you haven’t discussed your sexual orientation with **[**your regular doctor**/** a doctor or other health professional**]**? (If Q40=”yes” insert “your regular doctor”; if Q38=”no” or Q40=”no” insert “a doctor or other health professional”)

Based on those who have not discussed their sexual orientation with a doctor or other health care provider (n= 196)

	Total
You don’t think it’s important for them to know	21
It just never came up	37
You’re uncomfortable raising the topic	15
Your doctor never asked	17
Some other reason	9
Did not answer	1

Summary Q41/Q42 based on total

	Total
No, have not discussed sexual orientation with doctor	47
You don’t think it’s important for them to know	10
It just never came up	17
You’re uncomfortable raising the topic	7
Your doctor never asked	8
Some other reason	4
Did not answer	*
Yes, have discussed sexual orientation with doctor	52
Did not answer	1

Q43. How comfortable do you feel discussing topics related to sexual behavior with **[**your regular doctor**/**a doctor or other health professional**]**? (If Q40="yes" insert "your regular doctor"; if Q38="no" or Q40="no" insert "a doctor or other health professional")

	Total
Very comfortable	35
Somewhat comfortable	36
Somewhat uncomfortable	23
Very uncomfortable	5
Did not answer	1

Q44. When you visit a doctor or other health care provider, how often do you discuss the topic of HIV?

	Total
Every time	12
Only some of the time	18
Rarely	24
Never	37
Never visit doctors	9
Did not answer	1

Q45. The last time you discussed HIV with a doctor or other health care provider, did you raise the topic or did your doctor bring it up?

Based on those who report that they have ever discussed the topic of HIV with a doctor or other health care provider (n= 242)

	Total
You raised the topic	33
Your doctor brought it up	31
Both/neither	36
Did not answer	--

Summary of Q44/Q45 based on total

	Total
Have ever discussed HIV with a health care provider	54
You raised the topic	18
Your doctor brought it up	17
Both/neither	20
Did not answer	--
Never discuss HIV with health care providers	37
Never visit doctors	9
Did not answer	1

Q46. Has a doctor or other health care provider ever suggested that you be tested for HIV, or not?

	Total
Yes	44
No	56
Did not answer	*

Q47. Have you, yourself, ever been tested for HIV?

	Total
Yes	72
No	27
Did not answer	1

Q48. When was the last time you were tested for HIV?

Based on those who report that they have ever been tested for HIV (n= 341)

	Total
Within the last 3 months	16
At least 3 months but less than 6 months ago	11
At least 6 months but less than 12 months ago	15
12 months ago or longer	52
Can't remember	6
Did not answer	--

Summary Q47/Q48 based on total

	Total
Yes, ever tested	72
Within the last 3 months	12
At least 3 months but less than 6 months ago	8
At least 6 months but less than 12 months ago	11
12 months ago or longer	37
Can't remember	4
No, never tested	27
Did not answer	1

Q49. How often do you USUALLY get tested for HIV?

Based on those who report that they have ever been tested for HIV (n= 341)

	Total
Less than once a year	41
About once a year	26
Two or three times a year	11
Four times a year or more	6
Other	15
Did not answer	*

Summary Q47/Q49 based on total

	Total
Yes, ever tested	72
Less than once a year	30
About once a year	19
Two or three times a year	8
Four times a year or more	4
Other	11
Did not answer	*
No, never tested	27
Did not answer	1

Q50. The last time you were tested for HIV, did you go to a doctor or clinic SPECIFICALLY to get an HIV test, or did you decide to get an HIV test as part of another health visit, such as a routine check-up?

Based on those who report that they have ever been tested for HIV (n= 341)

	Total
Went specifically to get an HIV test	33
Got tested as part of another health visit	60
Other	7
Did not answer	1

Summary Q47/Q50 based on total

	Total
Yes, ever tested	72
Went specifically to get an HIV test	24
Got tested as part of another health visit	43
Other	5
Did not answer	*
No, never tested	27
Did not answer	1

Q51. Thinking about the most recent time you were tested for HIV, please indicate whether each of the following was a major reason, minor reason, or not a reason why you decided to get tested. (items randomized)

Based on those who report that they have ever been tested for HIV (n= 341)

	Major reason	Minor reason	Not a reason	Did not answer
a. You were concerned that you might be infected	22	27	48	3
b. A doctor or other health care provider suggested it	24	17	58	1
c. A partner suggested or asked that you get tested	10	11	77	2
d. It's something you do regularly	35	22	42	1
e. It just seemed like a good idea	50	25	22	2

Q52. Please indicate whether each of the following is a major reason, minor reason, or not a reason why you have not been tested for HIV **[if Q48=4;** in the past year**]**. (items randomized)

Based on those who report that they have never been tested for HIV or last test was 12 months ago or longer (n= 273)

	Major reason	Minor reason	Not a reason	Did not answer
a. You don't think you're at risk	55	14	30	--
b. You're afraid to find out the results	15	14	71	--
c. You Don't know where to go to get tested	12	8	80	--
d. Your doctor hasn't brought it up	10	16	74	--
e. You're worried about the cost	10	8	82	--
f. You just haven't gotten around to it	19	22	59	--

Q53. When having sex, how often do you use condoms?

	Total
All of the time	21
Most of the time	17
Only some of the time	13
Rarely	12
Never	20
Not applicable	16
Did not answer	*

Q53 Results based on those who did not select "Not applicable" *(n=353)*

	Total
All of the time	25
Most of the time	21
Only some of the time	16
Rarely	14
Never	24
Did not answer	*

Q54. For each of the following, please indicate whether or not it has happened to you because you are, or were perceived to be, **[**gay**/** bisexual**]**? If yes, was that in the past 12 months, or longer ago than that?

	Yes, happened in the last 12 months	Yes, happened, but more than 12 months ago	No, has not happened	Did not answer
a. Been threatened or physically attacked	3	23	74	*
b. Been treated unfairly by an employer in hiring, pay, or promotion	3	12	84	*
c. Been rejected by a friend or family member	5	27	67	1
d. Been discriminated against in trying to get housing	2	5	93	1
e. Received poor treatment from a doctor or other health care professional	3	12	84	1

Q54a. Has someone ever attempted to force you to have sex or engage in a sexual act against your will? If yes, was that in the past 12 months, or longer ago than that?

	Total
Yes, happened in the last 12 months	4
Yes, happened, but more than 12 months ago	14
No, has not happened	81
Did not answer	*

Q55. Which best describes you:

	Total
Married	20
Living with a partner (including a civil union)	22
Divorced	5
Separated	1
Widowed	1
Never been married	51
Did not answer	1

Q56. Are you currently in a committed relationship, or not?

Based on those who say they are divorced, separated, widowed or never been married (n= 243)

	Total
Yes	19
No	81
Did not answer	--

Summary Q55/56 based on total

	Total
Married/living with a partner/ in committed relationship	53
Divorced/ separated/ widowed/ never married/ not in committed relationship	47
Did not answer	*

Q57. Would you say you live in a neighborhood known for being an LGBT neighborhood?

	Total
Yes	13
No	86
Did not answer	1

QINS1. Below is a list of the different kinds of health plans or health insurance people have, including those provided by the government.

Please indicate whether or not you are currently covered by each type of insurance or not.

	Covered	Not covered	Not sure	Did not answer
Health insurance through your or someone else's employer or union	52	43	4	2
Medicare, a government plan that pays health care bills for people aged 65 or older and for some disabled people	16	78	4	2
Medicaid or any other state medical assistance plan for those with lower incomes	11	77	7	5
Health insurance that you bought through [INSERT NAME OF STATE HEALTH INSURANCE EXCHANGE]	4	84	7	5
Health insurance that you bought directly, but not from [INSERT NAME OF STATE HEALTH INSURANCE EXCHANGE]	6	84	6	5
Health insurance from some other source	7	83	6	5

Insurance Combo

	Total
Insured	82
Uninsured	13
Unknown	4

PARTY ID. PARTY1. Generally speaking, do you think of yourself as a Republican, Democrat, Independent, Another party please specify, No preference?/ PARTY2/PARTY3. [asked of those who identify as "Republican" or "Democrat" in PARTY1] Would you call yourself a strong (Republican/Democrat), not very strong (Republican/ Democrat)?/ PARTY4. [asked of those who identify as "Independent" "Another party" "No preference" or skipped PARTY 1] Do you think of yourself as closer to the Republican Party, Democratic Party?

	Total
Strong Republican	4
Not Strong Republican	5
Leans Republican	8
Undecided/Independent/Other	2
Leans Democrat	23
Not Strong Democrat	20
Strong Democrat	36

IDEO. In general, do you think of yourself as…

	Total
Extremely liberal	16
Liberal	39
Slightly liberal	12
Moderate, middle of the road	20
Slightly conservative	4
Conservative	5
Extremely conservative	3

QPP10003. Are you currently registered to vote?

	Total
Yes, I am registered to vote at my present address	77
Yes, I am registered to vote at a different address	8
No, I am not registered to vote	13
Not sure	2

REL1. What is your religion? **[DO NOT ROTATE]**

	Total
Baptist—any denomination	8
Protestant (e.g., Methodist, Lutheran, Presbyterian, Episcopal)	15
Catholic	17
Mormon	1
Jewish	3
Muslim	*
Hindu	--
Buddhist	*
Pentecostal	3
Eastern Orthodox	*
Other Christian	7
Other non-Christian	3
None	42

QPPP20071. Would you describe yourself as a born-again or evangelical Christian?

Based on those who say they are Baptist, Protestant, Catholic, Mormon, Pentecostal, Eastern Orthodox, or Other Christian (n=230)

	Total
Yes	32
No	68

Summary of REL1 and QPPP20071 based on total

	Total
Baptist/ Protestant/ Catholic/ Mormon/ Pentecostal/ Eastern Orthodox/ Other Christian	50
Born-again or evangelical Christian	16
Not born-again or evangelical Christian	34
Jewish	3
Muslim	*
Hindu	--
Buddhist	*
Other non-Christian	3
None	42

REL2. How often do you attend religious services?

	Total
More than once a week	5
Once a week	10
Once or twice a month	5
A few times a year	12
Once a year or less	20
Never	46

AGE.

	Total
18-24	11
25-34	26
35-44	20
45-54	19
55-64	16
65-74	5
75+	3

HOUSEHOLD SIZE.

	Total
1	29
More than one	71
2	39
3	20
4	6
5	2
6	1
7	1
8	2

ANY CHILDREN UNDER AGE 18 IN HOUSEHOLD

	Total
Yes	12
No	88

NUMBER OF HOUSEHOLD MEMBERS 18 OR OLDER.

	Total
1	30
More than one	70
2	44
3	19
4	5
5	1
6	*
8	1

RACE/ ETHNICITY.

	Total
White, non-Hispanic	69
Hispanic	12
Black, non-Hispanic	11
Other, non-Hispanic	4
2+ Races, non-Hispanic	4

EDUCATION.

	Total
Some college or less	60
Less than high school	7
High school	17
Some college	36
Bachelor's degree or more	40
Bachelor's degree	25
Master's degree	10
Professional or Doctorate degree	5

EMPLOYMENT STATUS.

	Total
Working	67
Working- as a paid employee	61
Working- self-employed	6
Not working	33
Not working- on temporary layoff from a job	--
No working- looking for work	10
Not working- retired	9
Not working- disabled	10
Not working- other	4

INCOME.

	Total
Less than $35,000	31
$35,000- $74,999	28
$75,000 or more	40

HOME OWNERSHIP STATUS.

	Total
Owned or being bought by you or someone in your household	60
Rented for cash	36
Occupied without payment of cash rent	3

REGION.

	Total
Northeast	17
Midwest	17
South	37
West	29

METRO STATUS.

	Total
Non-Metro	11
Metro	89

LANGUAGE OF INTERVIEW.

	Total
English	96
Spanish	4

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Dynamic social support networks of younger black men who have sex with men with new HIV infection

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Abstract

Rising rates of HIV-infection among younger black men who have sex with men (YBMSM) in the United States have generated a public health emergency. Living with HIV requires deep and persistent social support often available only from close confidants. Enlisting endogenous support network members into the care of HIV-infected YBMSM may help shape sustainable supportive environments, leading to long-term improvements in mental and HIV-specific health outcomes. The present study examined trends in support network change over time after new HIV diagnoses among fourteen YBMSM. Participants completed a social network survey that utilized sociograms to record support confidants (SCs) preceding HIV diagnosis and at one and nine months post-diagnosis. Reported SCs included family of origin, friends, sex partners, and other associates. Analysis revealed three distinct patterns of change: high gain, high turnover, and stable networks. These patterns offer valuable insights into the social support of YBMSM during the period following diagnosis. This research underscores a growing movement to embrace key support figures in the lives of YBMSM, who may be critical to promoting overall health and adherence to HIV-care.

Introduction

HIV incidence among younger black men who have sex with men (YBMSM) in the United States increased by 48% between 2006–2009 – more than in any other age, race, or risk group (Prejean et al., 2011). This disparity is driven by a complex syndemic of environmental, psychosocial, and network factors (Dyer et al., 2012; Feldman, 2010; Laumann & Youm, 1999; Oster et al., 2011) that also predict poor engagement in care and virologic failure (Christopoulos, Das, & Colfax, 2011; Giordano et al., 2007).

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Current strategies to increase engagement in care among YBMSM often focus on exogenous support systems including peer outreach (Hightow-Weidman et al., 2011; Magnus et al., 2010) and intensive case management (Wohl, Garland, et al., 2011). While effective, these programs are resource-taxing and may be difficult to support in the long-term (Hidalgo et al., 2011; Mugavero, Norton, & Saag, 2011). Harnessing existing social support networks of HIV-infected individuals offers a promising alternative, whereby the close confidants of a patient are recruited to enhance his or her adherence to care. Social support networks can play a powerful role in the well-being of HIV-infected persons by attenuating the burdens of treatment and social stigma, and by affecting positive changes in health behaviors (Burgoyne, 2005; Buttram, Kurtz, & Surratt, 2012; George et al., 2009; Wohl, Galvan, et al., 2011).

This approach emerges from social network theory, which dictates that individuals are embedded within distinct social networks that vary based on dyadic and structural metrics (Bandura, 1986; Laumann, 1973; Valente, 2010). Within these networks, behavior change is possible through naturally existing mechanisms of influence that operate via exchanges of information, support, and other social relations (Akers, 1973; Barrington et al., 2009; Davey-Rothwell & Latkin, 2008; Schneider et al., 2013). These mechanisms also draw on a model of social support positing that interpersonal transactions of various forms (e.g., emotional, financial) may mediate the achievement of HIV-specific outcomes, including sexual risk reduction, medication adherence, and retention in care.

Living with HIV requires deep and persistent social support; support often available from existing *confidants*–friends, partners, kin and other individuals–with whom one shares personal information and may be influenced by (Elkington, Bauermeister, & Zimmerman, 2011; Foss, Vickerman, Heise, & Watts, 2003). For example, a growing body of evidence suggests that capitalizing on the family networks of HIV-infected or at-risk YBMSM may improve long-term engagement in HIV care and overall well-being (Lauby et al., 2012; Serovich, Grafsky, & Craft, 2011). In a recent study, YBMSM with higher family network proportions engaged in less risk behaviors and even discouraged risk behaviors in their MSM friend networks (Schneider, Michaels, & Bouris, 2012). In short, enlisting endogenous network members in the care plans of HIV-infected YBMSM may help shape a sustainable and deeply impactful supportive environment, while also overcoming the resource limitations of existing strategies.

An important step in recruiting support is the disclosure of one’s HIV status. The decision to disclose is a highly individualized process affected by a complex interplay of factors, including relationship dynamics, financial dependencies, and the appearance of disease symptoms (Bird, Fingerhut, & McKirnan, 2011; Kalichman, DiMarco, Austin, Luke, & DiFonzo, 2003, and both disclosure and postponed or non-disclosure are associated with significant levels of anxiety (Overstreet, Earnshaw, Kalichman, & Quinn, 2012; Wohl et al., 2010). In addition to disclosing their HIV status, YBMSM may simultaneously reveal their sexual behavior to unaware network members, potentially causing additional stress and disruption (Latkin et al., 2012).

Given these factors, the aim of the present study was to evaluate the social support networks of newly HIV-diagnosed YBMSM. To achieve this goal, we (1) employed a network perspective to identify types of network members (e.g., parents, friends, sex partners); (2) evaluated the relative stability and persistence of these relationships over nine months; and (3) detected trends in HIV-status disclosure and their relationship to network dynamics.

Methods

Participants and Recruitment

Data were generated from a cohort of 14 YBMSM newly diagnosed with HIV who were referred from a social network study (Schneider et al., 2013). YBMSM were included if they: (1) identified as Black/African American; (2) were aged 18–30, inclusive; (3) self-reported sexual intercourse with a male partner in the previous 12 months; and (4) had their first confirmed reactive HIV test within three months prior to recruitment. Network variables were collected during interviews following regularly scheduled appointments with an HIV provider. Interviews were conducted by HIV clinic staff with previous training in post-test counseling, crisis management and cultural competency with long-time histories working with YBMSM. All study procedures were approved by two Institutional Review Boards.

Measures

Index Attributes

Structural stability indicators of housing status, employment, and insurance type at time of diagnosis were abstracted from patients' medical records. In addition, CD4 count and viral load at HIV diagnosis were abstracted as indicators of health.

Name generator

We extended the standard *confidant* name generator "Who do you share important information with?" to include "…*and* would you expect to help you out in a time of need?" (Laumann, 1973; Marin, 2004; Marsden, 1987) to ensure the inclusion of network members who provide instrumental and emotional support (Cohen & Wills, 1985). The name generator was limited to ten confidants, as this has been sufficient in eliciting all network members meeting the generator criterion (Burt, Marsden, & Rossi, 1985). The list of network members, referred to hereafter as support confidants (SCs), was reviewed by YBMSM for completeness before proceeding with SC-specific questions.

Network Visualization and Name Interpreter

We used participant-aided network diagrams, or sociograms (Hogan, Carrasco, & Wellman, 2007), to assist in network elicitation. Respondent-directed visualization of personal networks has been demonstrated to improve participation, accelerate name generation, and provide reliable checks for various network measures (Hogan et al., 2007). This technique is engaging, well-suited to resource limited settings, and has been previously employed by the research team (Schneider et al., 2010; Schneider et al., 2012).

SCs elicited by the name generator were ascribed three attributes. First, YBMSM identified their role in the network by answering the question: “What is your relationship to this person?” A limit of one role per SC was deemed sufficient. Second, a binary variable for “closeness” was used to separate “very close” from “less close” members; “very close” SCs were sketched into the “inner circle” of the sociogram. Third, YBMSM indicated which SCs they had disclosed their HIV status to, which was marked on the sociogram. Participants were also asked to identify alter-alter ties, or ties between network members. This was accomplished by asking “Does A talk to B when you aren’t around?” The question was phrased to identify inter-SC relationships that existed independent of the ego-participant’s mediation, and these ties were indicated by a line drawn between respective SCs. Data were collected at the first clinical visit after learning their HIV status, 1 month and 9 months (e.g., at t=0, t=1, and t=9, respectively).

Network Analysis

Figure 1 provides standard definitions for each network metric used in the study. These included standard egocentric measures such as size, density, constraint and betweenness, which were calculated for each sociogram at each time point using UCINET (Borgatti, Everett, & Freeman, 2002). The stability of each participant’s network was calculated using the following equation (Bien, Marbach, & Neyer, 1991; Han, Ghose, & Iyengar, 2011):

$$\text{Network Stability}=\frac{\text{Number of SCs named at both t=0 and time t=1}}{\text{Number of SCs } i \text{ named at t=0}}$$

Other measures included the proportion of SCs who the participant had disclosed to at each time period and the proportion of SCs in distinct role categories. SCs were consolidated into four categories: (1) family of origin, (2) friend, (3) sex partner, and (4) other.

Descriptive statistics were calculated for network composition and disclosure at each time period, where network composition was evaluated using the proportional value of each SC type. The Wilcoxon signed ranks test was used to compare changes in network composition and disclosure across two periods. Spearman’s correlation was calculated to determine the associations for these variables at each sample period. All statistical analyses were conducted using SPSS Version 19 and the level of significance was set at $p < 0.05$.

Results

Respondents & Support Confidants

A total of fourteen individuals were included in the analysis. Table 1 displays the health and structural stability indicators collected for participants. A total of 83 unique SCs were named across all three time periods. Fifty-two SCs were named at time 0, which increased to 62 at t=1 and to 66 members at t=9. Figure 2 summarizes network compositions at each time period. Because the number of SCs designated as “gay” or “play” families was small, these members were typified as “Others” in order to isolate family of origin dynamics. Others also included roommates, pastors, and support group members. Sex partners included former and current partners.

Composition and Network Metrics

A total of 31 new ties were added to the network between the time of diagnosis and nine months after; 18 of these new SCs were reported at t=1 and the remaining 13 at t=9. Four participants did not gain any SCs over time, and the median increase in network size for the remaining ten participants was 3 [standard deviation (SD) = 1.85]. Eight SCs were lost between t=0 and t=1, including two sex partners, two friends, and four family of origin network members. A single friend SC was gained at t=1 but lost by t=9.

Change in social network metrics including stability, density, constraint and betweenness are presented in Figure 3. The average stability across all fourteen SC networks was 0.83—that is, 40 of the 48 SCs reported at t=0 remained at t=9 (the SCs of two YBMSM for whom network information was unavailable at t=9 are not included here). The average stability across all participants at t=1 was 0.85, and increased to 0.97 at t=9. There was a greater turnover in sex partners, friends, and family of origin network members from t=0 to t=1 (stability 0.71, 0.89, and 0.83, respectively) than from t=1 to t=9 (stability 1.00, 0.95, and 1.00, respectively). While density and constraint averages decreased over time (0.63 to 0.49 for density; 0.71 to 0.53 for constraint), average betweenness increased from 1.42 at t=0 to 4.33 at t=9.

Longitudinal Patterns of Change

Three distinct patterns in network change over time were identified: high gain, high turnover, and stable. Participants with high network gain (n=4) increased their network size by at least four and as many as six new members while losing a maximum of one existing member. These participants had relatively small networks prior to their diagnosis, usually consisting of family of origin and a sex partner. The high gain condition resulted almost exclusively from the adoption of an exogenous supportive network, such as a support group or family of choice, as illustrated in Panels 1 and 2 of Figure 4. High gain networks increased in density over time by inheriting the existing cohesion within the adopted group, and HIV disclosure to SCs was high in this category. Although the change in network size was significant for these participants, it did not affect the stability of their support networks, as measured by the loss of network members.

In a network with high turnover, YBMSM gained and lost approximately the same number of network members. These networks exhibited low stability over time despite little change in overall size, as exiting members were replaced by new SCs. Most participants exhibiting this pattern (n=5) had between three and five SCs before diagnosis, and member loss occurred during the first month after diagnosis. As a whole, this group reported diverse “other” membership before and after diagnosis, including female sex partners, pastors, roommates, and family of choice. Panel 3 in Figure 4 exhibits a sample of this network pattern.

Finally, a portion of participants (n=5) reported zero turnover over the course of the study (a single participant included here reported one new SC but no losses). These networks had high stability measures over time, varied in initial size from 3 to 7, and consisted primarily of friends and secondarily of family of origin. This subset included two YBMSM with the lowest disclosure rates, including one who had not disclosed to any network members. An example of this group is presented in Panel 4 of Figure 4.

Disclosure and Network Statistics

Spearman correlations were run for network measures at each time point. At time of diagnosis, density was positively correlated to constraint ($\rho = 0.80$, $P = 0.002$). At t=1, constraint and density remained positively correlated ($\rho = 0.80$, $P = 0.001$) and at t=9, the relationship was no longer significant. Results are not reported for constraint and betweenness or density and betweenness because these measures are conceptually similar and negatively correlated.

At t=1, there was a significant negative correlation between the proportion of network members disclosed to and the proportion of friends in the network ($\rho = -0.74$; $P = 0.003$). There were no other significant associations between disclosure and network composition, density, constraint, or betweenness.

Discussion

The results offer important insights into social dynamics in the critical period after HIV diagnosis, as well as the potential for interventions that harness organic support systems. The changes in egocentric network measures in Figure 3 offer a unique interpretation of the social adaptations made by YBMSM following their HIV diagnosis. One key finding was the overall increase in betweenness in support networks. Betweenness is traditionally used as an indicator of centrality or control within an egocentric network; an individual with high betweenness can better monitor and regulate the flow of information within their network (Freeman, 1979). This position could enable a YBMSM to enforce the confidentiality of his health and behavior – for example, an SC is more likely to learn of the YBMSM's HIV-status directly, rather than from another member. Additionally, greater social control in one's network has been shown to improve assertiveness and health (Cornwell & Laumann, 2011).

Although HIV-status disclosure did not correlate with any of the egocentric metrics, our analysis of support and disclosure patterns is enriched by incorporating indices of social and structural stability. For instance, YBMSM who disclosed their HIV-status early and to more of their SCs had networks with high stability post-diagnosis. One description of network stability is a resilience to perturbations – stable networks tend to revert to baseline conditions following a disruption, indicating adaptability and coherence (Csermely, 2006). Through early and broad disclosure, YBMSM in stable networks demonstrated confidence in their networks to adjust to the knowledge of their HIV status without significant loss of support. Incidentally, participants with stable networks also reported more stable housing and had higher CD4 counts (mean 408 cells/mm^3) upon initiation of HIV care. Resilient networks provide an opportunity for interventions that *include* the SCs of YBMSM with a demonstrated propensity to offer the sustained social support necessary in HIV-care.

Interventions targeting YBMSM with weak support networks could pose a greater challenge. In this study, YBMSM with high gain networks had few SCs at time of diagnosis and more often reported unemployment and transient housing. Additionally, they had overall lower CD4 and high viral load results (means = 229 cells/mm^3 and 89,119 copies/mL, respectively). Taken together, these structural and health outcomes indicate fragmented support systems and substantial volatility in the lives of these YBMSM. The “accumulation” of SCs following HIV diagnosis may signify a heightened perception of vulnerability and the need to reach out for support. Moreover, YBMSM with high gain networks reported high rates of HIV status disclosure to their new SCs (27 of 31 new SCs). The support-seeking behavior in this group poses another unique opportunity for intervention wherein a new SC to whom the HIV-infected individual has disclosed to could be recruited to provide personal support and health promotion.

A growing body of evidence suggests that family members, especially parents, can be critical for supporting the health of YBMSM (Bouris et al., 2010; Garofalo et al., 2008; Schneider et al., 2012), including research that fruitfully involves parents to influence the health of young people (Guilamo-Ramos et al., 2011). In the present study, YBMSM reported high family of origin membership (i.e., biological parents and siblings) in their support networks at all three time periods (55% at t=0; 34% at t=1; 42% at t=2). This finding supports the effort to develop family- and parent-based interventions to enhance health outcomes within this population.

While these results augment the current literature on social support networks and HIV-care, important limitations must be noted. First, the small sample restricts external validity and prevents deeper contextualization of network dynamics. Additionally, given the significant personal and social disturbance that receiving an HIV-diagnosis may cause, recall bias may have impacted the construction of participants’ support networks prior to their diagnosis (Ferligoj & Hlebec, 1999). Finally, we did not elicit information on the kinds of support perceived or received or the reasons for the addition or loss of SCs, important areas for future research.

Despite these limitations, the present study underscores a growing movement to embrace the position of key support figures in the lives of YBMSM with HIV. Interventions that harness the organic support systems of YBMSM to improve health outcomes, particularly related to HIV infection, offer great promise for long-term efficacy with conservative resource utilization. However, it is important to acknowledge that the time period following HIV diagnosis may entail significant restructuring of social networks, and these dynamics may vary greatly depending on previously existent support conditions. In order to design appropriate and safe interventions, it is key to establish a baseline understanding of these dynamics and patterns. Not only does this information inform the intervention framework, it would assist in thorough process and outcomes evaluation. Future qualitative and quantitative work should seek to deepen our understanding of interpersonal dynamics within the support networks of HIV-infected YBMSM, to inform the development of interventions that improve health outcomes within this population.

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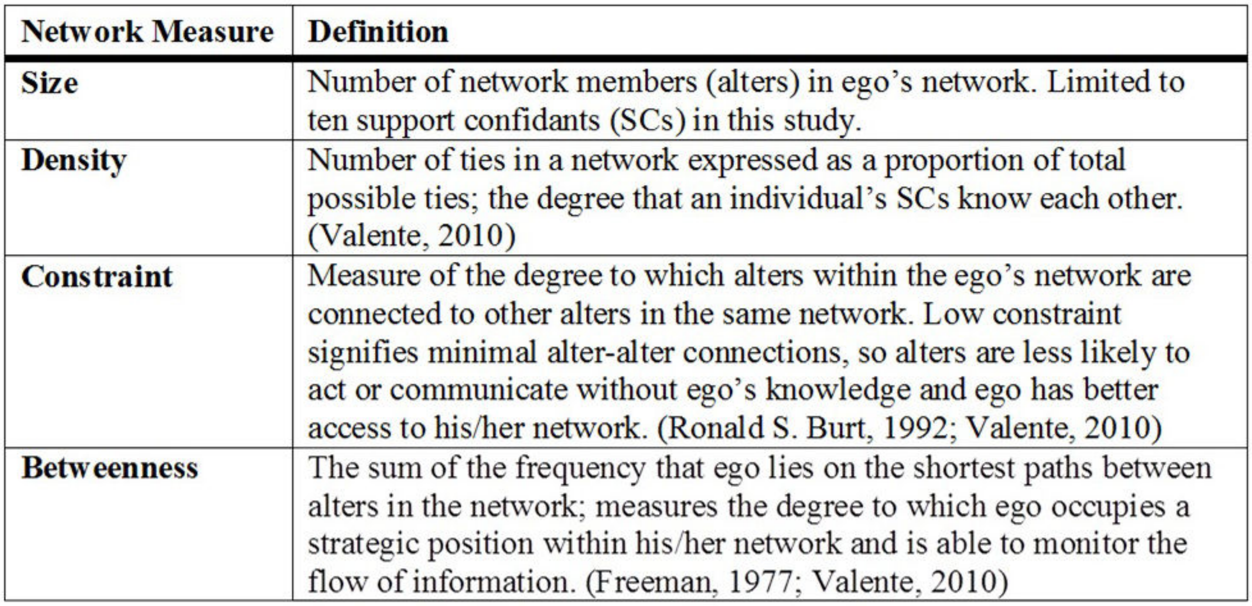

Network Measure	Definition
Size	Number of network members (alters) in ego's network. Limited to ten support confidants (SCs) in this study.
Density	Number of ties in a network expressed as a proportion of total possible ties; the degree that an individual's SCs know each other. (Valente, 2010)
Constraint	Measure of the degree to which alters within the ego's network are connected to other alters in the same network. Low constraint signifies minimal alter-alter connections, so alters are less likely to act or communicate without ego's knowledge and ego has better access to his/her network. (Ronald S. Burt, 1992; Valente, 2010)
Betweenness	The sum of the frequency that ego lies on the shortest paths between alters in the network; measures the degree to which ego occupies a strategic position within his/her network and is able to monitor the flow of information. (Freeman, 1977; Valente, 2010)

Figure 1.
Standard Egocentric Network Measures and Definitions

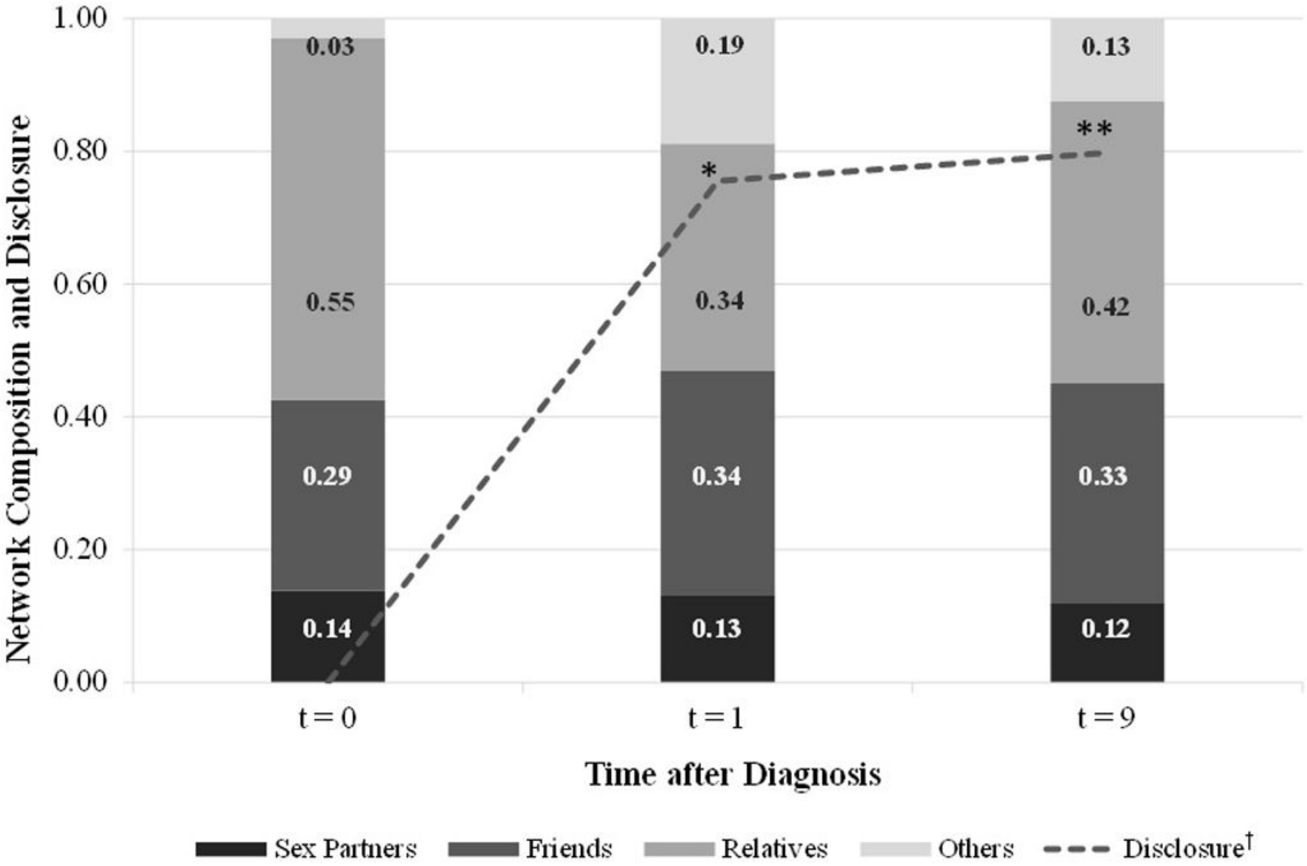

Figure 2. Social network composition and HIV disclosure among newly diagnosed younger black men who have sex with men over time (n=14)

*Change from time 0 significant at ≤ 0.001.

**Change from time 0 significant at ≤ 0.01. No significant change from time 1.

† Disclosure of positive HIV serostatus was always zero at the pre-diagnosis stage, t = 0, though this did not reflect the patient's situation at the time the interview was conducted. To obtain information on the network immediately prior to an HIV diagnosis, clients were asked to identify network members who were part of the support network prior to their diagnosis. No patients were approached during the same visit that they received their positive HIV test results.

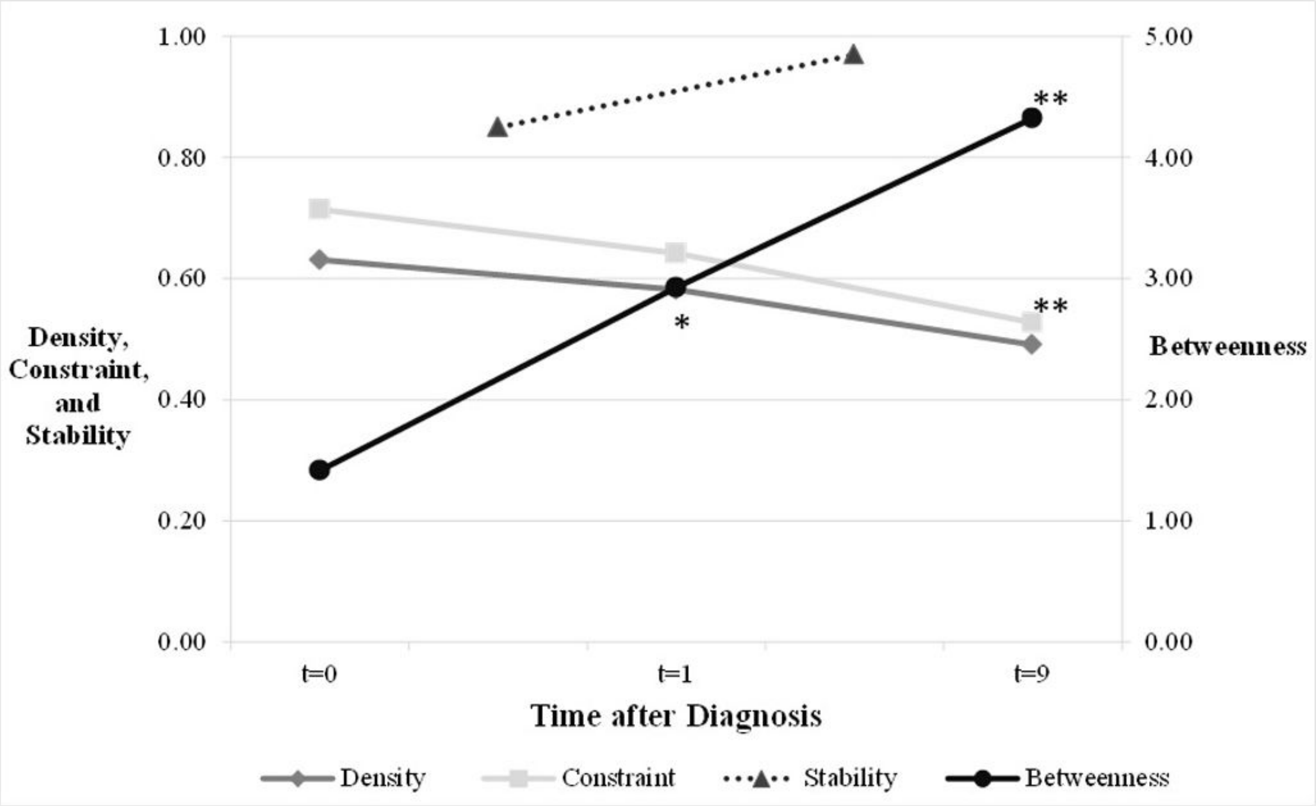

Figure 3. Social network density, constraint, and betweenness among newly diagnosed younger black men who have sex with men over time (n=14)

*Change in betweenness from time 0 significant at ≤ 0.05

**Change from time 0 significant at ≤ 0.05. No significant change from time 1.

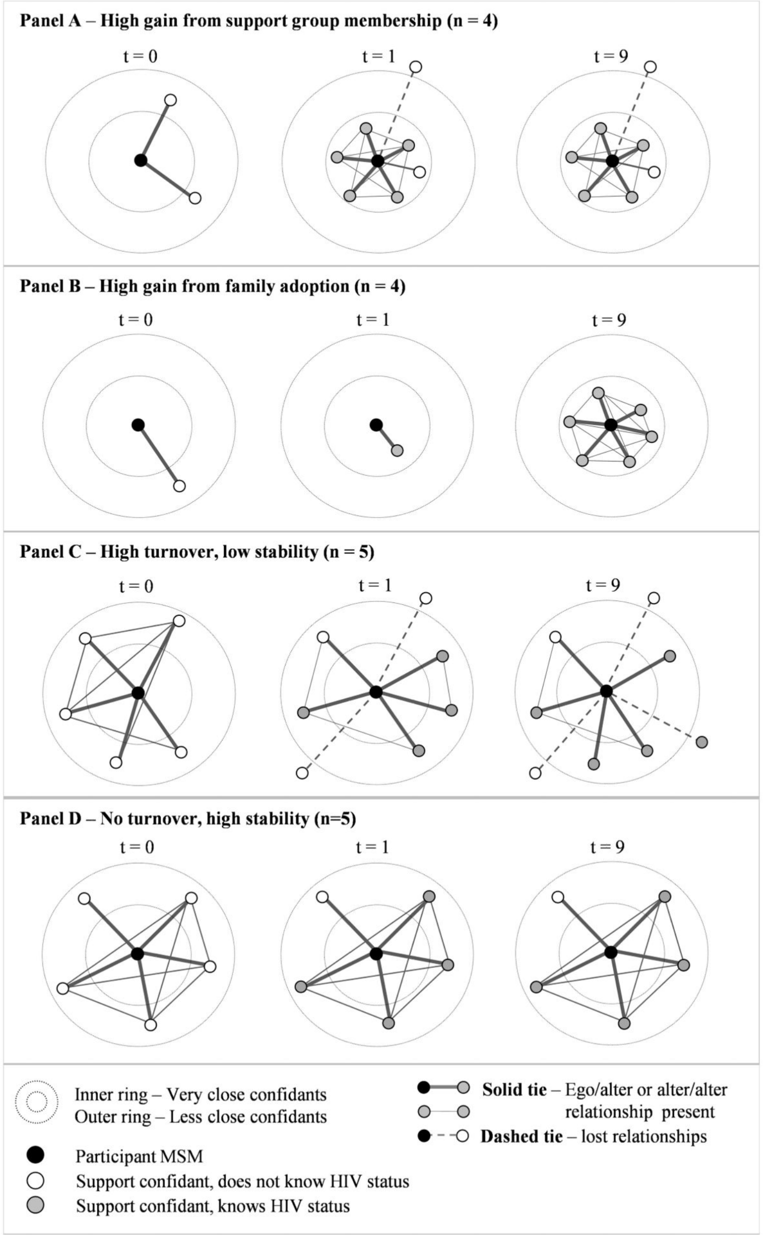

Figure 4.

Trends in the dynamics of the social support networks of newly diagnosed younger black men who have sex with men over time (n=14).

Table 1

Structural and health characteristics of younger black men who have sex men newly diagnosed with HIV (n=14).

Characteristic	**N (%)**
Employment	
Student	1 (7)
Employed	4 (27)
Unemployed	9 (67)
Housing	
Permanent	9 (60)
Non-permanent	4 (33)
Insurance	
Private	1 (7)
Public	2 (20)
Uninsured	11 (73)
CD4 upon care initiation	
[Mean (Med)]	360 (372)
Viral Load upon care initiation	
[Mean (Med)]	38,527 (8,670)

[*] Number non-missing. Percentages may not add to 100% due to rounding. Missing values: Housing – 1

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Keeping Them in "STYLE": Finding, Linking, and Retaining Young HIV-Positive Black and Latino Men Who Have Sex with Men in Care

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Abstract

Young men who have sex with men (YMSM) of color are at particularly increased risk for HIV infection compared to white MSM. National data highlight the need to link YMSM of color to care to improve their overall health and stem further infections, yet, there is limited data on interventions and clinical outcomes focused on engaging and retaining youth, specifically HIV-infected YMSM of color in care. To address the medical care needs of this underserved population, in 2005, the Health Research and Services Administration (HRSA) created the YMSM of Color Initiative. Utilizing a social marketing campaign targeting youth and members of their sexual and social networks, testing and outreach on college campuses and within the broader community, and a tightly linked medical–social support network, we created STYLE (Strength Through Youth Livin' Empowered), a novel intervention that sought to diagnose, engage, and retain HIV-positive black and Latino YMSM in HIV primary care services. Over a 3-year period, 81 men were either newly diagnosed or reengaged in care. Overall, 63% of the cohort was retained in clinical care; defined as attending at least one medical visit every 4 months. Compared to the 3 years prior to STYLE, the odds ratio for whether or not someone attended a clinic visit was 2.58 (95% confidence interval [CI] 1.34–4.98) if enrolled in STYLE. We conclude that compared to a pre-STYLE cohort, STYLE was an effective intervention that increased HIV diagnoses, provided efficient and timely engagement in care for both those newly diagnosed and those who had fallen out of care and improved overall retention.

Introduction

Young men who have sex with men (YMSM) of color are at particularly increased risk for HIV infection compared to white MSM. From 2001 to 2006, a 12.4% increase in the number of HIV/AIDS diagnoses among all black MSM was observed, with an increase of 93.1% observed among black MSM aged 13–24 years.[1] In a 7-city study of young MSM age 15–22, HIV prevalence was greatest among young MSM of color: 14% among non-Hispanic blacks, 12% among mixed race, 7% among Hispanic/Latinos compared to only 3% among whites.[2]

In addition to elevated rates of HIV acquisition and transmission and engagement in high-risk sexual behaviors, youth aged 15–24 have the lowest utilization of medical office visits of any age group and this rate has actually decreased over the period from 1995 to 2005.[3] Among those aged 20–29, men have lower rates of utilization of ambulatory and preventive care compared to women. Moreover, for both males and females, black and Hispanic individuals have lower utilization rates than whites.[4] We are thus missing crucial opportunities to counsel youth on prevention strategies and to provide HIV testing and linkage to care for those at risk for or infected with HIV.

Youth diagnosed with HIV face a wide variety of problems, many of which existed prior to and are exacerbated by HIV infection, including financial and housing instability, substance abuse, mental health concerns, stigma and isolation, as well as the impact of the disease itself on their overall health and wellness.[5–11] Engagement and retention in care has been linked to improved health outcomes, better medication adherence and increased overall survival.[12,13] One study of HIV-infected and at-risk youth found the probability of being retained in primary care beyond an initial visit for males was 64% and only 24% beyond 1 year.[5] There are limited data on interventions and clinical outcomes focused on engaging

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and retaining youth, specifically HIV-infected YMSM of color in care.[12,14–16]

To address the medical care needs of this underserved population, in 2005, the Health Research and Services Administration (HRSA) created the YMSM of Color Initiative. The goal of the initiative was to design and test novel interventions to engage and retain young (ages 17–24) HIV-positive MSM of color in HIV care. Although the southeastern United States is experiencing disproportionate HIV infection rates, has higher numbers of AIDS cases, has higher proportions of blacks, and is experiencing the most rapid growth rate of Latinos in the country,[17,18] there have been limited HIV interventions in this part of the country.[19] A previously unrecognized outbreak of HIV infection among black YMSM college students in North Carolina was discovered,[20] and through December 2006, 191 HIV-infected college students of whom 84% were black and 92% MSM or men who have sex with men and women were identified.[20,21] To address these findings, the University of North Carolina School of Medicine, Division of Infectious Diseases (UNC-ID) developed STYLE (Strength Through Youth Livin' Empowered). Utilizing a social marketing campaign targeting youth and members of their sexual and social networks targeted outreach to venues where YMSM congregate, and tailored HIV support services, we sought to diagnose, engage, and retain HIV-positive black and Latino YMSM in HIV primary care services. The primary goal of the study was to improve retention in HIV care for YMSM, with the hypothesis that YMSM of color will demonstrate improved retention compared to historical controls if HIV services are specifically targeted to this community. Moreover, we hypothesized that newly diagnosed men would have better retention in care compared to those who had previously been in care but had been out for 6 months or more.

Methods

Program description

The main elements of STYLE included: (1) a social marketing campaign developed with the input of a youth advisory board and focus groups; (2) intensified outreach to black and Latino MSM youth-serving venues and increased provision of HIV testing services on college campuses, and within the broader community utilizing both venue-based and social and sexual network testing approaches;[22] and (3) a tightly linked medical–social support network for HIV-infected youth newly diagnosed or reengaging in care that included an infectious disease board-certified physician who oversaw the provision of care to all patients; the majority being seen at one of two clinical sites (one tied to a local academic medical center and the other located within a local health department). Prior to the initiation of STYLE, there were no services specifically provided for young HIV-positive MSM of color in the local area. STYLE was designed to address the previously unmet needs of this population by providing an array of services above and beyond the standard of care. These services included, a peer outreach worker, a case manager and as well as members of the research staff that formed a medical–social support network for the youth, the creation of weekly support group meetings, and availability of members of the research staff by text and/or phone to assist with appointment scheduling or to answer medical questions. HIV-positive YMSM of color identified at STYLE sponsored HIV testing events or through HIV testing conducted through partner agencies and local health departments received an appointment with the physician within 72 h, creating a near-immediate connection to medical care. Partner agencies and health departments had a strong incentive to refer YMSM to our program because it was the only program with services specifically targeting YMSM of color in the region. While both black and Latino HIV-infected YMSM were recruited into the study, printed outreach materials bearing the STYLE logo were targeted specifically for black MSM; a similar campaign was not designed for Latino MSM. However, other HIV/STD related information distributed at STYLE events and at STYLE clinical sites were made available in Spanish. In addition to HIV medical care services, STYLE provided clients with ancillary social support services, including case management and support groups, through a partnership with a local AIDS Service Organization (ASO). STYLE was able to leverage the resources of an academic medical center, an ASO and a local historically black University (HBU) as part of an overall strategy to identify, test, and link HIV-positive YMSM of color into medical care.

Data collection

For the overall HRSA/SPNS project, eight study sites and one evaluation and support center was funded to assist local evaluations and conduct a multisite evaluation and these data are presented elsewhere.[23] Each of the eight sites operated independently, using different strategies to conduct outreach, HIV testing and linkage to care for HIV-positive YMSM of color. The eight sites used a common data collection tool and common eligibility requirements to allow for cross-site comparisons. Data collected from the sites were entered into a secure Web-based data entry portal maintained by the evaluation center. STYLE-specific data collected between the start of our site's client enrollment in June 2006 and the end of the grant cycle in August 2009 were analyzed for this paper. Eligible participants were (1) biologically born male, (2) HIV positive, (3) diagnosed HIV positive within the past 6 months or reengaged in care after being out of care for at least 6 months, (4) a male who had sex with males, (5) self-identified as non-white, (6) between 17 and 24 years at the time of the first interview, and (8) able to provide written informed consent. Eligible participants were administered a standardized face-to-face interview by experienced interviewers at baseline and every 3 months thereafter. For newly diagnosed HIV-positive YMSM, baseline interviews were administered within 30 days of the client's initial visit with a physician. For clients reengaging in care, baseline interviews were administered within 30 days of their reengaging visit. Baseline interviews lasted approximately 1 hour and also included a qualitative interview component that was not conducted during the follow-up interviews, which averaged 30 min in duration. Potential participants were referred to the STYLE study through being identified as HIV positive through STYLE-sponsored outreach HIV testing events, the NC Screening and Tracing Active Transmission Acute HIV testing program (STAT)[24] and through referrals from HIV testing conducted at local health departments and ASOs. Potential participants were also identified and referred to STYLE by the NC Disease Intervention Specialists (DIS). DIS conduct voluntary postdiagnosis interviews with all individuals with reported cases of HIV and syphilis. During the interview, they conduct a risk assessment, provide risk reduction information, and make referrals for medical care and case management. Although the DIS were not a formal part of the STYLE intervention, the strong ties between the university and the NC HIV/STD Prevention and Care Branch of the North Carolina Department of Health helped to make our project highly visible to the DIS, which facilitated the referral process. Over the course of the 3 years of participant recruitment, only two individuals who were approached about participating in the STYLE cohort study refused to participate. These two individuals stated that their discomfort with discussing issues related to HIV as the primary reason for refusing to participate in the study. Interviews were generally administered immediately after scheduled HIV clinic appointments. However, if a participant was unable to stay beyond the time allotted for his clinical appointment, study staff would make a separate appointment to meet with the participant to complete the interview, within a 2-week time period. Interviews were conducted in either English or Spanish based on participant preference. Participants were compensated $50.00 for completion of the baseline interview and $25.00 for each follow-up.

As the majority of eligible YMSM of color at the UNC-ID clinic during the study period consented to enroll in STYLE, and thus there was no comparison group, data were abstracted from a clinical cohort preceding the implementation of STYLE to serve as a control group. Abstracted data were restricted to the 30 black or Latino YMSM (age 17–24) who had their first visit in the UNC-ID HIV clinic between January 1, 2003 and December 31, 2005, as they were most similar to STYLE participants based on available demographic data. Because these patients were not participants in STYLE they did not complete any questionnaires. The data available for these patients are restricted to their demographic information (age, race, gender, and sexual identity), which was used to select them from the other patients receiving HIV care at UNC-ID clinic.

Clinical recommendations about attending regularly scheduled visits were similar during this time period as during the implementation of STYLE.

All participants provided written informed consent to participate in the study. The University of North Carolina Institutional Review Board (IRB), and the George Washington University IRB approved all instruments and protocols.

Study variables

A participant was considered newly diagnosed if they had no prior diagnosis of HIV infection before entering STYLE, and was considered reengaged in care if they entered STYLE after having been out of prior HIV clinical care for at least 6 months. All participants were analyzed in six periods of 4 months each (periods 1–6) from their entry into clinical care for up to a total of 2 years. Participants who entered STYLE later and consequently were not enrolled for at least a 2-year period were analyzed with five or fewer 4-month periods corresponding to the amount of time they were enrolled. A visit was defined as having had a medical care visit attended by participants in which a follow-up survey was completed or for which clinical data was abstracted (e.g., CD4 count, viral load). If both clinical data and follow-up survey data was absent for any given 4-month period that participant was considered to have missed their scheduled visit. Patients were considered retained in regular care if they had at least one visit per 4-month period. Conversely, patients were considered to not to be retained in regular care if they missed one of their scheduled visits. Our retention measure was broad enough to capture a wide range of care utilization patterns and reflects the HIV Department of Health and Human Services (DHHS) guideline recommendations for patients to have CD4 and viral loads drawn every 3–4 months.[25]

The questionnaire used was adapted from standardized tools, including the Young Men's Survey, the Youth Risk Behavior Survey, National HIV Behavioral Surveillance tools, the HIV Cost and Service Utilization Study, and previous SPNS and Adolescent Trials Network instruments. Client related factors measured included age, race/ethnicity, income, educational level, and sexual identity. The Center for Epidemiologic Studies Depression Scale (CES-D) was used to measure depressive feelings at baseline and behaviors and has been used extensively in medical, and nonpatient populations, including those at risk for or infected with HIV.[26,27] Distance to care was estimated as the driving distance from each patient's home address zip code reported at the time of enrollment to his respective clinic site. Clinic addresses and zip codes were geo-coded using ArcGIS Version 9.3 (Environmental Systems Research Institute, Inc., Redlands, CA) with point-locations assigned to the centroid of zip codes. Driving distance was then calculated between points using the StreetMap Find Route Tool. Clinical health outcomes were obtained by a chart review of the participants' CD4 count, viral load, antiretroviral (ART) medication usage, and baseline ART resistance testing evaluations (genotypes). While the follow-up survey included most of the same measures as the baseline survey, it did not include many of the lengthy scales included in the baseline survey, most notably the CES-D scale used to measure depression, which precludes our ability to make longitudinal assessments of depression in our study.

Statistical analysis

Univariate and bivariate analyses were used to describe participant characteristics. We also compared retention in care for participants enrolled in STYLE to a cohort of similar age black and Latino male patients being seen in the same academic HIV clinic over the 3-year period prior to STYLE's creation. Visits across the 4-month periods were modeled longitudinally as a function of whether or not the participant was enrolled in STYLE. To model our binary outcome (if a visit was made or not) over the 4-month periods, we utilized the hierarchical generalized linear model (HGLM). Normal hierarchical linear models take into account the nested structure of data, but are inappropriate to use when the dependent variable is not continuous. Similarly, logistic regression should be used for binary dependent variables, but is inappropriate to use when there is a nested structure in the data (e.g. repeated measures in individuals over time). HGLM, however, can be used in the analysis of multilevel categorical dependent variables.[28] HGLM has been used to model condom use and HIV status disclosure in longitudinal data, and has also been used in a similar manner to our analysis to model program retention.[29,30] Analyses were conducted using SAS software, version 9.2 (SAS Institute Inc., Cary, NC) and HLM software, version 6.08 (Scientific Software International Inc., Lincolnwood, IL).

Results

Demographic characteristics

Eighty-one HIV-infected YMSM of color were enrolled in STYLE. The mean age of the sample was 21 years; 83% identified as black and 11% as Latino. Sixty-two percent described themselves as gay, 22% as bisexual, 1% as heterosexual, and 15% as other. Two thirds of the men reported a history of vaginal sex with a woman over the course of their lifetime. Almost half of the sample was enrolled in school at study entry. Participants lived a mean of 47 miles from the HIV clinic where they are receiving care.

Two thirds of the cohort was newly diagnosed. The mean time from diagnosis to enrollment for those newly diagnosed was 56 days; the mean time from last clinic visit to enrollment for those reengaging in care was 509 days (or approximately 17 months). The majority (75%) of newly diagnosed persons had been diagnosed less than 3 months prior to enrollment. One third of the STYLE cohort was diagnosed during the acute stage of HIV infection, defined as having a negative HIV antibody test in the presence of positive HIV nucleic acid testing.[24,31] Twelve percent of the sample had transmitted drug resistance, defined as having a baseline genotype that demonstrated the presence of at least one mutation in the 2009 World Health Organization revised listing of surveillance drug resistance mutations.[32] As shown in Table 1, there were no differences in ethnicity or education when comparing newly diagnosed to those reengaged in care. However, compared to those participants who were reengaged in care, newly diagnosed persons were on average younger, had less depressive symptomatology and reported lower levels of financial distress. Health status data indicate that compared to those newly diagnosed, those reengaging in care had similar CD4 counts but slightly lower viral loads at baseline.

Outcomes after enrollment

Overall, 63% of the STYLE cohort was retained in clinical care (67% in the newly diagnosed group and 55% in the reengaging group made all of their scheduled visits). Figure 1 shows the percent attending visits in each four-month period. Among the newly diagnosed group, 84% of all scheduled visits were made, compared to 73% of scheduled visits made in the reengaged group (t statistic = 1.96; $p = 0.05$). Importantly, among those who missed at least one 4-month visit, and were therefore considered not retained in regular clinical care, among the newly diagnosed, participants still made 73% of their visits, and the reengaged still made 67% of their visits. The two most common reasons cited for missing appointments included forgetting and having issues with transportation.

Sixty-two percent of subjects ($n = 50$) initiated ART during the course of their enrollment in STYLE. Most participants, 68% ($n = 34$) were started on a non-nucleoside reverse transcriptase inhibitor (NNRTI)-based regimen consisting of the only currently available single tablet regimen, 30% ($n = 15$) were placed on a boosted protease inhibitor (PI) regimen and one subject was started on an integrase inhibitor-based regimen. Thirty-four of the 50 subjects on ART were enrolled prior to August 31, 2008 and thus had the ability of having at least 1 year of follow-up data. Seventy-nine percent ($n = 29$), 75% ($n = 24$), and 76% ($n = 21$) of subjects were suppressed (viral loads <200 copies), at 3, 6, and 12 months, respectively. The mean change in CD4 count for all persons over the course of

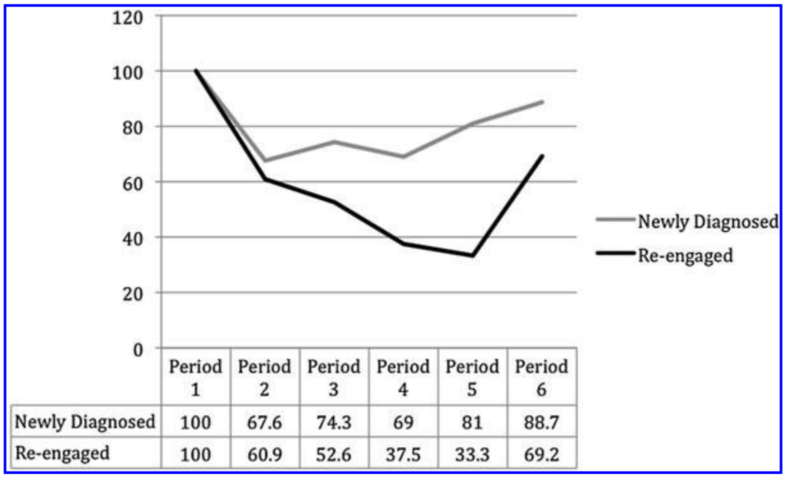
Table 1. Characteristics of Newly Diagnosed and Recently Reengaged Persons in STYLE Cohort

	Newly diagnosed n = 52	*Reengaged in care* n = 29	*Test statistic*[a]	p *Value*
Age	20.7	21.9	−2.81	0.006
Race			0.63	0.73
Black, %	80.8	86.2		
Latino, %	11.5	10.3		
Multiracial/other, %	7.7	3.5		
Sexual Identity				
Homosexual/gay	63.4	58.6	0.18	0.67
Bisexual	26.9	13.8	1.86	0.17
Heterosexual	1.9	0	0.56	0.45
Other[b]	7.7	27.6		0.02
Comfort with sexual identity			1.26	0.53
Very comfortable	58.8	46.4		
Comfortable	37.3	46.4		
Uncomfortable	3.9	7.2		
Education (%)			4.71	0.09
<High school	19.2	24.1		
High school or GED	26.9	6.9		
>High school	53.9	69.0		
Distance to clinic, miles (mean)	51.3	38.7	0.95	0.35
Had health insurance, %	59.6	44.8	1.64	0.20
Baseline CD4 count (mean)	520.1	568.1	−0.66	0.51
Baseline CD4, %			3.24	0.36
<200	11.8	10.7		
200–350	15.7	21.4		
351–500	27.4	10.7		
>500	45.1	57.1		
Baseline viral load ($\log_{10}$)	4.4	3.7	2.43	0.02
Substance use in last 30 days				
Alcohol	55.8	55.6	<0.01	0.99
Marijuana	46.2	35.7	0.81	0.37
Any other recreational drug use	19.2	14.3	0.31	0.58
CES-D (mean)	15.4	20.4	−2.01	0.05
Suicide, %				
Ever made a plan	13.5	31.0	3.63	0.06
Ever attempted	7.7	27.6	5.84	0.02
Ran out of money (last 3 months), %	71.2	82.8	11.74	0.02
Study enrollment, days (mean)	357.5	389.4	−0.39	0.70

[a] For continuous variables a t-statistic was used, for categorical variables a χ^2 was used.

[b] Other includes: DL, confused/deciding (2), me (4), a man with a diverse sexual preference, I do what I do, I don't label/identify myself (2), open-minded.

CES = D, Center for Epidemiologic Studies Depression Scale.



	Period 1	Period 2	Period 3	Period 4	Period 5	Period 6
Newly Diagnosed	100	67.6	74.3	69	81	88.7
Re-engaged	100	60.9	52.6	37.5	33.3	69.2

FIG. 1. Retention over 2 years of newly diagnosed or recently reengaged young men who have sex with men (MSM) of color in STYLE cohort.

the study was an increase in 100 cells/mm^3 ($n=79$). Notably, the percentage of persons with CD4 counts 350 or more increased from 71% at baseline to 85% at study end. While not statistically significant there was a trend towards improved clinical outcomes in the newly diagnosed subjects compared to those recently reengaged in care (Table 2). The mean study enrollment time in days for those on ART was 385.6, and was not significantly different from 352.2 for those not on ART.

Comparison to prior clinic data

Thirty black or Latino MSM (age 17–24) had their first visit in the HIV clinic between January 1, 2003 and December 31, 2005. The pre-STYLE cohort attended 67% of their visits, compared to 80% of attended visits by those enrolled in STYLE (t statistic $= 2.16$; $p = 0.03$). The results from the longitudinal analysis of whether or not someone attended a clinic visit shows that the odds ratio for STYLE is 2.58 (95% CI 1.34–4.98) compared to the years pre-STYLE cohort. For both the pre-STYLE and STYLE cohorts there was a decreased likelihood of attending visits as time passed, for both groups, the odds of attending the next 4-month visit decreased 31% (95% CI 0.61, 0.79). The effect of STYLE did not change across time.

Conclusions

Prior studies have identified predictors of missed clinic visits and poor retention in care to include being young, non-white, and having a history of substance abuse or mental illness.[33–35] Using a conservative measure of retention, two-thirds of our cohort was retained in care; an impressive achievement considering our population was young (mean age of 21), 83% African American, and nearly half reported drug use and/or depressive symptoms. Furthermore, when compared to the 3-year period prior to STYLE, there was a 75% increase the number of new diagnoses among black and Latino MSM aged 17–24 in the 12-county region of the state surrounding where the STYLE intervention occurred (Communicable Disease Branch, NC Division of Public Health, personal communication). While we cannot conclude that STYLE was responsible for the increased number of infections detected in YMSM of color during that time period, the increased awareness around HIV, provision of outreach and testing events on college campuses and throughout the larger community as well as the development of community partnerships to foster immediate linkage to care cannot be discounted as insignificant.

Table 2. Clinical Outcomes of Newly Diagnosed and Recently Reengaged Persons in STYLE Cohort

Variable	*Newly diagnosed* N = *52*	*Reengaged* N = *29*	*Total* N = *81*	*Test-statistic*	p *Value*
Started ART	32 (61.5%)	18 (62.1%)	50 (61.7%)	0.002	0.96
Suppressed[a] at:					
3 months[b]	82.4% ($n=17$)	75% ($n=12$)	79.3% ($n=29$)	<0.01	>0.99
6 months[b]	78.6% ($n=14$)	70% ($n=10$)	75% ($n=24$)	<0.01	>0.99
12 months[b]	91.7% ($n=12$)	55.6% ($n=9$)	76.2% ($n=21$)	1.67	0.19
Change in CD4 count[c]	$N=51$	$N=28$	$N=79$	0.41	0.68
Mean [SD]	109.5 [244.9]	88.1 [174.4]	101.9 [221.5]	0.41	0.68
Median	59	15.5	41	0.41	0.68

[a] Viral load <200.

[b] Only includes those clients who had at least one year of follow-up.

[c] Includes all clients who at least one CD4 count measured. For those with only one value, a change of 0 was used.

ART, antire troviral; SD, standard deviation.

A thorough review of the current HIV literature could not find a standard and consistent measure of what constitutes retention in care, thus it is hard to make comparisons across studies. Sherer et al.[36] found that 55% of adult HIV-infected patients had at least one primary care visit in each 6-month period over a 2-year span. Other studies using this same definition found rates of 60–81% over a 1-year period when intensive case management and outreach strategies were utilized.[15,37] We chose a conservative measure of visits every 4 months as our primary outcome, however, if a similar measure as described above is used, our retention rate increases from 63% to 85% (data not shown). Moreover, even people who did not meet our strict definition of regular care still attended the majority of their scheduled clinic appointments and maintained consistent contact with program staff through email, SMS texting or attendance at weekly support group meetings. Text messaging and other innovative technologies have been used successfully to increase clinic attendance,[38,39] improve medication adherence,[40] assist adults and adolescents with chronic disease management,[41,42] and promote healthy behaviors such as diet, exercise and smoking cessation.[43–45] Future research should evaluate the use of mobile phone and Internet-based interventions such as adherence counseling, and the ability to schedule walk-in appointments online as a way to maintain greater communication and connection between youth and their HIV care providers.

Consistent with other studies[8,11] we found high overall levels of depression in these young men; with 50% having CES-D scores falling within ranges considered to be indicative for clinical depression and 15% having a history of attempting suicide. This is similar to rates seen in other large population-based studies in which 12–19% of their sample of MSM (including a rate of 8% in MSM younger than 25 years) had attempted suicide compared with rates of 1.5–4% among men in the general population.[46–48] Higher rates of depression were observed in those reengaging in care clearly indicating the need to incorporate mental health evaluations and treatment early into the provision of HIV primary care. This difference in mental health status between the newly diagnosed and reengaging participants may partially explain the higher retention rate among the newly diagnosed. However, because CES-D scores were only assessed at baseline, we cannot establish causality, though we hypothesize that early engagement in care through STYLE for the newly diagnosed persons may have served as a buffer to lessen symptoms of depression perhaps through increasing their network of social support.[11,49–51] Future research using qualitative methods should explore the relationship between early engagement and retention in care, depression, and other ongoing risk behaviors in HIV-infected youth.

Long distances to care and lack of provision of transportation services are associated with less access to and retention in care.[52,53] Patients in this study traveled a substantial distance for their HIV medical care, which is not uncommon for those living in rural settings accessing services associated with stigmatizing diseases like HIV, substance abuse, or mental health. This problem was likely accentuated by the low availability of public transportation systems and record high gas prices seen in our state during the course of the study. Additionally, newly diagnosed persons reported lower levels of financial distress compared to those who were reengaging. Previous studies have shown the importance of reducing financial barriers for successful retention in care.[15] Future studies should assess whether provision of reimbursement for travel through taxi vouchers or gas cards could result in overall cost savings through improved long term health outcomes and decreased utilization of emergency rooms and a reduction in hospitalizations.[54]

National data highlight the need to link MSM of color and other HIV-infected populations to care to improve their overall health and to stem further infections.[55–58] The DHHS HIV guidelines now recommend earlier initiation of ART to prevent long-term complications and preserve immune function.[25,59–61] In our study, youth achieved viral suppression rates greater than 75%, which compares favorably to levels of virologic success ranging from 51% to 79% for currently utilized NNRTI, or boosted PI regimens in adult cohorts.[62] While we tried to ensure that prior to initiating therapy, youth enrolled in our cohort were deeply committed to the process of attending regular clinic visits and comfortable with both the notion and the process of taking medications on a daily basis, there is still significant room for improvement. Having the youth as active and willing participants in making decisions regarding their health care—an act that requires a multidisciplinary team model of HIV care that addresses in a comprehensive and culturally sensitive manner all of the developmental, physical and mental health issues—is relevant to this population.

The study has the following limitations. The generalizability of our findings to other populations and regions of the United States may be limited as our sample size was relatively small and participants were located in one geographic area. However, our population is reflective of the current epidemic of HIV infection within this country, where a significant burden of disease falls upon minorities, youth, and those residing in the southern United States.[63,64] Furthermore, as one of the main goals of the overall SPNS initiative was to increase diagnoses within our target population, the youth in our study were followed for different periods of time based on when they were diagnosed. Although the measure of retention we utilized accounted for time enrolled in STYLE, since participants enrolled at different times throughout the study period it does not control for possible effects specific to any given month or year. Furthermore, we did not measure exposure to or uptake of our outreach materials or participation in events and are thus unable to assess whether this component of STYLE had an effect on retention in care. Additionally, there is no ideal control group to which STYLE can be compared. We utilized data from similar aged Black and Latino MSM in the same clinic in the period directly preceding STYLE, but there is always a possibility that a temporal effect, and not STYLE, was responsible for differences in retention. Furthermore, the limited information we were able to collect on this comparison group did not allow us to statistically control for other variables that might also be related to retention. Finally, we relied on self-report and the survey was administered face-to-face, thus bias may have been introduced.

While there has been a significant focus on increasing testing for HIV, the importance of timely linkage to and engagement in care, and knowing one's CD4 count, viral load, and other clinical parameters once diagnosed have not received such high priority national attention. Media campaigns that promote the value of not just knowing one's HIV status but the importance of being in regular care if infected are needed. Clinic support staff should make it a priority to spend extra time with new patients helping them understand the significance of learning and interpreting all of their laboratory results and being engaged with providers in an interactive conversation about their health.

We conclude that STYLE was able to provide efficient and timely engagement in care for both those newly diagnosed and those who had fallen out of care and improved overall retention compared to a pre-STYLE cohort. We believe that the results of our study demonstrate that successful interventions should promote HIV counseling, testing, and referral services at venues that youth frequent or use outreach to make testing easily accessible and linkage to care seamless. Future research should investigate both the barriers that preclude full engagement in care as well as the resiliency factors present among HIV-infected youth that promote consistent care over an extended follow-up interval.

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Early Linkage and Retention in Care: Findings from the Outreach, Linkage, and Retention in Care Initiative Among Young Men of Color Who Have Sex with Men

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Abstract

Early linkage and retention in HIV clinical care is essential for optimal disease management, promotion of health, and receipt of secondary prevention messages to decrease onward transmission of HIV. Youth, specifically racial/ethnic minority young men who have sex with men (YMSM), continue to acquire new HIV infections and have been shown to be less likely to engage in regular HIV care and adhere to scheduled medical visits. The goal of the current study was to evaluate the characteristics of participants and program delivery that were associated with early linkage and retention in HIV care among HIV-infected YMSM of color enrolled in an outreach, linkage, and retention study. Of the 334 patients included in the linkage analysis, 72% were linked to care within 30 days of diagnosis, 81% within 60 days, and 87% within 90 days. While no patient-level characteristics were associated with early linkage, having the person who provided the positive HIV test result refer the patient to HIV care ($p = 0.048$), specifically calling to make the appointment ($p = 0.009$), was associated with earlier linkage. Retention of Latino participants (96.2%) was significantly higher than for the African-American (79.9%) youth ($p = 0.006$). Overall, 221 participants had at least 1 year of possible follow-up and 82.8% of these participants were retained at 1 year. While unique challenges exist in the care of adolescents infected with HIV from identification to engagement and retention in clinical care, programs that are responsive and dedicated to the needs of these youth can be successful in retaining them in care.

Introduction

There exist unique challenges in the care of adolescents infected with HIV, from identification to engagement and retention in clinical care.[1,2] Early linkage and maintenance in care can maximize the potential for antiretroviral therapy (ART) regimens to restore immunity and promote overall health and wellness.[3–5] Moreover, early identification and treatment can reduce secondary HIV infections and transmission of drug-resistant strains through education regarding safe sexual practices and other harm reduction techniques.[6–8]

Prior studies have indicated that youth and minorities are less likely to engage in regular HIV care, with young racial/ethnic minority men who have sex with men (YMSM) being particularly difficult to engage.[9,10] Prior research has found that being young, a racial/ethnic minority, or having public or no health insurance was associated with attending fewer HIV clinic visits per year.[11] Outcomes can be improved by providing linkage and retention services that are youth-specific, culturally sensitive, and comprehensively address the multitude of mental health, substance use, and social issues.[12,13]

In 2003, the HIV/AIDS Bureau (HAB) of the Health Resources and Services Administration funded a Special Projects of National Significance (SPNS) Initiative to identify innovative strategies for outreach, linkage, entry, and retention in care for HIV-positive YMSM of color. Early results were published in 2009 and found that over the first 28 months,

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only 11.4% of study visits were missed without explanation or patient contact. Characteristics associated with retention in the study included being less than 21 years old, having a history of depression, receipt of SPNS YMSM program services, and feeling respected at clinic. Characteristics associated with worse retention included having a CD4 count less than 200 cells/mm^3 at baseline, and being Latino.[14] That report focused on retention in the study as a proxy for retention in care. The purpose of this analysis, which includes data on clinical visits, is to update and expand the findings presented in that earlier report, and to examine the characteristics of participants and program delivery that were associated with early linkage and retention in HIV care.

Methods

Participants

Participants were enrolled at eight SPNS-funded demonstration sites (Bronx, NY; Chapel Hill, NC; Chicago, IL; Detroit, MI; Houston, TX; Los Angeles, CA; Oakland, CA; and Rochester, NY), each with its own outreach, linkage, and retention strategies. Interventions at the sites varied based on local program design. Each of the eight sites operated independently but used a common data collection tool and common eligibility requirements (except as noted below) to allow for cross-site comparisons. Data collected from the sites were entered into a secure web-based data entry portal maintained by the evaluation center. Data were collected between June 1, 2006 and August 31, 2009.

Eligible participants were (a) born male; (b) HIV-infected and not currently in care; (c) self-reported sex with males; (d) self-identified as Hispanic ethnicity or nonwhite race; (e) between 13 and 24 years old at the time of the first interview; and (f) able to provide written informed consent. Eligible participants were administered a standardized face-to-face interview by experienced interviewers at baseline and every 3 months thereafter. All participants provided written informed consent to participate in the study. Local Institutional Review Boards (IRBs) and The George Washington University IRB approved all instruments and protocols. Uni- and bivariate analyses were used to describe participants and potential confounders.

Statistical analysis

For new-to-care participants, three sites (Bronx, NY; Chapel Hill, NC; and Rochester, NY) enrolled youth who were diagnosed with HIV within the past 6 months; one site (Chicago, IL) enrolled youth diagnosed within the past 3 months; and three sites enrolled all youth who had never been in care (Detroit, MI; Houston, TX; Los Angeles, CA). One site (Oakland, CA) only enrolled youth who had been newly diagnosed within 30 days and, because this criterion would bias that site's linkage to care rate, they were excluded from this linkage analysis. Six sites (Bronx, NY; Chapel Hill, NC; Detroit, MI; Los Angeles, CA; Oakland, CA; and Rochester, NY) also enrolled youth who were not new to care but had received either intermittent or no care for at least 6 months.

Clinical data were abstracted from medical records and assigned to the appropriate time window (baseline, 6-month follow-up, 12-month follow-up) based on the participant's date of entry into the study. Baseline values were required to be within 2 months of study entry; 6-month follow-up values were required to be between 4 and 8 months after study entry; and 12-month values were required to be between 10 and 14 months after study entry. If there were two clinical values within a window, the average of the two was used for analysis.

Pearson's Chi-square test was used to compare those participants new-to-care to those with previous care experiences; those with early linkage to those with delayed linkage; and those retained 1 year or more to those retained less than 1 year. Generalized estimating equations (GEE) with exchangeable correlation matrices were used to examine changes over time on key variables to adjust for the repeated measures on the same individuals. SAS v.9.1 (SAS Institute, Cary, NC) was used for all statistical analyses.

Variable definition

Early linkage. We defined linkage in care based on self-report of the time interval between when a participant first tested positive and when they first saw a medical provider. We classified those participants with a reported HIV medical visit within 30 days of their self-reported date of HIV diagnosis as having early linkage. For the 10 persons who did not report how much time elapsed between diagnosis and entry into care, the time between their self-reported diagnosis date and the date of their first HIV visit according to medical record review was used to estimate their time to link to care.

Retention in care. We defined retention as having at least three HIV care visits within the first year after enrollment with at least one visit in the first 6 months and one visit in the second 6 months. Participants who entered the study after August 31, 2008 were excluded from the retention analysis since they had less than 1 year of follow-up before the end of the study.

Social support. A ten-item scale was used to measure social support, with higher values indicating more social support. Nine items such as, "How often do you feel that you don't have people to hang out with?' and "How often do you feel you have no one to turn to?" were scored from 1 to 4 with 1 = "never," 2 = "sometimes," 3 = "most of the time," and 4 = "always." One item, "How often do you see/hear from close friends?" was scored from 1 to 5 with 1 = "less than once a month," 2 = "monthly," 3 = "a few times a month," 4 = "a few times a week," or 5 = "daily." Items worded negatively were reverse coded so that a higher value would indicate more social support. The average of the questions was computed to get a mean score for social support. If more than 25% of the items were skipped, the participant was assigned a missing value for the social support scale. The Cronbach α for the scale was 0.79.

Critical need variable. If a participant answered "yes" to any items assessing unstable housing; used alcohol on ≥ 7 days in past 2 weeks; reported emotional or psychological problems from using alcohol/drugs in past 3 months; or scored ≥ 16 on the Center for Epidemiologic Studies Depression Scale (CES-D),[14a] they were characterized as having an immediate critical psychosocial need.

Results

Prior care experiences

Characteristics of the entire sample ($n=363$) are presented in Table 1. Two-thirds ($n=244$) of the sample was never previously in care, while one-third ($n=119$) reported prior care experiences but had been either out of care for at least 6 months ($n=90$) or had less than two HIV primary care visits in the previous 6 months ($n=29$). Participants who were new to care were more likely to be younger ($p<0.0001$), African-American ($p<0.0001$) and less likely to be on ART ($p=0.0002$) compared to those with previous care experiences.

Linkage

Of the 334 patients included in the linkage analysis, 72% ($n=239$) were linked to care within 30 days of diagnosis, 81% ($n=270$) within 60 days of diagnosis, and 87% ($n=291$) within 90 days. No client-level characteristics were associated with early linkage. However, if the person who provided the positive test result referred the participant to care ($p=0.048$), specifically if he or she called to make the appointment ($p=0.009$), linkage to care was earlier (Table 2).

Retention

Overall, 221 participants had at least 1 year of possible follow-up (enrolling on or before August 31, 2008). A large percentage (82.8%) of these participants was retained at one year (Table 3). There was no difference in retention at 1 year between those participants who were new to care or those being re-engaged (84.3% versus 80.0%, respectively). Retention of Latino participants (96.2%) was significantly higher than for the African-American (79.9%) youth ($p=0.006$). While retention varied by site, these findings should be viewed with caution due to low numbers of participants at some sites. Specific interventions used by the sites associated with improved retention were having the availability of youth-focused support groups and programs ($p=0.002$) and having a medical provider with experience treating HIV-infected youth ($p=0.001$). As expected, persons with better retention in care were less likely to have a last known CD4 count below 200. Table 4 demonstrates the changes over time from baseline to 6 and 12 months on barriers to care and health outcomes. The youth reported increases in insurance ($p<0.0001$) and decreased episodes of running out of money or having to borrow money in the prior 3 months ($p=0.002$) at both 6- and 12-month follow-up compared to baseline. We saw positive changes over time in use of ART ($p<0.0001$) and a decrease in hospital and emergency room visits ($p<0.0001$) at both follow-up points.

Discussion

The purpose of this initiative was to find, link, and retain young racial/ethnic minority MSM in HIV care. Overall, we were successful in linking a large number of these youth to care in a timely fashion and retaining them at 1 year of

Table 1. Characteristics of Racial/Ethnic Minority YMSM Stratified by HIV Care Experiences ($N=363$)

	Never in care N=244	*Previous care experiences* N=119	p *Value* *Chi-square test*
Age, mean (SD)	20.0 (1.91)	21.1 (1.79)	<0.0001[a]
Ethnicity			
African-American	176 (72.1)	66 (55.5)	<0.0001
Hispanic	35 (14.4)	43 (36.1)	
Multiracial/other	33 (13.5)	10 (8.4)	
Education			
Some HS or less	68 (27.9)	37 (31.1)	0.019
HS or GED	79 (32.4)	22 (18.5)	
Some college or more	97 (39.7)	60 (50.4)	
Ran out of money for basic needs, last 3 months			0.716
Many times	73 (30.7)	37 (34.9)	
Once/twice/few	112 (47.0)	48 (45.3)	
Never	53 (22.3)	21 (19.8)	
Had to borrow money to get by, last 3 months			0.956
Many times	52 (21.7)	22 (21.0)	
Once/twice/few	129 (54.0)	56 (53.3)	
Never	58 (24.3)	27 (25.7)	
Time since diagnosis (days), median (IQR)	59.5 (29–104.5)	536 (302–885)	<0.0001
CD4 count category (%)[b]			
<200 cells/mm^3	28 (13.7)	9 (9.1)	0.125
201–349 cells/mm^3	43 (21.1)	29 (29.3)	
350–499 cells/mm^3	45 (22.1)	28 (28.3)	
≥500 cells/mm^3	88 (43.1)	33 (33.3)	
Undetectable HIV viral load, <200 copies/ml (%)[c]	5 (2.7)	16 (21.1)	0.001
On antiretroviral therapy (ART)[d]	38 (17.0)	39 (35.5)	0.0002

[a] *t*-test was performed.
[b] No CD4 cell count data on 60 participants (40 never in care and 20 with previous care).
[c] No HIV viral load data on 100 participants (57 never in care and 43 with previous care).
[d] Includes being prescribed ART that day.

Table 2. Clinical Characteristics of Racial/Ethnic Minority YMSM Stratified by Time from HIV Diagnosis to Entry into Care ($N = 334$)

	“Early” Linkage, ≤30 days (N=*239*) N *(%)*	*“Delayed” Linkage, >30 days* (N=*95*) N *(%)*	p *Value* *Chi-square test*
Site			0.029
Bronx, NY	47 (81.0)	11 (19.0)	
Houston, TX	30 (60.0)	20 (40.)	
Los Angeles, CA	46 (70.8)	19 (29.2)	
Rochester, NY	5 (62.5)	3 (37.5)	
Chapel Hill, NC	64 (79.0)	17 (21.0)	
Detroit, MI	29 (58.0)	21 (42.0)	
Chicago, IL	18 (81.8)	4 (18.2)	
Age			0.541
≤18	41 (68.3)	19 (31.7)	
19–24	198 (72.3)	76 (27.7)	
Race/ethnicity			0.135
African American	160 (70.2)	68 (29.8)	
Latino/Hispanic	54 (79.4)	14 (20.6)	
Currently in school			0.082
Yes	91 (77.8)	26 (22.2)	
No	143 (68.8)	65 (31.2)	
Currently employed			0.795
Yes	107 (70.9)	44 (29.1)	
No	127 (72.2)	49 (27.8)	
Health insurance status			0.496
Yes	149 (70.3)	63 (29.7)	
No (do not have it)	90 (73.8)	32 (26.2)	
Prior HIV care experiences			
Yes	179 (73.7)	64 (26.3)	0.163
No	60 (65.9)	31 (34.1)	
Depressive symptoms			0.663
≥16	117 (70.5)	49 (29.5)	
<16	104 (72.7)	39 (27.3)	
Moved ≥1 time in last 3 months	94 (72.9)	35 (27.1)	0.661
Prior HIV testing			0.589
1–2 times	98 (68.5)	45 (31.5)	
3–5 times	88 (73.3)	32 (26.7)	
>5 times	49 (74.2)	17 (25.8)	
Person who provided positive results referred to care			0.048
Yes	200 (74.9)	67 (25.1)	
No	26 (60.5)	17 (39.5)	
Person who referred to care…[a,b]			
Called and made appointment			
Yes	120 (81.1)	28 (18.9)	0.009
No	80 (67.2)	39 (32.8)	
Helped with transportation			
Yes	45 (80.4)	11 (19.6)	0.290
No	155 (73.5)	56 (26.5)	
Took to appointment			
Yes	46 (82.1)	10 (17.9)	0.160
No	154 (73.0)	57 (27.0)	
Told where to go			
Yes	106 (76.3)	33 (23.7)	0.595
No	94 (73.4)	34 (26.6)	
Reason tested[b]			
Sick	71 (74.0)	25 (26.0)	0.537
Risk event[c]	65 (66.3)	33 (33.7)	0.172
Part of physical/routine exam	46 (65.7)	24 (34.3)	0.223
Testing or outreach event	6 (66.7)	3 (33.3)	0.742
Other/not reported	63 (73.3)	23 (26.7)	0.685

[a] Only includes participants who answered yes to the question “Did the person who gave you the positive test result refer you for medical care?”

[b] Could choose more than one response.

[c] Risk event includes: condom broke or did not use a condom during sex, thought might be HIV-positive, informed to get tested by disease intervention specialists (DIS) or partners.

Table 3. Clinical Characteristics of Racial/Ethnic Minority YMSM Stratified by Retention in Care for One Year ($N=221$)

	Retained ≥*1 year* (N=*183*) N *(%)*	*Retained* <*1 year* (N=*38*) N *(%)*	p *Value Chi-square test*
Site			<0.0001[a]
Oakland, CA	6 (42.9)	8 (57.1)	
Bronx, NY	41 (97.6)	1 (2.4)	
Houston, TX	21 (72.4)	8 (27.6)	
Los Angeles, CA	45 (97.8)	1 (2.2)	
Rochester, NY	3 (100)	0	
Chapel Hill, NC	37 (75.5)	12 (24.5)	
Detroit, MI	24 (82.8)	5 (17.2)	
Chicago, IL	6 (66.7)	3 (33.3)	
Age			0.326
≤18	31 (77.5)	9 (22.5)	
19–24	152 (84.0)	29 (16.0)	
Race/ethnicity			0.006
African American	115 (79.9)	29 (20.1)	
Latino/Hispanic	50 (96.2)	2 (3.9)	
Currently in school			0.798
Yes	68 (83.9)	13 (16.1)	
No	114 (82.6)	24 (17.4)	
Currently employed			0.206
Yes	86 (79.6)	22 (20.4)	
No	93 (86.1)	15 (13.9)	
Health insurance			0.814
Yes	124 (83.2)	25 (16.8)	
No (don't have it)	59 (81.9)	13 (18.1)	
Prior HIV care experiences			
Yes	60 (80.0)	15 (20.0)	0.428
No	123 (84.3)	23 (15.7)	
Depressive symptoms			
≥16	89 (82.4)	19 (17.6)	0.858
<16	79 (81.4)	18 (18.6)	
Moved ≥1 time in last 3 months			0.306
Yes	67 (79.8)	17 (20.2)	
No	109 (85.2)	19 (14.8)	
Critical need variable[b]			0.720
Yes	111 (82.2)	24 (17.8)	
No	62 (82.7)	13 (17.3)	
Retention intervention (site specific)			
Case management[c]	143 (84.6)	26 (15.4)	0.199
Support groups[d]	45 (97.8)	1 (2.2)	0.002
Medical providers with expertise in HIV+ youth[e]	135 (78.5)	37 (21.5)	0.001
Flexible appointments[f]	52 (78.8)	14 (21.1)	0.343
Early Entry into Care (<30 days)[g]			0.405
Yes	125 (86.2)	20 (13.8)	
No	39 (81.3)	9 (18.8)	
Social support variable, Mean (SD)	3.20 (.56)	3.17 (.55)	0.755
Friends[h]			
None	21 (11.9)	4 (11.1)	0.727
1–3	104 (58.8)	19 (52.8)	
4+	52 (29.4)	13 (36.1)	
Last known CD4 cell count	($n=145$)	($n=11$)	
Mean (SD)	495 (227)	412 (304)	0.258
≥200 cells/mm^3	137 (94.5)	7 (63.6)	0.005
Last known HIV viral load	($n=66$)	($n=14$)	
Mean (SD), log10	3.28 (1.1)	3.58 (1.2)	0.349
<200 copies/ml	15 (22.7)	3 (21.4)	0.916

[a] Exact Pearson Chi-square test.

[b] Unstable housing, depressed, alcohol use on ≥7 days in past 14 days, had emotional or psychological problems from alcohol/drugs in past 3 months, scored ≥16 on CES-D.

[c] Service available at sites: Bronx, NY; Chicago, IL; Detroit, MI; Houston, TX; Los Angeles, CA; and Oakland, CA.

[d] Service available at sites: Bronx, NY; Chapel Hill, NC; Chicago, IL; Detroit, MI; Houston, TX; Oakland, CA; and Rochester, NY.

[e] Service available at sites: Bronx, NY; Chapel Hill, NC; Chicago, IL; Detroit, MI; Houston, TX; and Oakland, CA.

[f] Service available at sites: Bronx, NY; Houston, TX; and Oakland, CA.

[g] Excludes Oakland, CA.

[h] How many friends do you feel comfortable with that you can talk to about private matters, or can call on for help?

Table 4. Descriptive Statistics and Health Outcomes of Racial/Ethnic Minority YMSM at Baseline, 6 Months, and 12-Month Follow-up

	Time			
	Baseline (N=*363*) n *(%)*	*6 months* (N=*232*) n *(%)*	*12 months* (N=*173*) n *(%)*	p *Value* *GEE regression model*
Education (HS degree or more)	258 (71.1)	122 (71.4)	98 (71.5)	0.242
No insurance	134 (36.9)	43 (19.3)	28 (16.9)	<0.0001
Borrow or run out of money, past 3 months	298 (86.1)	133 (77.3)	99 (73.3)	0.002
Disclosure[a], mean (SD)	3.2 (2.1)	3.3 (2.3)	3.6 (2.4)	0.029
CD4 cell count	(*n*=192)	(*n*=131)	(*n*=102)	0.629
<200 cells/mm^3	25 (13.0)	9 (6.9)	8 (7.8)	
201-349 cells/mm^3	45 (23.4)	28 (21.4)	20 (19.6)	
≥350 cells/mm^3	122 (63.6)	94 (71.7)	74 (72.6)	
Undetectable HIV viral load (<200 copies/mL)	(*n*=185) 16 (8.6)	(*n*=122) 38 (31.1)	(*n*=92) 22 (23.9)	0.657
ART use	(*n*=334) 77 (23.1)	(*n*=207) 85 (41.1)	(*n*=153) 66 (43.1)	<0.0001
Hospital or ER use (%)	132 (37.1)	31 (18.0)	22 (16.2)	<0.0001

[a]Number of people to whom disclosed HIV status.

follow-up. To have maximum impact on both the individual and population level, once a client is diagnosed they need to be immediately linked to care. A recent meta-analysis found that only 69% of HIV-diagnosed persons in the United States (US) entered care.[15] Similarly, a prospective study found that 40% of persons recently diagnosed with HIV infection did not visit a clinician at least once within 6 months.[16]

In our study, we report extremely high rates of early linkage with 87% of the cohort being linked to care within 90 days. Most experts recommend linkage to care within 3 months and define failure as when a maximum of 6 months elapse following their HIV diagnosis without a medical visit.[17] Prior studies of the characteristics of new HIV-infected patients who failed to attend their initial scheduled appointment found that in addition to patient characteristics (younger age, black race, and public insurance), longer waiting time from the call to schedule the visit to the actual appointment date was associated with failure to establish care.[18,19] Scheduling an appointment promptly in the immediate time period surrounding testing takes advantage of the teachable moment associated with receiving an HIV diagnosis. During this critical period, youth may be more receptive to secondary prevention messages, behavior change, and engagement with the health care system.[20] In one study, most (77%) of those who ever entered care did so within the first 3 months following diagnosis.[21] We found that having the person who informed the youth of their diagnosis provide the initial referral to care significantly predicted earlier linkage. This may indicate that proactive linkage, perhaps in the form of a simple phone call, could be an especially useful and inexpensive intervention for this population.

We were extremely successful at retaining these young men in care, with a retention rate of 83% at 1 year. To our knowledge, this is one of the highest retention rates reported, using stricter retention criteria than often used in previous research.[10,16] As our cohort was either new-to-care or reengaging after intermittent past adherence to medical visits, we chose our retention measure to reflect the need for more frequent initial visits to establish provider-patient relationships, to provide education around diagnosis, and to start and monitor response to ART. In a recent meta-analysis, retention was 59% in eight studies that used a threshold of three or more HIV medical visits in 12 months, a criteria similar to the one that we used.[15] If we use a more liberal cutoff of one visit in each 6-month period, our retention rate increases to 89%. These results are even more noteworthy as our cohort consisted of racial/ethnic minority youth who in other studies have had lower retention rates then the general HIV-infected population.[1,9,10,22–24]

While each site utilized different retention strategies and had varying overall success at retention, some interventions were universal and likely contributed to our success. All sites used clinic appointment reminders and some form of case finding for patients who had missed appointments (typically in the form of telephone calls, Short Message Service (SMS) texts, e-mails or in rare cases, home visits). Previous studies found that receiving clinic reminders can increase attendance at visits.[25] In addition, all sites assisted patients in some way with transportation, either helping to coordinate transportation, providing financial assistance in the form of gasoline cards or bus passes, or escorting patients to their medical visits. Unfortunately, over a third of the sample was unable to be included in this retention analysis due to enrolling after August 31, 2008. However, of the young men who had between 6 months and 12 months of follow-up (*n*=65), 82% had at least two visits, and 55% had three or more medical visits in that brief time interval.

Most of the sites had a small number of dedicated providers who were actively engaged in the initiative and responsible for providing quality care to youth in an ongoing fashion. Previous research has identified the pivotal role of HIV providers in the success of engagement in care for people living with HIV.[26,27] Patients who feel like their provider is accepting, consistent, and responsive to their varying life circumstances are more likely to remain in care.[25] The importance of establishing and maintaining a positive provider-patient relationship that engenders mutual trust, respect, and lack of judgment may be even more important for gay and bisexual youth who may lack social support and often experience multiple layers of stigma from their families.[2,28] Although we could not definitively assess the relationship between patients and providers, among 183 patients who responded to a multiple choice question as to why they went to their medical appointments, 52% ($n = 96$) responded that they like their providers and 53% ($n = 97$) said they felt respected in the clinic (data not shown).

Previous research has documented the positive relationship between patients' receipt of ancillary services and their retention in primary HIV medical care.[29,30] In one important study, a higher proportion of 136 case-managed participants compared to 137 standard-of-care participants visited an HIV clinician at least twice within 12 months (64 versus 49%, respectively).[16] While patients at the sites that utilized case management services did not show improved retention in our study, our rates of retention for patients at those sites was 85%, considerably higher than rates found in the previous study. Interestingly, the patients at the sites with youth-specific support groups and social events showed higher retention, which is a finding not previously reported in the literature. In focus groups conducted with HIV-infected youth, participants stressed that to be successful, support services should be skills oriented, culturally sensitive, and focused on healthy living.[31]

Prior studies have demonstrated a relationship between a lack of retention in HIV care and worse clinical outcomes including higher viral loads, lower CD4 counts, and decreased survival.[3,32] In a study by Giordano and colleagues, patients out of care for as little as 3 months in their first year of therapy had worse survival.[3] Sherer *et al.* found that being in regular care was associated with lower viral loads in all time periods.[30] We did find a trend toward improved health outcomes as measured by a decrease in hospital and ER use ($p < 0.0001$) and increases in ART use ($p = < 0.0001$) for those retained in care at 6- and 12-month follow-up. This has the potential to decrease overall health care costs as well as to improve the quality of life for these young men.[33–35]

This study has several limitations. As we enrolled only participants who were linking to care at dedicated SPNS demonstration sites, our population may not be generalizable to HIV-infected young racial/ethnic minority MSM who fail to enter care. However, a third of our sample had been either "lost to care" or had poor adherence to medical visits, which indicates that we reached an "at risk" population with our interventions and kept this group in care. Participants in our study received a small monetary incentive to complete study-related surveys at 3-month intervals. However, participants did not need to remain in care to complete these surveys, which could have been conducted outside of the clinical setting or via the telephone. Additionally, while this study involved interventions to link these YMSM in care, the time from diagnosis to linkage to care for those young men who were previously in care reflects experiences that occurred prior to this study. Also of note, there were no significant differences between those new to care and those with prior care experiences in terms of early versus delayed linkage. Finally, we may have underestimated retention, since we do not know if participants moved or chose to get care elsewhere.

To our knowledge, this cohort represents the largest and most geographically diverse sample focusing on racial/ethnic minority YMSM entering care. As the HIV epidemic does not appear to be abating in this population, identifying best practices to link and retain these young men in care is critically important. Our findings would suggest that retention rates can be increased by engaging young racial/ethnic minority men early after their HIV diagnosis, providing a safe and nonjudgmental environment for care (*e.g.*, including offering participation in youth-specific programming), fostering a mutually gratifying relationship between the patient and his medical provider. Moreover, utilizing mobile technology is vital to establish and maintain a "connection to care" with these youth and facilitate ongoing communications (*e.g.*, reminders for medical appointments, rescheduling missed visits). These simple, inexpensive, and yet critically important interventions could be easily adopted by many clinics providing care for these young men with significant improvements in retention rates realized. While previous studies have found that engagement is worse for those groups continuing to be infected and affected by the epidemic, namely youth and minorities, programs that are responsive and dedicated to the needs of these youth can be successful in keeping them in care.

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Experiences in HIV testing and health care in Philadelphia

Young men who have sex with men

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Introduction

In recent years, reversing the incidence of HIV among young men who have sex with men (YMSM) ages 13-24 has become a priority of the Centers for Disease Control and Prevention (CDC) and local jurisdictions (Centers for Disease Control and Prevention, 2014). According to the CDC, the number of new infections among YMSM (aged 13-24) increased 22 percent, from 7,200 infections in 2008 to 8,800 in 2010 (Centers for Disease Control and Prevention, 2012). Stall, et al. (2009) estimate that HIV prevalence for 20 year old YMSM will be 25.4% by the time they reach the age of 30, 41.4% at age 40, and 54% at age 50. For African American YMSM, the model predictions are even more dire: 59.3% BMSM will be HIV-positive by age 40 (Stall, et al., 2009).

Black men who have sex with men (BMSM) bear a disproportionate burden of the HIV/AIDS epidemic in the U.S, particularly young BMSM. BMSM are the only group within the black community with increasing numbers of infections. Black gay men make up 0.2% of the U.S. population and make up approximately 25% of the new HIV infections each year (amfAR, 2015).

As of 2012, Philadelphia had an HIV incidence rate three times the national estimated average. The majority of new infections are among men, non-Hispanic blacks, persons aged 25-44, and MSM. Youth aged 13-24 accounted for one-third of estimated new infections in 2012. This is a 69% increase in the number of estimated new infections among youth between 2006 and 2012, largely due to the new infections in young, black MSM. Based on the estimated size of at-risk populations, MSM in Philadelphia are acquiring HIV at a disturbingly high rate; an estimated 1.2% of MSM in Philadelphia acquired HIV in 2012. This increase is driven by new infections in 13-24 year old African American MSM. As of December 31, 2013 there were 367 living AIDS cases and 876 living HIV cases among youth aged 13 to 24. Compared to Latino YMSM (5.2%) and white YMSM (1.1%), black YMSM have a significantly greater HIV prevalence of 12.5% (Philadelphia Dept. of Public Health/AIDS Activities Coordinating Office HIV Incidence Surveillance Program and Philadelphia eHARS data, 2014).

In addition to high prevalence rates among young people, Philadelphia is experiencing high rates of sexual risk among youth. According to the 2013 Youth Risk Behavior Survey (YRBS), 22% of sexually active students had sexual intercourse with 4 or more people in their lifetime. Forty-two percent of sexually active students did not use a condom at the time of last sexual intercourse. Eighteen percent of students report never having been taught about HIV/AIDS in school. Almost one-quarter of sexually active students reported using drugs or alcohol before the last sexual intercourse (Centers for Disease Control and Prevention, 2013). However, there are some indications that risk trends are improving, as STD cases in adolescents and young adults decreased between 2010 and 2013 (PDPH, 2014).

Public health messages about HIV testing are reaching YMSM in Philadelphia. According to the 2011 National HIV Behavioral Surveillance (NHBS), 91% of the 18-24 year old MSM and 82% of 25-34 year old MSM were tested for HIV in the last 12 months. Testing for sexually transmitted infection (STI) was not as common, only 40% of the 18-24 year olds reported any STI screenings in the previous 12 months. However, 8% of the YMSM reported having had an STI in the past 12 months (Philadelphia

Department of Public Health/AIDS Activities Coordinating Office).

It is not because of risk behaviors alone that YMSM, particularly black YMSM, face high risk of acquiring HIV and other sexually transmitted infections. Rather, the high prevalence of HIV and other STIs within the YMSM, youth, black and MSM populations and structural barriers like low income and lack of health insurance increase the chance that YMSM will engage in risk behaviors and be exposed to HIV at the time of those risk behaviors (Dorell, et al., 2011, Millet, Flores, Peterson, & Bakeman, 2007). HIV incidence in the YMSM and MSM populations, especially in the black and Latino populations is due in a large part to the high prevalence of HIV within these populations. Having condom-less anal sex within the context of high HIV and STI prevalence means a greater risk of coming in contact with and acquiring HIV. In fact, black MSM report less substance use and fewer sex partners than white MSM (Millet, Flores, Peterson, & Bakeman, 2007). And yet an estimated 32% of black gay men are HIV-positive (amfAR, 2015). Black MSM are also more likely to report preventive behaviors than other MSM in the US. However, black MSM have two-fold greater odds of low income, previous incarceration, and other structural barriers that increase their HIV risk than other MSM (Millet, et al., 2012).

Dorell, et al. (2011) found that black YMSM were more likely to be HIV-positive if they lacked access to primary care, were uninsured, did not have counseling about HIV and sexually transmitted infections, and failed to disclose their sexuality to their healthcare provider. Of those factors, not having a primary care provider and not disclosing sexual identity to a health care provider were independent risk factors for HIV infection for black MSM (Dorell, et al., 2011). Engaging YMSM in primary care, educating them about risk reduction strategies, and promoting good sexual health practices are important steps towards reducing HIV incidence.

In order to best serve the needs of YMSM, the HIV prevention system must address their complex social needs and their experiences as young black gay and bisexual men, and the intersection and interactions of those identities and the structural barriers that increase their HIV risk (Millet, et al., 2012, Mustanski, Newcomb, Du Bois, Garcia, & Grov, 2011, Malebranche, Peterson, Fullilove, & Stackhouse, 2004).

Study Purpose

The Philadelphia HIV Prevention Planning Group (HPG) provides community feedback to the Philadelphia Department of Public Health's AIDS Activities Coordinating Office (AACO) HIV prevention policies and program/system planning. The HPG requested that the Office of HIV Planning conduct focus groups with YMSM (and other at-risk populations) in order to better target HIV testing and prevention services in culturally competent and accessible ways. Successful diagnosis and linkage to HIV treatment requires meeting the medical, emotional, and social needs of individuals. The purpose of this study is to assess the individual-level, provider-level and system-level barriers experienced by YMSM in order to better understand how these barriers affect at-risk YMSM's use of healthcare and HIV testing and prevention services. The study findings will inform the Philadelphia Department of Public Health's planning and delivery of HIV prevention, testing, and treatment services.

Methodology

The Office of HIV Planning (OHP) conducted three focus groups in June 2014 with young gay and bisexual men (and other men who have sex with men) at community-based organizations serving LGBTQ youth and young adults. OHP partnered with these organizations (Youth Health Empowerment Project, The Attic, and Mazzoni Center) to recruit participants for the focus groups to help facilitate trust between OHP and the young men. OHP worked with the CBOs to identify the best times to hold the focus groups on-site to maximize participation. Focus groups were held during drop-in sessions and other times in which young men participated in program activities. OHP staff recruited participants on-site at the time of the focus group with the assistance of CBO staff. Inclusion criteria were: residency in Philadelphia, identifying as a man who has sex with men, English proficiency, and age over 18. Minors will not be included in any of the focus groups within this study, because of the concerns with securing parental consent.

OHP staff developed the moderator's guide to focus on participants' experiences with health care in the last 12 months, knowledge of HIV testing sites, and vision of ideal health care experiences. Questions about sexual behaviors, substance use, and other risk behaviors were purposely avoided. The investigators decided to focus on experiences in health care settings and with HIV testing, because the risk behaviors of YMSM are well documented and being explored through other local research. In addition, the purpose of this study is to inform the planning and provision of HIV testing and other prevention interventions for YMSM. Delivering these interventions where they will be most accessible and acceptable to YMSM is essential. The investigators designed the study to explore and identify the barriers and facilitators of health care access, in order to develop recommendations for the publicly funded HIV prevention system in Philadelphia.

OHP staff collaborated with the local investigators developing the National HIV Behavioral Surveillance pilot study of YMSM which was under development at the time of the design and implementation of this study. OHP staff worked with the NHBS investigators to include questions on access to care in those interviews; with the hope that further analysis and comparisons can be made upon the completion of both studies. YMSM under 18 were not included in this study because of concern of duplicating efforts with the NHBS pilot study, which targeted young men who have sex with men under 18.

All participants were asked to complete an 11 question anonymous survey at the conclusion of the discussions. The survey collected basic demographic data and HIV testing experience. Participants were free to refuse the survey.

During the focus groups, only first names or aliases were used. Digital audio recordings were made of the discussions and an outside contractor produced verbatim transcripts. All names and personally-identifiable information were stripped from the transcripts. Transcripts were uploaded to and analyzed in NVIVO 10, qualitative data analysis software by OHP staff.

All study materials and protocols were submitted to and approved by the Philadelphia Health Commissioners Review Committee, the department's institutional review board. All participants were given a $20 CVS gift card, two

SEPTA tokens, and a meal in appreciation of their participation.

Characteristics and demographics of participants

All participants were asked to fill out an 11 question survey at the conclusion of the focus group discussion. All participants completed a survey, but everyone did not answer all the questions. In total, 27 men participated in the three focus groups, ranging in age from 18 to 33 years old. Twenty-three participants were between 18-25 years old. Four participants were over 25, but were considered part of the peer group of younger men. Twenty-two of the men identified as black/African American, four identified as bi- or multiracial and one as white. Three men were Hispanic. Educational attainment varied, with 10 participants finishing high school or acquiring a GED and another 10 completed some college courses. The other seven men had not completed high school (2), acquired a vocational or technical degree (2), or graduated college (3). One participant was staying at a shelter; all the others rented/owned their own apartment or house (16) or were staying with friends or family (8). The majority of participants (15) earned less than $10,000 a year. The rest earned between $10,000 and $39,999.

The participants represented a broad collection of zip codes, 17 zip codes in all. Most of the participants resided in high HIV prevalence zip codes. 19142 (3), 19144 (3), 19102 (2), 19132 (2), and 19147 (2) were the five most frequent zip codes.

The survey included a question about who the men were sexually and romantically attracted to. All respondents to this question reported attraction to males. Some others also reported attraction to females (4), transgender individuals (1) and gender queer individuals (2). Respondents could choose as many responses as appropriate.

Of the 27 participants, 25 reported ever being tested for HIV. Two respondents did not answer the question. The most popular answer for why they were tested for HIV was "Just to find out" (6). Other answers selected were "As a part of a routine medical checkup" (5), "No reason" (4), "I was at risk" (2), and "Partner suggested it" (2). Three respondents gave other answers which included getting tested because of the incentives offered and to acquire life insurance. Some of the participants disclosed their HIV-positive status within the discussions, but participants were not asked their HIV status by moderators or the survey.

Theoretical Framework

The investigators developed this analysis based on the socio-ecological model in order to best highlight and consider the multi-level factors of influence on YMSM health care access. Human behavior has a social context. Young urban minority men who have sex with men must negotiate a variety of barriers and influences/pressures when it comes to health care access and healthy sexual behaviors which include individual, interpersonal, community, institutional/health system, and structural factors. Any efforts to end the HIV epidemic must acknowledge and address the interaction and intersection of all of the levels of social, economic, political, interpersonal, and psychological factors impacting health behaviors of individuals (Kaufman, Cornish, Zimmerman, & Johnson, 2014). This study attempts to highlight some barriers and facilitators of healthcare access that YMSM experience in Philadelphia.

Themes

Participants shared a range of experiences, points of view and opinions during the discussions. Even with all the variation in experience, several key themes emerged. Four of the six themes concern interactions with health care providers or access to services. Health insurance problems and lack of sexual health and HIV education reflect larger systemic barriers related to health literacy and access to appropriate information.

Major themes:

- **Interaction with front office staff**
- **Accessibility of services**
- **Health insurance problems**
- **Lack of sexual health and HIV education**
- **Confidentiality**
- **Impact of Stigma on healthcare access**

Interaction with Front Office Staff

Negative experiences with a front office staff member or a receptionist in a health care setting were common. These included being ignored, shamed, and treated rudely. Three participants mentioned witnessing a receptionist or other staff member speak loudly about a patient's health status or insurance situation, including an incident at a community health center when a staff member chastised a young woman about her sexually transmitted infection in front of other patients. The young men did not think such behavior was respectful or professional. Almost universally, the young men shared that they had a good relationship with their doctor or nurse practitioner, based on mutual respect and trust. The vast majority of negative experiences of shame or rudeness occurred outside the exam room.

Waiting for long periods of time before seeing a doctor was mentioned frequently, for both "walk-in" appointments and scheduled appointments. The participants understood that there are valid reasons why doctors are late or they cannot be seen at their appointment time. Their complaints were with the ways the delays and waits were handled by office staff. Often they would not be told how long their wait would be or why the delay was occurring. Some of the men perceived that people with insurance or "good insurance" got seen before they did, even when they had arrived before the other patients.

The thread that ran through all the conversations about the front of office staff was the need for common courtesy and proactive communication in interactions with patients. The participants perceived discrimination and lack of courtesy in many of their interactions with medical institutions. Most of the other nuisances and inconveniences of accessing healthcare were considered understandable or bearable, but being treated disrespectfully was considered a barrier to care by all three focus groups. Participants also shared some positive experiences and suggestions of how they would like to be treated by office staff. Suggestions included welcoming patients as soon as possible

"A lot of people don't have money for a co-pay in the way they expect for you to pay it upfront. Things like that. People don't have it. That's why people don't go to the doctor."

and informing them on how long they are likely to wait before being seen.

Accessibility of services

Among the concerns about accessibility were the distance traveled to health care providers, appointment times, appointment setting processes, and walk-in hours and procedures. Transportation and distance concerns were the most often mentioned problem with accessibility, with issues related to appointment times or operating hours closely following in frequency. Transportation concerns were most often mentioned in the context of having to travel far to receive services. For instance, a participant shared his experience of having to travel out to the suburbs to visit a specialist and then having to return for multiple visits. His challenge was not only the travel expense, but also the time it took to take public transportation to appointments. Other participants also talked about the burden of the time it takes to use public transportation to get to appointments. Patients may spend the better part of a day going to an appointment between travel time and the wait to see the provider. Primary care access is affected by limited transportation, reflecting the need for clinic locations in places YMSM can access easily.

Other participants were reluctant to receive services in their own communities and preferred to travel from their neighborhoods to Center City where they perceived more anonymity. Reasons mentioned for wanting to travel outside their neighborhoods included fear of a breach of confidentiality and the perception that care in their neighborhood was not high quality, or that it was "ghetto".

"The better your insurance, the better care you going to get"

Participants made the distinction between "ghetto" providers (hospitals, clinics, etc.) and those that they felt had good reputations and offered quality care. The geographic location of the organization did not necessarily dictate if it was "ghetto", but attitude and professionalism of the staff surely did (see examples above). "Ghetto" providers included prominent institutions (including teaching hospitals) and small community-based organizations. The young men did not want to be associated with "ghetto" institutions.

Participants shared experiences of trying to attain services, including HIV testing, and being frustrated by the hours of operation or the process for making an appointment. These frustrations included having to arrive (or call) early in the morning to attain a walk in appointment. The frustration stemmed from the process of having to call or show up first thing in the morning, having to take off from school or work, and not having a promise of an appointment. Other frustrations included not having the current hours of operation listed on the organization's website. A participant shared an experience of being sick and getting up extra early to get to the health center first thing to secure a walk-in appointment, only to find out that the health center was closed mornings on that particular day. The current hours were not posted on the health center's website. When the participants were asked to brainstorm about their ideal health care provider, many included that the organization would have evening hours, even as late as midnight to accommodate people who don't work traditional 9-to-5 schedules.

Health Insurance Challenges

Participants mentioned a variety of challenges in understanding and using their health insurance. Most, if not all of the men were insured, often through guardians or parents. There were many questions about what happens as they age: when do they need to have their own insurance, how to get insurance, what type of coverage do they need, how to afford the premiums and co-pays, etc. Co-pays were the most often mentioned barrier to accessing medications and health care. There was confusion about when co-pays apply and how much they would be.

Confusion about out of pocket costs and coverage may prevent a young man from accessing a needed service or medication. For instance, a participant described his experience of needing specialist care that was not fully covered by his health insurance. He explained that if the doctor's office had informed him of his co-pays and cost-sharing when he called to make the appointment he could have made a more informed decision about his care. Medication co-pays were often cited as barriers to medication adherence, not only for the participants but friends and family members as well. Even "nominal" co-pays of $2 or $3 could be a barrier, especially if someone had to pay for several medications at one time.

"I think one thing is particular to African American men in general....African American men are not encouraged to seek healthcare. I can understand it, because my family –I have traces to the Tuskegee experiments. So going to the doctor was very looked down upon....And on the flip side of it, unfortunately, is a lot of the healthcare providers don't really attend to the needs of the particular experiences that African American men go through."

These focus groups occurred in June 2014, after the implementation of the Patient Protection and Affordable Care Act (2010). Participants stated that "Obamacare" didn't work for them or their family. Participants shared experiences of friends and family members who had problems signing up for insurance on healthcare.gov and the confusion caused by the lack of information on plans and out of pocket costs. Participants also believed that Obamacare didn't address the needs of poor people who couldn't afford the premiums and cost-sharing. These conversations happened before Pennsylvania expanded Medicaid eligibility to low income adults.

Sexual Health Education

Most of the participants talked about a lack of sexual health education in their high schools. The few who received sexual health education described what was presented as either misinformation or information that did not meet their needs. Some stated that the "sex ed" given was focused on pregnancy prevention, and had little useful information to offer young gay and bisexual men. Some participants had positive experiences in school, usually because a school-based Gay Straight Alliance (GSA) invited speakers or the school hosted afterschool activities that offered the opportunity to learn about sexual health issues. One participant said that his Catholic high school offered comprehensive sexual health information, including information on prevention of sexually transmitted infections. The experiences varied, but the majority of participants were not satisfied with the information presented at school.

The participants agreed that the information and services they received from LGBTQ-serving organizations, especially youth-focused organizations, met their current health information needs. They trusted the information they received and the people who advised them. The men were most trusting of medical professionals for sexual health information, especially about HIV and STIs.

During the discussion in one focus group, misunderstandings about HIV transmission came up. A participant believed that HIV could be transmitted by mosquitos, after another participant was sharing his previous beliefs about HIV transmission. The other participants were well informed and explained why that was not true. The moderator allowed the group to correct misinformation, and then shared relevant clarifying information. Another misunderstanding concerned the scope of the HIV epidemic in Philadelphia: a participant thought 25% of the population was infected. Once it was apparent the others were not sure of the statistics, the moderator clarified that about 1% of Philadelphians were HIV-positive. So even though these young men are connected to organizations with HIV prevention and health education programs, there is still some misunderstanding and confusion among them about HIV transmission and their risk of infection.

Overall, the participants were well informed about how and where to get HIV testing and other sexual health information and services. The participants had either sought out this information or had received it through participation in a group or program. Some participants used Google to find information on sexual health and healthcare services. This highlights the need to make sure that relevant healthcare and social services information is easily accessible to YMSM (and others) who feel most comfortable going online to find information.

Impact of Stigma on Access to Care

Participants stressed the importance of healthcare providers treating them with care, courtesy and respect. Most of the young men felt that they received respectful care from their primary care providers. The participants expect their doctors and nurse practitioners to treat them respectfully and professionally. When they are not treated respectfully, they are unwilling to return to that individual provider for care, and feel shamed and stigmatized. From comments made about

"They pulled a lot of programs out of schools; especially in Philadelphia....They cut the sex education programs and also health classes. And the nurses, the real nurses in Philadelphia schools got cut as well. So that's probably why a lot of teens don't know about where to get healthcare or get tested because there is like no outlet for them to get that information. A lot of parents are kind of scared to let them know, or don't want to tell them about sex education or where to get tested, because then they feel like that's a pass to do these things; but it's really making sure your child is aware of the situation. I believe teens will do it anyway, have sex anyway, but you just want to let them know that you can be protected while doing it. A lot of parents are scared to even have that conversation with their kids."

these different experiences, it's clear that professional behavior is desired from all members of an organization's staff, but rudeness is more generally expected (and tolerated) from front office staff.

Participants did not share much about their particular experiences as minority gay and bi men. One participant shared an experience with a female doctor (at a city health center) who did not appear to be comfortable talking about his sexual behaviors or his sexuality in general. He did not feel that this doctor gave him high quality care or treated him respectfully, because she could not comfortably address his concerns and questions.

Participants' racial and ethnic identities were only mentioned or referred to a few times. The issues of pride and denial were mentioned when the conversation turned to why others might not access healthcare. The community norms that teach men, particularly black and Muslim men, that seeking healthcare is undesired or not a masculine behavior were mentioned a few times. The comments about these norms indicated seeking healthcare isn't desirable because it may indicate a lack of strength or ability to take care of oneself, and because seeking healthcare often means going outside the trusted community, in terms of race/ethnicity, geography, and culture. The participants were more likely to mention the healthcare experiences of their mothers, grandmothers and sisters than the male family members.

Confidentiality

Participants often mentioned a lack of privacy or confidentiality when speaking about healthcare organizations that they found undesirable or unprofessional. Examples of front office staff speaking about individual patient's information too loudly or in public spaces were shared, but the participants did not share any personal experiences with breaches in confidentiality or privacy. Even without personal experience, confidentiality concerns are central for YMSM thinking about HIV or STD testing and healthcare services. Some organizations have a reputation among Philadelphia YMSM as not respecting patients' personal information or protecting their privacy. Some organizations were considered undesirable in all three groups because of the perceived lack of professionalism of the staff. Even in the age of HIPAA, which the young men demonstrated an understanding of; there is still enough fear of stigma and general embarrassment about sexually transmitted diseases that the young men didn't want to take any chance that their personal business would be public, either through their peer networks or through family or neighborhood channels.

Young men were concerned that having peers test them, or even just work at organizations where they received HIV testing and prevention services, could leave them vulnerable to having their HIV status or other health information get out into the community. This fear of having a peer tell their social network about their HIV status or health information was a strong

"....nowodays, a lot of our peers are testing us. Somebody that I know tested me, and I'm like, 'What if I test positive and then he'll know, because he knows basically everyone that I chill with and talk to.' People can't keep quiet..."

Unacceptable Testing Site Characteristics

- Bad reputation
- I know people who work there
- Unprofessional staff
- Testing in public settings

Acceptable Testing Site Characteristics

- Healthcare provider
- LGBTQ-friendly organization
- Incentives offered
- Sexual health or HIV provider

theme whenever the discussion turned to unacceptable HIV testing providers or bad experiences in healthcare settings. The group discussions made it clear that the YMSM understood how HIV stigma worked within their communities and that it acts as a barrier to testing and HIV care services for many people, including their peers. They understood the purpose of having other young gay and bi men provide HIV outreach, education, and testing services but did not trust their peers to follow the rules. Medical professionals, especially primary care doctors, were mentioned as trusted sources of HIV testing services, sexual health information and STD screening.

HIV Testing

Moderators asked the participants to name all the places they could get an HIV test. In all three groups, the participants quickly named many options for places to go for a test, including hospitals, community-based organizations, mobile units, AIDS service organizations, emergency departments, LGBTQ organizations, home tests, and primary care providers. It should be noted that all of the young men had some affiliation with LGTBQ organizations in Philadelphia, attending support groups, receiving medical care or other services at these places (they were recruited from these sites). They appeared to be comfortable talking about HIV testing in general, and about their specific experiences. No one shared negative experiences with HIV testing, but they offered negative opinions and perceptions about some HIV testing providers.

From the group discussions, getting tested regularly was a common occurrence and expectation for their peer group. It is impossible to know how often the young men were tested because the survey only asked if they had ever tested and why. Two of the 27 participants did not answer the survey question about whether they had ever received a HIV test.

After the groups listed HIV testing providers, they were asked where they would and would not go to get an HIV test. The groups were consistent about where they would and wouldn't go and why. The two most popular reasons for not wanting to go to a particular testing site were lack of professionalism and concern about confidentiality. Trusted HIV testing sites were LGBTQ organizations and/or healthcare providers (including hospitals, clinics and primary care providers).

Participants held differing views about whether peers doing the outreach and/or testing was a barrier. As mentioned previously, some participants worried that a peer would be tempted to tell others about the testing results or even just tell others that they had visited a testing site. Other participants did not share the fear of a breach of confidentiality, and explained why having peers work in outreach and testing was a successful strategy to get young men to test. When the moderator pressed for examples of any experiences of breached confidentiality, no one gave a personal example. However, several of the men expressed that they were unwilling to take the chance that their testing experience would become fodder for gossip.

One of the groups discussed how incentives are seen positively, not necessarily because of the incentive's monetary value, but because the incentive offered a "cover" to those seeking HIV or STI testing. For example, one participant explained he would say he was going to the mobile testing site to get a slice of pizza, if questioned by a friend or neighbor.

> *"It would be a convenient location. It would be super clean. It'll be a fast-paced environment and it'll be diverse in sexual orientation and ethnicity. I also feel like, it'll be very polite, because nowadays people need that, especially sick people. They just need someone to be polite to them."*

Ideal Healthcare Setting

The moderators asked participants to describe their ideal healthcare setting including who would work there, what it would look like, where it would be, etc. Many of the participants offered detailed descriptions and thoughtful reasons why their clinic would have certain features. The most frequently mentioned characteristics of the ideal healthcare setting were diversity of staff, highly-qualified providers, and a feeling of acceptance and inclusion.

Characteristics of an ideal healthcare setting mentioned more than once included:

- **Free food and snacks**
- **Highly-trained professional staff**
- **Help with transportation**
- **Diverse staff**
- **Evening and weekend hours**
- **On-site access to medications**
- **Accessible location**
- **Friendly and polite staff**
- **Multiple services in one location**

The YMSM were sure to include spaces for other members of the community in their ideal settings, including childcare centers so parents and caregivers can receive healthcare services. Many of the young men also mentioned accompanying their grandparents to hospitals and clinics, and so also considered the needs of older people in the designs of their imaginary healthcare setting, like snacks and on-site access to medications. There was a general emphasis that any healthcare setting should be accommodating to everyone and serve all with respect and care.

Discussion

This study indicates that the barriers to care experienced by YMSM in Philadelphia vary from the systemic and structural to the interpersonal. YMSM, especially minority YMSM, face a society that discriminates against them because of their race, age, sexual orientation and/or gender identity. Perceived stigma due to one's sexual orientation (or other characteristics) involves heightened sensitivity to rejection that is marked by expectation of being treated as unequal (Meyer, 2003). This phenomenon can be seen in some of the experiences and opinions shared by the participants, especially when considering their stories of disrespect from providers.

Black MSM experience stigma and discrimination on many levels due to social prejudices against black people, especially black men, and their sexual minority status. Black and other minority YMSM must navigate the healthcare system with all the other barriers experienced by the general population: lack of insurance or being underinsured, health illiteracy, transportation challenges, competing needs, other responsibilities, and any number of other barriers (Cheung, Wiler, Lowe, & Ginde, 2012). Anticipated or perceived discrimination adds another layer of stress, which may also prevent the individual from seeking or accessing care (Meyer, 2003). The internalization of these negative experiences impedes engagement in healthcare, HIV testing, and treatment adherence (Irvin, et al., 2014, Malebranche, Peterson, Fullilove, & Stackhouse, 2004).

"I can only imagine how a person would feel if you're trying to open yourself up to be that vulnerable, and someone just blatantly disrespects everything that you are, and everything that you just come for them to talk about."

When providing services to YMSM and other minority populations, one should be sensitive to the previous experiences of stigma and actively work to make individuals feel accepted and welcome; to see the person beyond the labels society has stuck to them (Hussen, et al., 2013, Malebranche, Peterson, Fullilove, & Stackhouse, 2004). Experiencing stigma from healthcare providers is associated with longer time lapses for last examination for both HIV-negative and HIV-positive MSM. However, it may be possible that having a trusting relationship with an individual healthcare provider may negate the impact of prior negative experiences with health care (Eaton, et al., 2015). As mentioned by this study's participants, individuals may perceive discrimination based on characteristics outside of sexuality, gender or race/ethnicity. Income and insurance type are other reasons individuals give for perceived discrimination, however perception of discrimination is unlikely to account for the observed disparities in healthcare access and receipt of preventive health services (Irvin, et al., 2014, Trivedi & Ayanian, 2006).

YMSM who do not receive relevant sexual health information may have limited understanding of how anal sex and other sexual behaviors affect their risk of HIV or other STIs. In the absence of health education young men may rely on older partners, information gained from the internet, and pornography for information related to risk (Kubicek, Beyer, Weiss, Iverson, & Kipke, 2010). Young men who are exposed to HIV-related information are more likely to have positive beliefs about HIV testing and the perceived behavioral control to get tested. Knowledge about HIV does not correlate to intentions to get an HIV test; however, exposure to HIV-related information is directly associated with testing intentions. YMSM who are exposed to HIV-related information, whether they are knowledgeable about HIV or not, are more likely to get an HIV test (Meadowbrooke, Velnot, Loveluck, Hickok, & Bauermeister, 2014).

Public health programs often view individuals as a member of a "target population", rather than an individual. As one young man described, some safer sex messages feel stigmatizing to YMSM because they see their heterosexual peers engaging in unprotected sex and other risk behaviors, but they don't receive the same messages. YMSM may perceive that their healthcare providers expect certain behaviors from them, regardless of what the individual men actually do. These expectations may feel stigmatizing; even if the providers intend to be inclusive and accepting.

Providing a safe space for young men to discuss their sexuality and well-being is essential to providing effective HIV prevention services to YMSM. Healthcare providers must prepare to have these conversations with YMSM, to assess their true risk for HIV and other STIs and then provide comprehensive care to meet those medical and social needs (Hussen, et al., 2013, Mustanski, Newcomb, Du Bois, Garcia, & Grov, 2011). Exactly how to create those safe spaces will vary depending on the individual healthcare provider and the context in which care is provided. Some YMSM prefer to talk to peers, whether that is other YMSM or a healthcare provider of their racial/ethnic group, or a provider who identifies as gay or bisexual.

> *"A lot of places....they have issues in customer service. Where individuals who attend those locations are made to feel less than. They're not greeted professionally. It's usually based upon attitude. Even if a consumer is coming to them with attitude, they should be a little bit professional – to treat them as a client or consumer, as opposed to a buddy."*

The atmosphere and culture of the clinic, hospital or practice impacts the comfort level of YMSM. As the participants shared, they will not go where they do not feel welcome. A welcoming healthcare experience may include: snacks, comfortable waiting areas, easy procedures for setting appointments, expanded office hours in the evening or on weekends, and open communication between office staff and patients on expected wait times and other matters that affect the patient experience (Cheung, Wiler, Lowe, & Ginde, 2012, Anderson, Barbara, & Feldman, 2007). Anderson et al. found that having an outstanding office staff was one of the core domains of healthcare associated with patient's perception of high quality healthcare. Traits related to high quality office staff included professionalism, friendliness, and being helpful (Anderson, Barbara, & Feldman, 2007). These characteristics are in keeping with the concerns and preferences of many patients of primary care. A positive interaction (partnership-building, facilitating rather than directing, friendly) with a doctor often leads to high patient satisfaction. The more patient-centered the facility and provider are the more positive the patient experience (Williams & Williams, 1998).

Early diagnosis is essential to the goal of the National HIV/AIDS Strategy to reduce new HIV infections (U.S. Department of Health and Human Services, Dieffenbach & Fauci, 2009). According to recent research, undiagnosed individuals were responsible for 30.2% of the estimated 45,000 HIV transmissions in the U.S. in 2009 (Skarbinski, et al., 2015). Early diagnosis of men who have sex with men reduces the number of new HIV infections in two ways: diagnosed MSM are likely to reduce their sexual risk behaviors through condom use, sero-sorting, strategic positioning and other harm reduction methods (Crepaz, et al., 2009, Marks, Crepaz, Senterfitt, & Janssen, 2005) and diagnosed individuals can begin HAART and reduce their viral load to undetectable levels (if adherent). Transmission of HIV among MSM is significantly associated with recent infection, sexually transmitted diseases, and higher viral load (Fisher, et al., 2010). Thus, with routine HIV and STI testing and efficient linkage to care of newly-diagnosed MSM, there is likely to be a reduction in new infections.

A study of black MSM's access to HIV testing and prevention services found that inadequate access to culturally competent services, stigma and discrimination, and limited services in the areas BMSM live acted as structural barriers to these services (Levy, et al., 2014). Structural interventions like locating services within minority communities and helping BMSM build the navigation skills necessary to access healthcare and social services would serve to mitigate these barriers.

> *"For me, the reason why I go to Health Center 1 or something like that is because….they do multiple things. They test for syphilis, gonorrheo, and all that when you go in. Whereas, when you go somewhere that might just do HIV testing, you could be missing a whole lot of things."*

> *"Yes, who pays attention to HIPAA all the time? They go to church and they share communion and stuff. [chuckles] Accidentally talking about me across the communion line."*

Individuals come to HIV testing with their own beliefs, perception, attitudes and experiences. There is no one "right" way to offer HIV testing, as demonstrated by the variety of preferences shared by participants. Some participants want to be tested by a doctor as a part of routine medical care. Others like to be able to walk in and receive a test in a community setting whenever they feel like it is necessary or desired. Hussen, et al. (2013) developed a typology of HIV testing behaviors of BMSM that provides context to this study's findings. In the typology there are four types of HIV testers: Maintenance, Risk-Based, Convenience, and Test Avoiders (Hussen, et al.,2013).

Hussen, et al. (2013) found that the younger men were more likely to be Maintenance Testers and Test Avoiders. Most of the participants in these focus groups fit the description of Maintenance Testers, with others falling under the other three types. Maintenance Testers see themselves as advocates for their health and HIV testing as a part of routine health care. These men regularly access care, are open about their sexuality, and have internalized public health messages about HIV testing (Hussen, et al., 2013). Test Avoiders are also openly gay or bisexual; however they cite more experiences of bullying than the Maintenance Testers. Avoiders have a high perception of HIV risk, however their fear of the results and HIV stigma impede their engagement with healthcare and HIV testing.

Stigma experienced by sexual minorities impacts the HIV testing access of the remaining two types Risk-Based Testers and Convenience Testers. Hussen, et al. (2013) observed that these types generally describe their appearances as masculine, and they tend to endorse more traditional masculinity social norms and beliefs. Risk-Based Testers and Convenience Testers advocated for prevention strategies that focused on black men, not black gay men, highlighting black brotherhood as central to their identity (Hussen, et al., 2013).

"I personally have a problem with the expectation that people have, that people or LGB people are supposed to be doing more than straight people are doing. And it's very frustroting, because I think it's counterproductive....Because it makes people feel like they're singled out. It makes them feel like, 'I don't see this pregnant chick down at-- or this young mother, moking oll these kids-- Nobody's telling them or harassing them about their condoms use'. They might be, but you don't get the impression that that they're being harassed about it. When there's also consequences for their actions....But in regard to that environment, I don't think I've experienced that directly. But other than thot sensotion that you're talking to me a certoin woy, and I'm not sure that you talk to your heterosexual patients the same way. It may not be explicitly soid, but you give that impression moybe. I don't think you give them the same hassle. Even when they come in here with a STD or if they're coming here with-- if they're young ond pregnant or whatever, I don't think you give them that same woy."

This typology offers a way to conceptualize the heterogeneity of the black MSM and YMSM populations' experiences with HIV testing and HIV prevention messaging. Some men view HIV testing as possibly "outing" their sexuality. Public health messages about HIV testing often focus on gay men. The targeting of these messages may reinforce perceptions that HIV testing is something only "gay" men do. Participants supported this idea when discussing incentives for HIV testing; that incentives act as a "cover" for them so they can seek HIV testing while reporting to others that they were only going to receive the incentive. Relatedly, another participant explained he would pretend to be accompanying a female friend to Planned Parenthood in order to get services without risking exposing himself to possible ridicule or stigma. These beliefs about HIV testing and fear of stigma emphasize the importance of access to and engagement in primary care for YMSM.

According to the CDC's revised recommendations for HIV testing of adults, adolescents, and pregnant women in health-care settings (2006), all MSM should be offered a HIV test at least annually. For these recommendations to be successful in routinizing HIV testing for MSM and all Americans, healthcare providers must offer HIV testing and discuss their patients' sexual behaviors to recommend other appropriate screenings and interventions. This is especially important for MSM populations, considering the prevalence of HIV within MSM and YMSM communities. Healthcare providers cannot assume that men will always disclose their same-sex attraction or their sexual behaviors. For this reason, providers must be willing and able to have open dialogue with their patients about their sexual history and behaviors on an ongoing basis, in addition to offering annual HIV tests.

If YMSM are actively engaged in primary care and routine HIV and STD testing, they do not have to negotiate how stigma impacts how they seek HIV testing and prevention services. HIV prevention messages should promote HIV testing as a standard part of routine medical care, in order to normalize HIV testing and destigmatize HIV testing as something only "gay" people do (Parent, Torrey, & Michaels, 2012). Disclosing same-sex attraction to a healthcare provider is a difficult act for some MSM because of fear of discrimination and internalized stigma. In a study of MSM in New York City, 39% of MSM did not disclose their same-sex attraction to their health care providers and none of the bisexual men disclosed (Bernstein, et al., 2008). An online survey of MSM found that, of the 4620 MSM who reported visiting a health care provider in the last year; only 30% were offered an HIV test. The men who disclosed sex with men were more likely to be offered a test (Wall, Khosropour, & Sullivan, 2010).

Limitations

The analysis of these discussions cannot be generalized to reflect the experiences, needs or barriers of all YMSM. As mentioned previously, all the participants were recruited through LGBTQ and/or youth serving organizations with HIV prevention and testing programs. All of these young men had participated in at least one program or activity at these organizations. Due to this limitation, the results of these discussions cannot be applied generally to all YMSM in Philadelphia. YMSM who do not identify as gay or bisexual, or otherwise do not identify as part of the local "gay culture", may have different opinions and experiences. The young men in this study also reported regular engagement with healthcare; this may not be true for their peers.

Participants were aware that the purpose of the study was to inform the planning of HIV prevention services in Philadelphia, and so they may have given responses in support of organizations they frequented in order to protect the funding or reputations of those organizations. The participants also may have given socially acceptable answers in order to gain the respect and admiration of the moderators and/or their peers. The moderators were clear to emphasize that there were no correct answers or opinions.

Overall, caution should be exercised when applying the results of this study. This analysis is offered as insight into how YMSM view healthcare and the local HIV testing and prevention system, to be used alongside other data for policy and program planning.

Recommendations

In order to address the healthcare and HIV prevention needs of Philadelphia's YMSM, a combination of strategies, policies and programs are necessary.

Increasing access to and engagement with primary care for YMSM is essential. Engagement in primary care is an especially important tool in the HIV prevention "toolbox" in this age of biomedical interventions like pre-exposure prophylaxis and "treatment as prevention". HIV-negative YMSM can be linked to appropriate interventions and have regular sexual health screenings. YMSM who are regularly tested and engaged in healthcare will have a better chance of being linked to HIV care and treatment, should they acquire HIV. Programs that engage YMSM in healthcare should address their complex needs, including mental health, substance use, chronic health conditions, and social needs, in developmentally appropriate ways.

A combination of routine testing in all primary care settings and targeted community-based testing is necessary. Risk-based testing alone may miss high-risk individuals who are reluctant to disclose same-sex attraction and/or their sexual behaviors or substance use.

Comprehensive evidence-based sexual health education, inclusive of all gender identities and sexual orientations, is needed in the Philadelphia school district. Young people need sexual health education that promotes not only their health but their well-being.

HIV testing protocols should address concerns about confidentiality. HIV testing programs ought to consider who provides the counselling and testing, where testing occurs, and how to address concerns about confidentiality and privacy. It may be beneficial to include information about privacy protections and confidential testing protocols in outreach and marketing materials, in order to address those concerns before they can become barriers to testing.

Special attention should be paid to creating welcoming and accepting organizational cultures. Healthcare organizations need to prioritize the barriers, challenges and concerns of YMSM. YMSM want to go to providers who can relate to their experiences and accept them as they are.

Relevant information about local services, sexual health, and HIV/STD testing should be online in the places YMSM are likely to find it. Reliable online content will help many YMSM, especially those who are reluctant or unable to access services in the "gay" community. More local research is needed to better understand how Philadelphia's youth access online health information.

Community level efforts are needed to address HIV stigma and discrimination of LGBTQ individuals, which persist and act as a barrier to open communication about the sexual health needs of YMSM.

Public health programs and healthcare organizations must be sensitive to the effects of stigma and discrimination on YMSM; especially minority YMSM who face not only stigma because of their sexuality and/or gender expression, but also live in a society with pervasive structural racism.

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