

Experiences in HIV testing and healthcare

Adult Heterosexuals

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Introduction

A low perception of HIV risk persists among heterosexuals in Philadelphia, despite the fact that there are almost equal numbers of heterosexuals living with HIV/AIDS (3,153) as men who have sex with men (3,140). However in recent years, diagnoses of HIV among heterosexuals have been decreasing, from 316 in 2010 to 254 in 2014. According to estimates done by the Philadelphia Department of Public Health (PDPH), 166 heterosexuals acquired HIV in 2013. Despite declining incidence in the overall heterosexual population, racial disparities in HIV incidence and prevalence among heterosexuals are stark. In 2014 there were 5,105 Black heterosexuals living with HIV/AIDS, 8 times as many as Whites (612) and 5 times as many as Hispanics (985). The overall reported numbers of HIV cases of Non-Hispanic Blacks is twice as many as Non-Hispanic Whites and Hispanics combined. In 2014, there were 4,026 Black women living with HIV/AIDS, 7 times more than White women and 5 times more than Hispanic women (PDPH, November 2015).

The National HIV/AIDS Strategy (NHAS) includes Black men and women as key populations. The rate of HIV infection for Black women was 20 times that of White women in 2010. In 2010, HIV was the leading cause of death for Black and Latina women of reproductive age (CDC, 2012). In the United States, 1 in 16 Black men (including heterosexual and men who have sex with men) will be infected with HIV in their lifetimes. Black men accounted for 69% of all heterosexual exposures in 2009 (Raj & Bowleg, 2012). Trends have been shifting over the last few years; the number of new cases of HIV among Black women is decreasing, nationally and locally (CDC, 2015; PDPH, November 2015). One of the NHAS indicators includes reducing

disparities in the rate of new diagnoses by at least 15 percent in Black females (among other populations at disproportionate risk) by 2020 (White House Office of National AIDS Policy, 2015).

Although the number of new cases is decreasing, some individuals are still getting diagnosed years after their seroconversion and receiving an AIDS diagnosis at the same time they learn they have HIV. Delayed diagnosis is problematic for the individual's health and the public's health. People who are unaware of their HIV-positive status may unknowingly expose others to HIV. PDPH estimated in 2013 13.5% of HIV-positive heterosexuals were unaware of their status. This compares to 13.2% of men who have sex with men and 5% of people who inject drugs (PWID).

In Philadelphia, 28.2% of newly diagnosed women (90% of all women are infected through sexual contact with males) and 32.2% of all newly-diagnosed heterosexuals (males and females) had an AIDS diagnosis within 3 months of HIV diagnosis in 2014. Concurrent diagnoses among women increased between 2010 and 2014 from 25% to 28% (PDPH, November 2015).

Challenges in engaging women and men in HIV testing and HIV care are myriad and include entrenched societal barriers like poverty, often deep poverty, and high rates of incarceration for men of color. Other barriers to engagement in HIV prevention and care include: drug abuse, domestic violence, homelessness, lack of social support, child care and family responsibilities, lack of provider cultural competency, and lack of perceived risk by heterosexual men and women (CDC, December 19, 2014; Nunn, et al., 2012; Nunn, et al., 2011).

According to the CDC, sexual risk among heterosexuals of low SES is quite common, including unprotected anal and vaginal intercourse, and recent diagnosis of sexually transmitted infections. Many people engage in high-risk sexual behaviors but do not recognize their own risk of acquiring HIV (Nunn, et al., 2011). In Philadelphia, 82% of men in the 2014 National HIV Behavioral Surveillance System sample had vaginal sex without a condom and 36% had anal sex without a condom in the previous 12 months. For the women in the same sample, 86% had vaginal sex without a condom and 21% had anal sex without a condom in the previous 12 months. Substance use is common among low SES heterosexuals in Philadelphia, 40% of the sample reported any drug use (excluding alcohol) in the previous 12 months. Marijuana was the most commonly reported drug. Drug use lowers one's inhibitions and may lead to greater sexual risk taking and lower condom use (CDC, December 19, 2014).

Racial disparities in HIV infection rates are not due to behavior alone. Powerful social factors like poverty, gender inequality, racial segregation and discrimination, and gender norms drive the epidemic in African American and other minority communities. When examined geographically, areas with significant numbers of people living with HIV/AIDS are often areas with concentrated poverty and minority populations (PHMC, 2011). Geography and racial segregation matter because people tend to socialize with people similar to themselves. This is a major factor in how HIV is concentrated in certain geographic and cultural communities.

There are biological and social (interpersonal and structural) factors driving racial disparities in HIV infection in Philadelphia (Bowleg, et al.,

2014; Nunn, et al., 2014; Raj & Bowleg, 2012; Hall, Espinoza, Benbow, & Hu, 2010; Powers, Poole, Pettifor, & Cohen, 2008). This analysis will focus on several of these factors including poverty, HIV stigma, and trauma. Recommendations will be given on how to increase access to HIV testing and prevention services and primary care, as well as how to decrease disparities in access and engagement with HIV treatment.

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 heterosexuals (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 heterosexuals at high risk for HIV (and those living with HIV) in order to better understand how these barriers affect their use of healthcare and HIV testing and care 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 four focus groups (two groups with men and

two groups with women) with adult heterosexuals in October and November 2014. OHP recruited participants through various community-based organizations and HIV service organizations. Information about the focus groups was included in a North Philadelphia community newsletter. Recruitment was challenging and took place over three months. A few community members aided our efforts by referring potential participants and posting flyers in public spaces.

Inclusion criteria for participation were: residency in Philadelphia, identifying as a heterosexual man or woman, English proficiency, and age between 25 and 65. Minors were not included in any of the focus groups within this study, because of the concerns with securing parental consent. Young adults at high risk for HIV will be recruited for future focus groups.

OHP staff developed the moderator's guide to emphasize 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 risk behaviors of many populations 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 adult minority heterosexuals. Delivering these interventions where they will be most accessible and acceptable to Philadelphians 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.

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 ruled exempt from full review by the Philadelphia Department of Public Health's Institutional Review Board, due to the nature of the study. All participants were given a \$20 CVS gift card, two SEPTA tokens, and a meal in appreciation of their participation.

Limitations

The analysis of these discussions cannot be generalized to reflect the experiences, needs or barriers of all heterosexuals in Philadelphia. Focus groups are not a representative sample of population by design. Focus groups give us a deeper understanding of issues and social factors experienced by participants from targeted communities.

As mentioned previously, all the participants were recruited through community-based providers and HIV service organizations. These participants are likely to be more informed about HIV and HIV testing than many of their

peers. The men and women 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 men and women view healthcare and the local HIV testing and prevention system, to be used alongside other data for policy and program planning.

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, there were 21 participants between the four groups, 9 women and 12 men. Ages ranged from 29-62, with most participants in the 50-59 age range (5 men and 5 women). The majority of participants were African American or Black (19). One woman identified as White and another participant did not respond. One woman identified as Hispanic, all other participants either identified as non-Hispanic (16) or did not answer the question (2). Nine of the participants had graduated high

school or earned an equivalency. Four women and two men did not complete high school. The remaining 6 participants received some college education (3), a college degree (1) or vocational training (2). Most of the participants earned less than \$10,000 annually (14). Three earned between \$10,000 and \$19,999, one person earned \$20,000-\$29,999, and two earned \$30,000 and \$39,999. Most participants rented or owned their own homes (17). One man was staying in a shelter, one woman had Section 8 housing, and two men were staying with family or friends. All the men and women (except for one woman who didn't answer the question) identified as heterosexual (romantically and sexually attracted to the opposite gender).

All participants reported receiving an HIV test at some point in the past. Reasons given for being tested included "just to find out if I was infected" (4), "I was at risk for HIV" (6), "doctor suggested I get tested" (3), "because I felt sick" (2), "as part of a routine medical check-up" (1), or another reason (5). Other reasons included: being in an abusive relationship and getting really sick, receiving a gift card as an incentive, "because it was free", and "during incarceration". These reasons match previous research on the experiences of African Americans in Philadelphia (Nunn, et al., 2012).

Even though participants were not asked their HIV status in the survey or discussion, several participants, both men and women, disclosed that they were living with HIV/AIDS. All the participants, regardless of HIV status, are included in this analysis.

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 heterosexual adults' health care access. Human behavior has a social context. Philadelphians, particularly minority men and women living in or near poverty, 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 adult heterosexuals face.

Themes

Opinions and observations differed between individuals and even between groups, but overall three general themes emerged: the necessity of patient dignity, the prevalence of trauma, and the effects of social determinants on healthcare access and health. Traumatic experiences varied, but many of the

Sometimes women don't want people to know how we really are. Because we need a lot of stuff. And I don't want to sit there and talk to somebody with a degree and from another culture that hasn't walked in my shoes, and tell them how bad I'm really doing and that my lights is about to be turned off. I don't want you to know that about me.

participants shared the long term effects of trauma on their mental health and their access to health care. The social determinants mentioned include poverty, mental illness, HIV stigma, distrust of healthcare providers, experiences of homelessness, and caregiving responsibilities. Most of the themes appeared in the male and female groups; however, caregiving was most frequently mentioned within the female groups and healthcare avoidance/distrust in the male groups.

Social Determinants

Poverty and healthcare access

Poverty was the uniting social determinant throughout the discussions, even if poverty was not mentioned directly. Living in poverty limits possibilities, creates situations of forced choice, and requires significant resources (physical, mental and otherwise) to meet even the most basic needs. Participants shared ways in which living in poverty limited or prevented them accessing care, which included lack of transportation and perceived discrimination based on experiencing homelessness or being uninsured.

Even when participants had health insurance, they sometimes could not afford co-payments for medications, even if these co-payments were considered "nominal". Sometimes even coming up with a few dollars was difficult, especially for individuals with no income or relying on SSI or SSDI. A woman shared a story about her daughter who went to the emergency room for an infection, but had no money to fill the prescription given to her. Some of the participants had a limit on the number of prescriptions covered under their insurance, so they would have to decide which prescriptions to fill while at the pharmacy, with no consultation with their healthcare provider.

Homelessness

Male participants observed that people experiencing homelessness were sometimes ignored by outreach workers and healthcare providers. One participant, who had been on the street for several years himself, described men who were living on the streets and no one seemed to be helping them get the necessary mental health care, or even shelter. Outreach workers did not engage with the most troubled people on the street. The participants also commented that when they are living on the street or in the shelters, their health is not a priority, especially if they are in active addiction.

Men who had accessed healthcare at the homeless shelters said they received good care, but often they had to wait too long to see a doctor because there were so many other people waiting. Participants felt that waiting for a long time was demeaning. They didn't think that they would wait as long in private health centers or if they had insurance.

Mental Illness and Trauma

Participants shared their struggles with mental illness and addiction. A few men shared their mental health diagnoses of post-traumatic stress disorder, depression, anxiety, and obsessive compulsive disorder. Men shared their experiences of physical violence, including a man who had a bullet lodged in his back. Male participants also shared experiences of homelessness and incarceration which were traumatic to them.

Women shared their experiences dealing with addiction, sexual assault and trauma. In one focus group, women bravely shared their experiences of sexual trauma and offered each other support and encouragement. One woman was struggling to cope with familial sexual

abuse and rape that had happened years before. She was in recovery after years of heroin use. The other women offered support and encouragement for her to work through her feelings and to seek professional and peer support to help her with her trauma. Two other women in that group also experienced childhood sexual abuse and rape. They used counseling to process their trauma and to get help with addiction.

Caregiving

Women are often the primary caregivers in their families, sometimes for multiple generations. The female participants shared their challenges making doctor's appointments when caring for children and grandchildren. Most healthcare providers do not have childcare on-site or toys or other age-appropriate items in the waiting rooms for children. Some providers do not allow children to go into exam rooms, so women put off their healthcare in order to care for their loved ones. One woman prioritized her ailing father's well-being and healthcare access over her own for the year she provided end of life care for him.

Women often encourage the men in their lives to access healthcare, not only just for routine preventative care and follow-ups but also in

That's why I never go to the hospital. Even though when I was sick, sometimes I wouldn't go because of pride, ego, scared of hearing about what might be wrong with me....I don't like hospitals. It seems like when you go in the hospital; you might go in with a minor cut and come out with major surgery.

Sometimes ignorance is bliss. Because everybody's not going to feel the same way you feel....It ain't even just about HIV. It could be something about anything. If you're going to affect something else, then I think they should know. If you're having sex with somebody I think they should know. If you gonna spread it in some kind of form where it's going to affect the next person, I think they should know. But then, I think that's an individual choice too. Because you could have a choice to do that. But my family is not understanding and so forgiving. I would be eaten up by my family if they found out I had this. It would be a tremendous stress, and I know they would be talking about me every time I come to the dinner table.

urgent matters. One woman said that she ended a marriage because she couldn't deal with her husband's neglect of his own health; it was bringing her own health down. Other women shared stories of helping their husbands/partners take care of chronic conditions and encouraging them to prioritize their health.

Mistrust of Doctors

The men gave reasons for healthcare avoidance, which include denial and mistrust of doctors. A man living with HIV said he sometimes avoided healthcare because he didn't want to be reminded that he was HIV-positive, especially when he was feeling healthy and looking good. Other men shared

experiences of having procedures and tests done that felt invasive and unproductive. One man was having health issues that weren't addressed properly until a second doctor asked him about his nutrition and tested his vitamin levels. He attributed the care given by the second doctor to her also being African American and understanding his culture. Some of the avoidance was related to feeling like the providers don't understand the experiences of Black men. Lack of clear communication leads to doctor mistrust. Participants shared experiences of healthcare providers dismissing their questions and concerns. They were told not to worry because the doctors had things under control. Participants felt disrespected by these types of dismissive comments, not reassured.

Stigma

Participants experienced stigma because of their HIV status, insurance status, experiences of homelessness, mental health diagnoses, gender, and substance use. Often participants felt shame or embarrassment in stigmatizing experiences. Some participants expected shame or stigmatizing reactions from providers or healthcare workers because of differences in gender, race, culture or socio-economic status. One participant said she felt shamed and dismissed by a medical student at her primary care appointment, because he didn't believe her self-reported alcohol consumption. Another woman was reluctant to share her sexual and reproductive history with doctors because she felt she would be judged.

Several participants perceived discrimination or stigma from front office staff, most frequently in the form of having to wait a long time for walk-in appointments even when they were among the first to arrive. Some attributed the

perceived discrimination to their HIV status, others to their lack of health insurance. In general, waiting long periods of time to see a doctor was seen as discrimination and/or demeaning. HIV discrimination was a concern for individuals living with HIV when they had to access healthcare outside of their regular primary care or HIV specialist, like in an emergency. Perceptions were that they would be treated worse in places that offered walk-in appointments and otherwise served uninsured and low income patients.

Participants living with HIV also had concerns about HIV stigma and discrimination from their family members, including children and parents. Most of the participants had disclosed to their close friends and family, some were even outspoken activists. One man reported not telling anyone in his family that he had HIV. He decided that he would wait until there was a reason for them to know because he was concerned about being ostracized. A woman shared a story about her daughter not wanting her to hold her granddaughter, because of fear of HIV transmission from scratched mosquito bites. Other participants didn't feel concerned about HIV stigma, even if they experienced it. They wanted to live openly in order to get the support and resources they needed to stay healthy. Participants who had disclosed to

A lot of people don't get medical attention that they need because of personal decisions, personal issues, lifestyle, things of that nature. Because I know for me – as a recovering addict – when I was out there getting high, that was the last thing I was thinking about – going to get a checkup.

family members reported having supportive relationships with those who knew their status.

There was some passionate discussion in one of the men's groups about disclosure. The consensus was that everyone should disclose to sexual partners or anyone else who may have a reasonable risk of being exposed to HIV. They agreed that it was an individual choice and that people will have different reasons for wanting to keep their HIV a secret from their family members.

Dignity and Cultural Competency

Every group, almost to a person, discussed the importance of healthcare providers and staff treating patients with respect and kindness. Negative experiences with healthcare were related to how the patient was treated, not the clinical care provided. Participants shared specific stories of disrespect or neglect that highlighted the need for clear communication, compassion, cultural understanding, active listening, a partnership, and basic kindness.

Participants who had a strong relationship with their providers were happy with their care. Feeling comfortable asking questions and talking about difficult topics like sexuality and HIV status disclosure were hallmarks of a strong patient-provider relationship. With a positive relationship came the expectation of a mutual respect and loyalty. Participants were willing to change medical practices in order to continue to see a favorite doctor. Two participants expressed disappointment that they had favorite doctors leave a practice without informing them beforehand, seeing this as a breach of their trusted relationship. One man shared his feelings of disappointment and abandonment when he was in the hospital and his long time doctor didn't come to see him and was unavailable for consult. The man believed

that his hospital stay was unnecessarily extended because his doctor did not see him.

Participants felt disrespected by a lack of transparency in the way appointments were made and kept. Walk-in appointments were the only options for people who couldn't wait a month or two for an appointment, or needed a refill on a prescription. Participants shared stories of arriving early for a walk-in appointment and waiting for a long time only to be told to come back the next day. This was not acceptable to them.

Some of the individuals who have been HIV-positive for a long time felt like their doctors didn't value them as much as their newer patients. They felt like they were just a number and the visits were quick and impersonal. The high volume of the clinics was acknowledged by participants, but they also expected to be treated like a valued patient, not just "a chart".

How the front office staff greeted and treated the patients was a recurring topic. If the front office staff were polite and friendly, then the visits were good. Participants shared experiences of being ignored by front office staff, either by not being greeted (or even acknowledged) or by pushing paperwork through the window with no verbal interactions. Participants valued eye contact with front office staff and healthcare providers. Examples were given of providers only looking at the electronic medical records and not interacting with the person in front of them. A woman called providers "chart clutched"; meaning they called patients from the doorway, clutching their chart but not offering eye contact or a handshake.

Participants said it is important to them to have their diagnoses and procedures explained to

them in simple ways, and for the doctor to make sure they understand everything before leaving the exam room. Medical jargon is a barrier to understanding. Participants talked about how individuals might not be empowered enough to ask questions, so doctors should offer simple explanations and anticipate common questions. One woman shared her story about being terrified of a blood transfusion because she thought she was going to be "hooked up" to another person to receive their blood, because of the images she had seen on television. She was scared and crying when her doctor told her she needed a transfusion, but he didn't ask her why she was upset or explain the procedure.

Having a friend or family member present at doctor's appointments was noted as a way to help patients remember and understand diagnoses and treatment. Lack of social support was sighted as a barrier to attending appointments, because people are afraid of what they might learn from the doctor.

Participants were happiest with doctors who were their partners. They wanted to participate in healthcare decisions and have their opinions

When I was diagnosed, I acted like I didn't hear it. I acted like it didn't happen. And like I said, there are still some days I still live that way. Some days I don't feel like taking medications. Sometimes I don't feel like going to the doctors. They're constantly reminding me that I have HIV, so I go through my days like I'm okay, like I'm fine. I don't dwell on it. I don't keep it up in my head. If I do, that'd keep me sick.

and concerns respected and addressed.

Ideal Place for Healthcare

The groups had a lot to share about their dreams for the ideal place to receive healthcare. They focused on their own barriers to care and those they see within their communities like lack of health insurance, competing responsibilities like child care, and lack of health literacy. The importance of respect and dignity played a central role in their ideas.

Participants agreed that many people didn't understand how to take care of their health, even in the most basic ways like sleep, hygiene, food safety, and nutrition. One participant said that often people were told that they need to sleep more or eat better but not shown how to do go about making real life changes to accomplish these goals. Social support was stressed as necessary to help people access healthcare and then to follow treatment regimens and other healthy lifestyle goals. One of the women pointed out that even if a mother knows what foods are healthy, she may not be able to afford them for her family. Participants

It would be a friendly place, with respect for the clients and their confidentiality. It'd be a smiling place, where everybody's smiling...."How are you doing this morning? You okay Mr. M? How can I help you?"....I want a concerned place. I want someone to feel like, 'People care about me. I'm part of something.' That's what I want my client to feel like.

suggested that incentives coupled with health education could help people make necessary changes, or at least engage them in educational efforts.

Participants stressed that healthcare needs to be within the communities most in need of access, whether in the form of one-stop-shops or mobile vans offering basic health screenings and education. Community-based settings helped reduce the barriers associated with transportation access and travel time. These community-based settings should be confidential and non-judgmental. They should be places patients can feel proud of; "not in some hospital basement". The one-stop shops would offer social support, either case management services or peer support. The groups recommended that all staff, front office and clinical staff have training on cultural sensitivity.

Participants preferred waiting areas with spaces for children to play, outlets to charge mobile phones, and computers to do research or check email. These spaces would feel more like a lounge than a waiting room. Food, water, tea and other comforts would be offered to make waiting more bearable. Child care would be available during clinic times when women were more likely to attend, with toys and other items for children like diapers and formula.

Incentives to address barriers to care like tokens, food, and gift cards for necessities should be available for all who need them. Participants stressed that women are often caregivers for family members, especially for children and grandchildren. Anything that can be offered to women to help care for their families would increase access to healthcare and make women feel more comfortable.

HIV Testing

Only three groups discussed HIV testing in depth. One of the women's groups spent considerable time discussing trauma and there was not enough time to delve into HIV testing. However, the themes that came out of the other three groups were consistent: incentives for testing are necessary to reach the most at-risk, both community-based testing and routine HIV testing in primary care and hospitals are necessary, and confidentiality is essential.

Participants were asked to brainstorm all the places they knew to get an HIV test in Philadelphia. The lists were long and inclusive: AIDS service organizations, community-based providers, hospitals, mobile units, homeless shelters, and city health centers, most commonly Health Center 1. Participants had some disagreement about which of these was more or less acceptable, depending on their individual needs and experiences.

Of those providers deemed "acceptable" places to get an HIV test, expertise in HIV, friendly staff, cultural competency, respect for privacy and confidentiality, linkage to HIV services, incentives (cash, food, gift cards) were seen as important characteristics. AIDS service organizations, primary care providers, mobile testing units, Hispanic and Black community-based organizations, homeless shelters and Health Center 1 were all listed as "acceptable" by participants.

Some participants stated that AIDS service organizations were not their preferred choice, because of fear of HIV stigma, that someone would see them there. Health Center 1 was not acceptable to others because they thought it was too crowded and took too long to be seen.

This concern was the view of "free clinics" in general.

In all three groups, incentives for HIV testing were seen as necessary to get women, people experiencing homelessness, and Black men tested. These groups in particular were mentioned by participants as desiring some kind of incentive for their participation in testing programs. Incentive types and amounts varied from \$10 to \$20 for Wawa, groceries, and other necessities. Several of the participants said that incentives had gotten them to take an HIV test in the past and they thought incentives should come back. The male participants agreed that even though men should want to get tested and take care of their health without incentives, that incentives will often get them in the door. Incentives can combat healthcare avoidance, denial and fear.

Participants stressed that often people are afraid to get an HIV test because they are afraid that they will be HIV-positive. Social support in terms of a "buddy" or a sensitive and caring person doing the counseling and testing will make all the difference. Testing with friends and partners were also suggested as ways to help

Gift cards. It's sad but it's real. You know what I mean? It's so pitiful but it's real though. A man won't go and find out what he needs to know about himself, what keeps him healthy, what keeps him a fine machine....But if you don't offer the black man something.... me myself if you don't offer me something that pique me-- that pique me, that get me on that page, you'll lose me out there.

The discrimination is the biggest issue I had with any doctor....it could be an emergency and you might have to go to the nearest emergency clinic....so you go as a walk-in and just the treatment, the discrimination – not the fact you have to explain your medical history, because you would have to do that regardless – it's after you explain is when you get that change of look. Everything, the whole dimension of the person just changes like that. You can feel it....But you're sick so you have to chalk it up, and hold that ball up in your throat. You can't really say what you want to say, or if you do you might say it in the wrong way and they might not want to attend you.

people feel more comfortable with the idea of HIV testing and to lessen the effects of HIV stigma.

Discussion

In order to be effective, healthcare providers must address and mitigate the socio-economic factors that put their patients and the community at-risk for HIV and other diseases. As evident in these discussions, heterosexual adults at high risk for HIV live in environments where resources and social support are often inadequate to meet their complex needs. Social and structural factors play a large role in heterosexual transmission and acquisition of HIV, particularly in racial disparities (Nunn, et al., 2015; Nunn, et al., 2014; Bowleg, et al.,

2014; Group, 2011; Hall, Espinoza, Benbow, & Hu, 2010). Health disparities have many causes and factors including (but certainly not limited to): HIV stigma, physician bias, patient mistrust of physicians, reluctance to undergo invasive procedures, health literacy, fundamental religious beliefs, insurance coverage, and economic influences (Eiser & Ellis, 2007; Brandon, Isaac, & LaVeist, 2005).

The following discussion references the current literature on trauma and PLWHA, trauma-informed care, cultural competency and dignity in healthcare, and HIV testing and prevention, to provide context and support for the participants' experiences and opinions. Recommendations for HIV testing, prevention, and HIV care services for this population, as well as general public health interventions, directly follow.

Trauma and HIV

Trauma is result of an experience which creates a sense of fear, helplessness or horror, and overwhelms the person's resources for coping. Trauma may have long-lasting effects that interfere with a person's sense of safety, ability to self-regulate, sense of self, perception of control and self-efficacy, and interpersonal relationships (Hopper, Bassuk, & Oliver, 2010).

Prevalence of trauma is high among many of the same communities that are most at risk for HIV including those in this report: women of color, African American men, especially those who have experienced homelessness and incarceration (Hopper, Bassuk, & Oliver, 2010; Cavanaugh, Hansen, & Sullivan, 2009; El-Bassel, Caldeira, Ruglass, & Gilbert, 2009; Gillespie, et al., 2009).

In a predominantly African American sample of patients seeking primary and gynecological care

in an urban clinic, lifetime prevalence of Post-Traumatic Stress disorder was 46% and for Major Depressive Disorder it was 37%. Eighty-eight percent of the sample had experienced a significant trauma in their lifetime. Among women in the sample, 33% had experienced intimate partner violence and 55% had experienced an assault with a weapon (not by a partner). Nineteen percent of the same sample reported childhood sexual abuse, 24% of the women and 11% of the men. Thirteen percent of the women reported experiencing a sexual assault (Gillespie, et al., 2009). In another study, African Americans seeking care at a mental health clinic had a high prevalence of trauma and reported symptoms of PTSD, but had low diagnosis of the disorder. Forty-three percent of that sample met the criteria of PTSD. Of the women in the sample, 45% had experienced sexual assault (Schwartz, Bradley, Sexton, Sherry, & Ressler, 2005).

People living with HIV have higher rates of trauma than the general population, especially among women (LeGrand, et al., 2015). Wyatt et al. (2002) found that regardless of race/ethnicity HIV-positive women were more likely to report adult sexual abuse. That study found that women's sero-positivity was predicted by more sexual partners, unemployment, more sexually transmitted

A woman is very protective about her sexual history. She's worried about being judged, because when they ask the questions, "How many children have you had?" "How many abortions have you had?" that type of thing, they feel like they're being judged in that way.

infections, more severe history of trauma, and less education. In this sample of women, race/ethnicity was not an independent predictor of HIV risk. African American women were slightly more likely to report severe intrafamily child abuse than other women. HIV-positive women were more likely to report a more severe history of trauma than HIV-negative women. Wyatt et al. (2002) concluded that the higher rates of HIV in women of color was likely due mainly to differences in socio-economic resources, exposure to violence and exposure to risky sex, not to characteristics inherent in their racial or ethnic groups (Wyatt, et al., 2002). Experiences of intimate partner violence (IPV) are associated with increases in sexual risk taking. Cavanaugh et al. (2009) found that women with IPV-related Post Traumatic Stress Disorder had four times greater odds of recent sexual risk. This finding came with the caveat that sexual risk is often not in the control of a woman in a violent relationship (Cavanaugh, Hansen, & Sullivan, 2009).

Homelessness is a traumatizing life experience and often homeless individuals have experienced multiple traumas prior to losing housing. These traumas include physical violence, abandonment, neglect, discrimination, sexual abuse and assault, etc. Living on the street leaves many individuals to be re-victimized and re-traumatized (Hopper, Bassuk, & Oliver, 2010).

Racial discrimination is an ongoing trauma experienced by Black men and women and other people of color. Bowleg, Fritz et al. (2014) interviewed Black men in Philadelphia about sexual risk and experiences of racial discrimination. Of those men, 97% reported experiences of everyday racism and 91% reported posttraumatic stress symptoms at

least some of the time. The three most common reported symptoms included: being overly aware and alert of what was going on around them (69%), feeling irritable or having outbursts of anger (67%), and trying to avoid certain activities, situations or places (63%). Men who reported more experiences of racial discrimination also reported more sexual HIV risks like condomless sex. Incarceration was also related to posttraumatic stress symptoms and sexual risk in the sample. Racial discrimination-based stress may be a pathway to increased sexual risks for Black men. More research is needed to understand the relationships between racism and sexual risk. Increasing social support for Black men has been shown to buffer the effects of racial discrimination (Bowleg, et al., 2014).

The effects of trauma on health are varied. Trauma may cause healthcare avoidance, particularly for survivors of intimate partner violence. Health exams can be invasive and trigger traumatic responses, because of feeling a lack of control over one's body (Elliott, Bjelajac, Fallar, Markoff, & Reed, 2005). Evidence is growing that trauma negatively impacts immune function (LeGrand, et al., 2015). People living with HIV/AIDS who have any experience of intimate partner violence also have lower levels of viral suppression. Traumatic reactions and even fear of traumatic reactions, in healthcare settings can be a barrier to healthcare and interfere with how patients hear or remember information given by healthcare providers. Trauma is associated with poorer mental health, substance abuse, ART adherence and immunologic outcomes (LeGrand, et al., 2015).

Trauma-Informed Care

Healthcare providers' abilities to address their patients' experiences of trauma are central to their abilities to help patients live healthy lives. Trauma-informed care understands, recognizes, and responds to the effects of trauma. Trauma-informed care provides individuals with the dignity, respect, and compassion they need. It is developing a partnership with the patients, working on problems together, identifying strengths, building social support (including peer support), clear communication, emphasizing confidentiality and privacy, and access to necessary resources and treatment (LeGrand, et al., 2015; Hopper, Bassuk, & Oliver, 2010). Trauma-informed care at the minimum tries to do no further harm to the individual and avoids any healthcare-associated trauma. Trauma-informed care works to create an environment that is accessible and comfortable for everyone. This differs from trauma-specific services which are interventions that address the impact of trauma, with the goals of decreasing symptoms and facilitating recovery

I've seen a lot of doctors. Doctors don't talk to you in layman's terms. They talk over your head. When I ask them what's wrong with me, they don't really give me a good explanation of what's wrong. They always give me the ten letter word or they're talking about me to each other. When I try to intervene, they'd be like, "Don't worry about it Mr. _____. We're going to find out. Give us a couple more days and we'll let you know at the end of this week."

(Hopper, Bassuk, & Oliver, 2010).

The participants described trauma-informed care when they shared their ideal healthcare setting and how they wish to be treated by their healthcare providers: respect, kindness, clear communication, social support, access to resources, active listening, partnership with provider, and comfortable physical environments (waiting rooms and exam rooms). They emphasized that how they are provided care matters as much, or even more, than the clinical care provided.

Trauma in the lives of people living with HIV and those at high risk for HIV is gaining more attention. More research is needed to fully understand how trauma and HIV interact, but there is a solid evidence base for screening for trauma in both HIV care and HIV testing settings (LeGrand, et al., 2015; Whetten, Reif, Whetten, & Murphy-McMillan, 2008). Trauma affects decision-making and behavior, including HIV risk behaviors like substance use and sexual risks (Cavanaugh, Hansen, & Sullivan, 2009; Wyatt, et al., 2002). As stated previously, trauma also affects the body's immune response and individual's mental health, both of which play a role in viral suppression (Whetten, Reif, Whetten, & Murphy-McMillan, 2008).

Incorporating trauma-informed care practices into healthcare settings require a cultural shift within organizations and training for all staff, not just clinical staff. An emphasis on safety, both physical and emotional safety, is essential. Ways to emphasize safety include having clear boundaries and roles, predictable environments, collaborative decision making, privacy, confidentiality and mutual respect, and respect and understanding of cultural differences and diversity. Trauma-informed care is strength-based and future focused (Hopper,

Bassuk, & Oliver, 2010). Opportunities should be given to patients/clients to make choices. During examinations patients should be informed about what is going to happen, what is happening, and then reminded what happened. Some patients will benefit from having a trusted friend or family member in the room with them, to help with remembering information and as social support (Elliott, Bjelajac, Fallar, Markoff, & Reed, 2005).

Cultural Competence and Dignity

Cultural competency is more than knowing an individual's cultural practices and context. Cultural competency also includes demonstrating humility and mutual concern, and establishing individual rapport with a patient/client (Eiser & Ellis, 2007). Treating patients with dignity is central to their satisfaction with healthcare, adherence to treatment and receipt of preventive care (Eiser & Ellis, 2007; Beach, et al., 2005). Beach et al. (2005) found that patients reported higher levels of satisfaction with their care if they were treated with dignity and were involved in decision-making with their care provider. These associations were consistent across all racial/ethnic groups. For racial and ethnic minorities, being treated with dignity was significantly associated with adherence to treatment (Beach, et al., 2005).

Johnson et al. (2004) found that there are significant differences in how people of different racial and ethnic groups perceive bias and cultural competence. Lower levels of education, poorer health status, having more unanswered questions, and perceiving less participation in care were all independently associated with a respondent's perceptions that their doctors looked down on them and the way they lived their lives. Racial and ethnic

minorities are more likely to perceive bias and a lack of cultural competence in the health care system than Whites (Johnson, Saha, Arbelaez, Beach, & Cooper, 2004).

Training healthcare staff to be knowledgeable about the cultural contexts of their patients is essential for improving health outcomes and individuals engagement in care. All staff should be respectful and humble when communicating with patients. Communication style is incredibly important. Explanations should be given more than once and with as much assistance of diagrams and illustrations as possible. Use of medical terminology should be avoided (Eiser & Ellis, 2007).

Health disparities have many causes, but healthcare and other social service providers can help to mitigate those causes by how they treat and communicate with clients. Understanding the cultural and social contexts of patients' lives will only improve how healthcare is provided and the health outcomes of individuals. Minimally, respectful communication will foster dialogue and joint decision-making which will lead to greater patient understanding and participation in their health and healthcare.

HIV testing and HIV prevention

Studies of high-risk heterosexuals document that overall, people at-high risk for HIV are not getting tested as frequently as recommended (CDC, December 19, 2014; Nunn, et al., 2012; Raj & Bowleg, 2012; Nunn, et al., 2011; Jenness, et al., 2009). There are many reasons for this including low perceived risk of infection and persistent HIV stigma (Nunn, et al., 2011). People report being open to and accepting of routine HIV testing in clinical settings, however many of those most at-risk do not encounter testing in these settings because of a general

lack of engagement in primary care (Jenness, et al., 2009). Even individuals who have been diagnosed with a sexually transmitted infection are not commonly offered an HIV test (CDC, December 19, 2014). However, Nunn, Eng et al. (2011) found that primary motivations for testing for African Americans in a Philadelphia rapid testing program included testing during routine medical care and presenting with sexually transmitted infections and urinary tract infections. It appears that people are willing to be tested in these situations, even if HIV risk perception might be low.

Evidence is clear that routine HIV testing in all primary care settings and sexual health clinics is necessary in cities like Philadelphia. Routine testing negates the need for individuals to perceive HIV risk and then request a HIV test. Philadelphia has an opt-out testing process which makes it easier to test people for HIV in primary care settings, emergency departments and other clinical settings. Particular priority should be given to men and women who test positive for sexually-transmitted infections (STIs), given their obvious sexual risk. HIV testing is not routinely offered to people testing positive for STIs. In a national sample of women at high-risk for acquiring HIV through sexual contact, less than half of the women who had a diagnosis of a sexually transmitted infection in the previous 12 months had a HIV test in that same period, despite their elevated risk of acquiring HIV because of the STI (CDC, December 19, 2014).

Routine testing may not reach the most vulnerable people, due to the barriers previously discussed like a lack of primary care, low perceived risk, and lack of health insurance. Geographically-targeted and culturally-tailored interventions and messages to promote the

Spiritual death means a lot of people give up.... It gets to the point where everything around you has been negative for so long you just give up. You start thinking like that's the way to be. You start accepting the fact that this is how it is going to be for the rest of your life.... When you're out here in these streets, when you live in the streets day after day after day, like not really knowing where your next meal is coming from, not being able to wash.... At some point, man, you do that long enough, you will really think like, "this is it."

widespread uptake of Pre-exposure prophylaxis (PrEP), HIV testing and HIV treatment are needed in high prevalence areas. As recommended in Nunn, et al., (2015) local leaders need to be engaged to tailor and target these messages and resources are needed in these communities. Field work and outreach will be essential to getting the messages and services to those who need them most (Nunn, et al., 2015; Nunn, et al., 2014). For Black communities, messages need to be broad so all classes of individuals are reached instead of those "most at risk", to address the generalized epidemic among Philadelphia Black men and women (Raj & Bowleg, 2012).

Women, particularly African American women, have unique needs in HIV prevention and HIV care. Women's role as caregiver can be a barrier to accessing care. Stein et al., 2000 found that the odds that women put off care were 1.6 times that of men. Having a child in the household was also associated with putting off

care. Services that help caregivers access healthcare, either through childcare services or the adjustment of clinic hours are necessary.

Women may not always be able to negotiate condom use due to intimate partner violence or intimidation. Gender roles and the absence of available adult males due to mass incarceration and homicide are real factors in the social and sexual norms in African American urban communities (Bowleg, Teti, Massie, Malebranche, & Tschann, 2011; El-Bassel, Caldeira, Ruglass, & Gilbert, 2009). HIV prevention messaging and interventions should address these factors, in addition to advocating for condom use and PrEP access.

PDPH has prioritized HIV testing and linkage to care for several populations including incarcerated and recently released individuals and African American men and women. All PDPH funded medical providers are required to develop and implement routine HIV testing policies, utilizing fourth generation testing whenever possible. Fourth generation testing can detect acute HIV infections, which means identifying people earlier in their infection which decreases the chances of the person unknowingly transmitting HIV and also leads to better health outcomes for the individual, if they begin anti-retroviral therapies as soon as possible.

In routine and targeted community-based HIV testing there is an opportunity to educate and offer PrEP to men and women at high risk. PDPH is currently implementing programs to educate the community and healthcare providers about PrEP. The city health centers and other healthcare providers are currently providing PrEP to at-risk individuals and working on ways to increase access throughout Philadelphia. PrEP is a potentially game-

changing HIV prevention tool, particularly for heterosexual communities, considering the low perception of risk and the power dynamics of condom negotiation.

Recommendations

The following recommendations are based on the experiences and opinions of the focus group participants as well as the current literature and epidemiological data in Philadelphia. These recommendations seek to address health disparities and decrease HIV incidence and prevalence in Philadelphia.

Trauma-informed care should be the standard of care. Considering the pervasive experiences of trauma for men and women of low socio-economic status (childhood and adult), all healthcare settings should work towards a trauma-informed culture.

Sexual and reproductive health care must be trauma-informed. All women should be screened for current intimate partner violence, as well as childhood and past sexual and emotional abuse. Appropriate referrals should be made for mental health and social support services.

Honor and maintain a patient's dignity in all care settings. Patients who feel they are treated with dignity and are active participants in healthcare decision-making are more likely to adhere to treatment and trust their medical provider.

Holistic care that includes services for mental and physical health is essential for long term health and continued engagement in primary and HIV care. Social support should be integrated into all healthcare settings, whether through case management, navigations services or peer

support. Service providers should consider incorporation of childcare and respite services in services targeted to women, considering their caregiving responsibilities.

Continue and expand current efforts to make HIV testing routine in all primary care. Efforts should ensure routine screenings are happening in communities where HIV is most prevalent. Routine testing doesn't rely on patient disclosure or recognition of HIV risk behaviors and will increase the likelihood that individuals are diagnosed and linked to care in a timely matter.

Include information about PrEP during pre- and/or post- test HIV counseling services. Individuals who test HIV-negative (for whom PrEP is appropriate) should receive information about where and how to access PrEP and provided with relevant referrals.

Community-level campaigns to raise awareness about HIV risk and prevention in the Black and Latino communities are needed. The campaigns should be broadly marketed to all members of the Black and Latino communities, not just to individuals of a certain risk profile or class. Local community leaders should be the messengers of the campaign.

Provide adult health education in community settings to raise health literacy to decrease health disparities. Programs should include information about sexual health and HIV/STI prevention, hygiene, nutrition, sleep, and the importance of health screenings. Specific interventions should focus on the health needs of Black men.

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