Beyond Knowledge and Agency: HIV Risk for Women of Color in HIV-Dense Neighborhoods

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Abstract

The human immunodeficiency virus (HIV) poses a formidable risk to the health of women, who made up almost 20% of new HIV infections in 2014 in the U.S. (the most recent year for which data are available). Women represent 25% of those infected with HIV. Sixty-two percent of infected women are African American; Latina and White women each represent 17% of cases in women. The CDC reports that heterosexual transmission accounts for 87% of HIV cases in women. However, it is not clear why some women in HIV-dense neighborhoods become infected, and others do not.

Keywords

HIV; Women; Color; Sexual risk behaviour

Introduction

The human immunodeficiency virus (HIV) poses a formidable risk to the health of women, who made up almost 20% of new HIV infections in 2014 in the U.S. (the most recent year for which data are available) [1]. Women represent 25% of those infected with HIV. Sixty-two percent of infected women are African American; Latina and White women each represent 17% of cases in women [1]. The CDC reports that heterosexual transmission accounts for 87% of HIV cases in women [2]. However, it is not clear why some women in HIV-dense neighborhoods become infected, and others do not.

The literature suggests that there are multiple determinants of HIV infection in women, in addition to sexual risk behaviors. For example, relationship dynamics may affect HIV risk behaviors and underlying motivations to engage in risk reduction behaviors. To wit, women, particularly adolescents and young women are more likely not to use condoms with a regular or steady partner than with a casual partner [3,4]. Trust appeared to be the major issue. If women trust their regular partner, they often do not believe that they need to use condoms [5]. Studies that examined behaviors often trusting relationship may simply not believe or want to believe that their partner will get angry [7], another issue may be that women in communities face a greater risk of HIV infection with each new sexual act, than other women [1]. We use the term HIV-dense to describe a neighborhood which has a higher prevalence of HIV and AIDS morbidity and mortality, than is found nationally or in the rest of a city. Therefore, it is essential to understand and address underlying determinants of HIV infection.

It is likely that other determinants play a role in HIV disparities [8,9] including racial and other social factors [10,11]. For example, national data suggest that the sexual behaviors (eg. number of lifetime sexual partners) of White and Black women aged 15 – 44 are quite similar, yet the disparities in STI and HIV-rates between these two groups is striking [12]. However, because people tend to have sex with partners of the same race/ethnicity women from HIV-dense communities face a greater risk of HIV infection with each new sexual act, than other women [1]. We use the term HIV-dense to describe a neighborhood which has a higher prevalence of HIV and AIDS morbidity and mortality, than is found nationally or in the rest of a city. Therefore, it is essential to understand and address underlying determinants of HIV infection.

No studies could be found which assessed risk behaviors and other factors in uninfected women and compared them to recently infected women’s reports of their behaviors prior to diagnosis. This study was designed to illuminate why some women in an HIV-dense community become infected and others do not. Clearly, while many factors have a hypothesized association with HIV-transmission, there has been sparse research in the U.S. to elucidate which of these factors are most likely, in real world circumstances to result in actual HIV-transmission in women. This is the first study, to our knowledge, to examine HIV-positive and negative women living in HIV-dense neighborhoods.

Furthermore, context is needed to more thoroughly understand risk behaviors. For example, while professionals may assume that women do not use condoms because they are fearful that their partner will get angry [7], another issue may be that women in trusting relationship may simply not believe or want to believe that they need to use condoms [13]. Studies that examined behaviors often did not assess the motivations of those behaviors. The present study, with quantitative and qualitative data, allowed for a more nuanced assessment of this.

Methods

This study utilized quantitative and qualitative data. Women completed a questionnaire via ACASI and then participated in-depth interviews. The interviews allowed the women to provide insights that the researchers may not have asked about. IRB approval was obtained before the study began.

Recruitment of HIV-positive women

Ten HIV-infected women were recruited at clinics and other sites in urban neighborhoods in the Northeast which serve this population. The primary neighborhood where we recruited is an HIV-dense neighborhood [14]. Interested women responded to a posted flyer...
and contacted the research assistant by phone. They were screened for eligibility. If they were eligible and interested in participating, the RA and participant arranged a place and time to meet to conduct the study.

Eligibility criteria

So that the women had better recall of behaviors at the time of diagnosis or presumed infection, we only included those who were diagnosed with HIV within the last 36 months. Eligibility criteria included a diagnosis of HIV within the last 36 months, Black or Latina and ability to read and understand English. Women of all ages were recruited.

Training of research assistant

The research assistant was a woman of color, who had had experience interviewing women about sensitive issues. She was trained by the PI, so she understood the purpose of the study and methods.

Recruitment of HIV-negative women

As part of study participation and consent procedures, HIV-positive participants were informed that we would also like to include one or two of their female friends or relatives for the study, who are similar in age and of the same ethnicity and neighborhood. They were given a flyer about the study (including a contact number, and email address for the RA) to give to their friend or relative.

Due to the sensitive nature of HIV, we did not ask for a friend who is HIV-positive. However, the women in the HIV-negative group completed a brief screening survey, including the date of their last HIV test and the results, in order to determine their HIV status as accurately as possible. None of those women reported being HIV-positive. Only 8 HIV-negative women were referred to the study.

After providing informed consent, women completed a survey on a computer using Audio Computer-Assisted Self Interview (ACASI). ACASI has important advantages over written and verbally-administered questionnaires: 1) it increases recall reliability and reduces social desirability bias, thus providing better reports of risk [15-17]. 2) Participants can read the questions on the computer or listen to them through headphones, thus addressing literacy concerns in a way that causes no embarrassment [15,16]. Participants were given $ 25 for the survey and an additional $ 25 for the interview.

Instruments

The study employed a survey questionnaire which the PI has used in previous studies [18,19]. It has questions about demographic data, HIV-risk factors and behaviors. HIV-positive women reported on behaviors prior to their diagnosis. The survey was amended to include very detailed questions about sexual behaviors (vaginal, anal and oral), including condom use, rough sex, sex while high, and general characteristics of sexual partners (including age, whether he is HIV-positive, has sex with men and women, and has used injecting or other drugs). Questions about the woman’s health history included contraceptive use, pregnancy history, HPV diagnosis or abnormal Pap smear and date and history of sexually transmitted infections (STIs). In addition, questions were asked about substance use and history of incarceration (self and partners). These questions were asked in order to develop a more thorough understanding of an individual’s potential HIV exposure through heterosexual sex and injection drug use (IDU) [15].

Before use in the study, content validity of the revised questionnaire was established by sending the draft questionnaire to two experts in HIV transmission. They were asked to comment on the relevance of each item in the questionnaire, and suggest additional questions. A content validity index (CVI) was determined, and the questionnaire modified, until each item achieved a CVI of at least .8. Subsequently, the questionnaire was pilot-tested with five women from the target population, in order to ensure that it was comprehensible and there were no confusing questions. Respondents were debriefed by the PI so that any confusion was identified and clarified. The questionnaire was amended based on the respondents’ comments.

Data Collection and Analysis

Interview protocol

All respondents who participated in the ACASI survey were invited to participate in the interview. HIV-infected and uninfected women were interviewed, to gain a nuanced understanding of their life experiences, most especially their sexual relationships. The interviews for women who were both positive and negative for HIV began with the interviewer asking the participants whether they had any questions about the survey or if they wanted to comment on it. Nobody expressed a need to ask questions or say more. The interviewer then asked the HIV positive women about their life circumstances before they were diagnosed with HIV, while HIV-negative women were asked about current life circumstances. Since the positive women were recently diagnosed, the time frame for both groups was relatively similar. The open-ended questions were designed to obtain a description of their romantic partners and sexual relationships and to allow the researchers to gain more understanding of the meaning of the responses to the survey. More specifically, in both cases, the interviewer asked about behaviors related to sexual encounters, self-protection from sexually transmitted disease and what the interviewees would teach other women about how women should protect themselves from STIs. The interviews took place in a private room.

The interviews were transcribed verbatim and reviewed by the first author to ensure accuracy [20].

Results

Quantitative data analysis

Data were analyzed using chi-squared tests to seek differences between the two groups.

Based on the survey, unexpectedly we found very few differences between the two groups of women.

The two samples of women were similar demographically. Mean age was 31.3 for women who were positive for HIV and 29.8 for uninfected women. All participants were Black except for one woman who identified as Latina.

Chi squared analyses were performed to assess any difference between the two groups on quantitative variables including sexual behaviors, substance use, having sex while high, history of incarceration and history of sexually transmitted infections (STIs) including abnormal Pap smears and educational attainment. The 2 groups of women differed only on educational attainment.

Uninfected women were more likely to report “some college” or “college graduation” (p=.058), demonstrating a trend (Table 1).
We are having sex protected. I know for sure that’s how I roll now, unless it’s like something that I know is real…

Sarah states that she will protect herself when she is sexually active unless she knows the relationship she is in is “real”. But she previously thought she was in a safe relationship because she was in love so how will she know if the relationship is real and how can this protect her?

Tanya who is HIV positive shares a similar experience

I just felt that I could trust him more. I actually fell really in love with him. I felt well I am in love, so I can open up and trust him and everything. He is being honest. You know whole fact that we lived together. I never lived with any of my previous boyfriends. Most of them lived with family as well like me at the time. Him living on his own, I was like yay…. (then later in the interview) …He basically said he was not with anybody else. I was not with anybody else. I said okay, good. I felt we could be open and trust each other. Against my better judgments, we mostly did not use condoms.

Tanya interprets the act of living with a person as their commitment to protect one another from STIs and HIV. Yet, her comment “against my better judgment” suggests that she was conflicted about not using condoms.

Rachel who is HIV negative expresses love for her partner. She is not using condoms because she knows that he is the only person who she is having sex with so she feels she is protected. But is she really protected?

He is 72 years old. He retired and he will give me anything I want. He will give me anything so, yes, I love him. That is all I can say, I love him. Yes, I love him.

We used to practice safe sex. Oh yes and from then on [after the first time they had sex] we went without rubbers, baby. Yes.

Yet she adds later in the interview that…

Sometimes he comes in the house and he is smelling like perfume and all that shit. So, if I catch anything I know where I got it from.

The interviewer asks if it is worth [the risk] and Rachel says “Yes.”

And Natalie, who is uninfected, says that when she had unprotected sex with one of her partners it was because it was different from when she had previously had sex with casual partners.

Like I could honestly say that with this guy’s like we’ve—like we made love. Like we didn’t just have sex so—it’s a—it was a different type of feeling than, you know, having casual sex with someone that you know, [we had an] emotional connection.
Knowledge does not protect from the risk or diagnosis of HIV

Although interventions to protect against the spread of HIV often involve educating people about how to protect themselves [19,23], the issue of love and trust suggests that education and the knowledge it bestows may not be enough to override the intense desire that most people have for intimacy and love. Our data suggest that both HIV positive and HIV negative women had knowledge about how to protect themselves from HIV and STIs and yet, for the most part they behaved similarly by not using condoms to consistently protect themselves from STIs. Natalie, who was HIV negative was in an on again off again relationship with a man with whom she had unprotected sex. During her interview she stated that she felt badly for not protecting herself and for not using condoms even though she was aware of the risks. Her concerns were reinforced when she was diagnosed with trichomoniasis. She and her partner were then treated and also got tested for HIV and both were negative. Natalie then continued to engage in unprotected sex with her partner despite the fact that she was not sure he was only having sex with her.

Athena was HIV positive, and was well aware of how to protect herself from HIV. When asked how she became HIV positive she responded, “Not using a condom…that was my mistake.” Yet, she learned in high school how to protect herself and strongly professed the need to do so.

They go back to high school basics: condoms, knowing STIs, and HIV because of it is a STI, and knowing your information on your partner. That is really important, because I did not know my ex had it, and he did not tell me until after I found out I had it.

Reggie who was HIV negative describes her relationship with her partner with respect to his sexual activity outside their relationship and their inconsistent use of condoms. Yet, her conversation suggests she is well versed about how to protect herself from STIs.

The first time we had intercourse, I was 21…We did have conversations about getting tested because he had other sexual partners at that time... He was willing but... The first time we had [sex], it was unprotected…back then I do not know—if he was having unprotected sex with someone else and then having unprotected sex with me, who knows. The last time I got checked for STIs and everything, I was clear, I was good, but that was in June 2013, something like that. It was last year. I had to get a physical for a new job. The questions made me think about that. I think I have to talk to him about that and see what is going on, what he has done.

Future goals are not always protective

Despite the fact that several women expressed a future orientation, with attainable goals such as higher education, which should have made them less likely to take risks [24,25] we found risk taking among some of these women.

For example, Reggie reported plans to pursue a bright future that included higher education. Despite this she still engaged in risky behaviors which seem incongruous with her plans, which would seem to reinforce self-protective behaviors but do not.

Well, I am going go back to school in January so that is good. I am working. This job I have been at is almost a year. I just got a new place, an apartment of my own, which I am really excited about.

Another case featured Denise who was HIV positive and had high hopes for her future. Denise had college experience. She described herself as assuming that she thought she would be safe when in college despite her lack of attention to protecting herself from STIs.

They tell you about the things that go around on campus but they do not tell you, they do not get into detail about what happens, so people just brush it off and think, oh, that is not going to happen to me. I was one of those who thought I was invincible and nothing was going to happen to me.

Denise had the motivation and capacity to get into college and pursue an education, which would suggest an increased incentive to protect herself. Yet, despite this and her knowledge about HIV prevention she failed to use condoms and was HIV positive.

The mismatch of assertions with behaviors

One theme that was unique to a few of the women who were HIV negative and not consistently protecting themselves from STIs and HIV was their assertions about how women should protect themselves. Yet, despite this, they did not follow through and only used condoms inconsistently even when they knew that their partners were sexually active outside their relationship. For example, Rose had a two year-old and a relationship with her partner. She reports that she was trying to become pregnant with the same partner and she alludes to the fact that they were both having sex with others.

When I got pregnant with my son… we were going through like a rough patch, he thought I was cheating and I thought he was cheating. It was that back and forth situation. I wasn’t like emotionally there with him. I just wanted to be physical. You knock me up, we’re going to do it.

The interviewer then asked Rose if she used protection when she was pregnant based on her report that she and her partner were having sex with other people and her response was.

When I was pregnant, no. I was already knocked up, what’s the point of using condoms?

Yet, during the interview she was adamant about how she protects herself from STIs and how not doing so was like playing “Russian Roulette.”

See, my thing when I get together with somebody, we going to the doctor together. We going to find out together. Ain’t no I’ll go to the doctor, bring you back a paper. No, we going in together so we can find out. Go handle your business, call me in the room when they giving you your results. I’m going to tell you to come in the room, look I’m clean. I need to know if you clean. I think more women need to start doing the same thing. Come on, you’re going to be my partner? We’ve got to go to the doctor together to see what you got or what I—to find out. With that, I think you’re playing Russian Roulette with your life… You’re putting your life in somebody else’s hands. You can’t do that.

Rose is assertive and clear about how when beginning a relationship she protects herself from STIs by visiting a clinic with her partner and sitting in on the final consultation when her partner’s status is provided. But then, once she was in a relationship, even when she assumed her partner was having sex with others, she no longer protected herself. Thus, she was adamant about protecting herself before getting into a relationship and then she took great risks. Similar to the other HIV negative women, they remained HIV negative as far as they knew despite their behavior.
Discussion

This study sheds light on a common finding in previous studies, i.e. that women are less likely to use condoms when they trust their partner. Trust as a barrier to condom use [4,19] has been documented before. For some women love means trust, but for others it does not. Love trumped trust for some women. These women expressed love their partner, even when they knew they couldn’t trust him. For example, Rachel comments that her partner sometimes comes home smelling of perfume. Yet, she loves him and still does not use condoms.

Some women did equate love with trust. For example Tanya said, “I felt well I am in love, so I can open up and trust him and everything. Yet women such as Rachel knew their partner was not monogamous, but love alone was enough for them to forgo condoms.

Therefore, women’s desire for love supersedes what health care professionals typically regard as sensible, risk-reduction behavior. Rather than having no partner, women may prefer to be with a man who presents risk, such as having multiple partners. They may believe that love will keep them safe. Or, as one participant said, it is worth the risk to have a relationship with a man, even one who is not monogamous.

Unlike other studies, in this sample, we did not find that fear or power imbalances affected condom use. The women felt that they had the agency to decide when to use condoms.

In addition, structural factors, such as racial inequities which increase HIV-risk for epidemiological reasons, may augment risk in this population. For example, there are more Black women in many communities than available Black men. This is due, in part, to the high incarceration rate for Black men [26]. Furthermore, residential segregation by race is also a factor in poorer health status in general for Blacks [27,28]. Thus, not only did the women in this sample seek love, but they are engaging in sex with a limited pool of men who place them at higher risk for exposure to HIV by virtue of these factors, including for some, incarceration [29] and injection drug use – both of which are more prevalent among Black men [30]. As mentioned, the CDC says that because people tend to have sex with partners of the same race/ethnicity women from HIV-dense communities face a greater risk of HIV infection with each new sexual act, than other women [1]. This may help explain why the rate of HIV/AIDS among Black women is disproportionately high.

In this study of comparable groups of recently infected and uninfected women, the only quantitative variable which differed between the two groups was that uninfected women were more likely to report some college education or college graduation, which showed a trend toward significance at the .058 level, even in this small sample. It is not clear why having some college education is associated with a lower risk of HIV infection between those with less than a high school education, high school graduates and those with more than a high school education [31]. It is not clear, however, what factors associated with a higher level of education in our sample may have been protective, or vice versa. Similarly, a large study of young African-American women found that having a college degree or higher was significantly associated with lower vulnerability to STIs and HIV, controlling for risk indicators including age and receipt of public assistance [11]. In this study HIV-negative women were more likely to report some college education. The authors hypothesized that perhaps attending college is associated with a lower risk sexual network, or personal characteristics such as future orientation. However, their study was not designed to explain the association.

There was one woman in the present sample who thought that being in a college environment made her safe. While, clearly, on the whole, higher education may be protective, that assumption may also be a two-edged sword, with some women willing to take risks because they are in a “safe” environment. This dichotomy merits further study.

It is possible that an HIV diagnosis during adolescence or young adulthood might interfere with a woman’s plans to go to college. However, in the current study, the mean age of the HIV-infected women was 31, and they were diagnosed within the last 36 months, so it is unlikely that the diagnosis kept them from pursuing their education. Furthermore, it is not clear whether there is something different about women who choose to or are able to go to college. However, these data suggest that this was not the case in our sample.

This paper presents data which suggest a new paradigm with which to view Black women’s risk behaviors. Research typically has examined women’s risk-related behaviors based on a dominant paradigm that suggests that their behavior should be motivated by staying safe, and engaging in behaviors that keep them safe [19,23,33]. However, that paradigm may not be appropriate or sufficient for the sample in this study, or perhaps for other groups of women. The interpretation of the present data proposes a different interpretation of the behaviors of women who are at risk for HIV by virtue of living in communities where HIV is prevalent, that the need for love is paramount and supersedes the need to protect their health.

In addition, the literature has long shown that women are more likely to protect themselves with a casual partner than with a regular or long-term partner [3,4]. These data add understanding to this finding. A main issue appears to be the depth of feeling a woman has for her regular partner; while she is not invested in her casual partner. Therefore, given that these women understand the risks, they are not willing to risk their health for a man who is not important to them, but do risk their health to retain a loved partner.

Like other studies [34], these data also suggest that women can be knowledgeable about how to protect themselves from HIV and STI’s, while not actually engaging in risk reduction. The desire to bond with a sexual partner which promotes intimacy, may override a rational approach to safety based on knowledge and refusal skills. Therefore, the focus on educating women about condom use may not be as effective as broaching the concept of how trust and love and can put women at risk. Yet, the need for intimacy is based on trust and love and is a foundation upon which healthy relationships are based. This presents a conflict that may need to be addressed directly. Clearly, the issue of infection was on the participants’ minds – it is not as if they did not think they were at risk – but the love factor superseded it.

This has implications for HIV-prevention interventions. Interventionists must adopt a paradigm which addresses these factors to undergird prevention programs. Although staying safe might be the health provider’s primary goal, it may not resonate in the same way with the women in the target audience. Prevention programs must start with the understanding that the desire for love and trust, which
are normal human desires, are primary, and the use of condoms may run counter to that desire. This may be an important teaching point for women. More research is needed with women, to understand how we might address these issues in prevention programs. The issue of trust has been in the literature for 20 years [4], yet despite multiple educational programs over the years, it remains a potent barrier to condom use.

Limitations

Clearly the quantitative findings are limited by very small sample size. While we cannot draw conclusions from most results, it is notable that even with this small sample, college education showed a trend toward significance, which is consistent with other studies [11]. Furthermore, although HIV-positive women were asked to answer the questions as they would have prior to their diagnosis, we do not know how long before diagnosis they were infected. In addition, it can be difficult to remember, which is why we only recruited women who were recruited within the last 36 months.

The qualitative limitations include the fact that the interviewees were obtained based on a convenience sample, rather than a purposive sample. This was necessary because of the sensitivity of the phenomenon of the study and the difficulty of accessing recently diagnosed participants. All the interviews were analyzed at the conclusion of the data.

Moreover, we do not know whether or to what extent taking the survey first may have biased the women’s responses to the interview. However, this technique has been used successfully previously and produced qualitative results which helped to explain the quantitative results [18].

Implications

This study suggests several avenues of research to further refine HIV-prevention education for women. The participants’ words should inform HIV-prevention efforts. When asked what they would tell women about HIV-prevention the women recited exactly what an educator would say, that women should use condoms all the time because it is impossible to tell whether a man is HIV-infected. And yet, their behaviors belie this advice. Their knowledge about HIV-transmission does not dictate their behavior; they appear to follow their hearts. If women are in love they are less likely to use condoms. Some women express uncertainty that they can trust their partners, but they still follow their heart. For example, one infected woman said: “I felt we could be open and trust each other. Against my better judgments, we mostly did not use condoms.” More research is needed to explore this ambivalence.

Therefore risk-reduction interventions should address relationship issues. In addition to providing self-efficacy and knowledge as is typically done in HIV-prevention programming [35], it may be important to help women think about their own relationships and decisions about when to use condoms. Indeed, the women in our sample demonstrated self-efficacy in protecting their desired relationships. What is needed is an understanding of how women can balance the need to protect themselves from HIV (the health care provider’s primary objective) and protecting their relationship (which may be the woman’s primary objective). Helping women think through this issue, providing them with an understanding that women more often become infected from a loved, steady partner than a casual partner [4] may help women make decisions that are more likely to reduce their risk. Qualitative studies with Black-at-risk women are needed in order to understand how to address the conflict between love and condom use to improve harm reduction while respecting women’s desire to love and trust their partner.

Furthermore, the need to help women develop self-efficacy implies that they do not have agency or power to be able to request that their partner use a condom, and to refuse sex if he does not. However, the stories related by both groups of women in this study suggest that most had agency, and made decisions about when to use it i.e. when they wanted and when they did not want to use a condom.

These findings also suggest that we should study what there is about higher education – either educational or social – that may be protective, including a qualitative study exploring educational issues in infected and uninfected women. Similarly, health education interventions may need to focus more on those with less education.

Another possibility is that the HIV-negative women made better choices about the men with whom they are involved. It is also possible that women who spend time at college (assuming some went away to college – though we did not ask about that), were away from their HIV-dense neighborhoods at a critical time, i.e. during late adolescence and young adulthood, which is a time when young people tend to have multiple partners, and also an age when HIV-transmission tends to occur most frequently [36]. This may also have been protective.

Conclusions

The behaviors and experiences of the infected and uninfected women in this sample, all of whom come from HIV-dense neighborhoods in the Northeast were similar and suggest additional nuance in approaching HIV-prevention for women. The women seem to understand HIV-transmission and know that they are at risk, but their desire for loving relationships is a barrier to them actually taking steps to reduce their risk. This study can serve as a starting point for working with the women to develop more finely tuned HIV-prevention programming, which will resonate with them.

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