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Women's decision-making about self-protection during sexual activity in the deep south of the USA: a grounded theory study

Deborah Konkle-Parker^a, Katherine Fouquier^b, Kaitlin Portz^c, Linnie Wheeless^c, Trisha Arnold^c, Courtney Harris^c, and Janet Turan^d

^aDepartment of Medicine/Infectious Diseases, University of MS Medical Center, Jackson, MS, USA

^bSchool of Nursing, Jackson State University, Jackson, MS, USA

^cDepartment of Psychology, Jackson State University, Jackson, MS, USA

^dDepartment of Health Care Organization and Policy, University of Alabama, Birmingham, AL, USA

Abstract

Many women continue to become infected with HIV, particularly in the Southeastern USA, despite widespread knowledge about methods to prevent its sexual transmission. This grounded theory investigation examined the decision-making process women use to guide their use or non-use of self-protective measures when engaging in sexual activity. Participants included women in the Mississippi cohort of the Women's Interagency HIV Study who were infected with or at high risk for HIV. Theoretical sampling was used to recruit a sample of 20 primarily African American women aged between 26 and 56 years, living in rural and urban areas. Data were analysed using constant comparative method to generate a theory of the process that guided women's self-protective decisions. Three key themes were identified: (1) sexual silence, an overall context of silence around sexuality in their communities and relationships; (2) the importance of relationships with male partners, including concepts of 'love and trust', 'filling the void' and 'don't rock the boat'; and (3) perceptions of risk, including 'it never crossed my mind', 'it couldn't happen to me' and 'assumptions about HIV'. These themes impacted on women's understandings of HIV-related risk, making it difficult to put self-protection above other interests and diminishing their motivation to protect themselves.

Keywords

HIV prevention; decision-making; African American women; self-protection

CONTACT Deborah Konkle-Parker, dkparker@umc.edu.

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Introduction

Although numerous efforts and significant resources have aimed to enhance the prevention and treatment of HIV in the USA over the past 20 years, the epidemic continues to have impact, with 218,254 individuals acquiring the virus between 2010 and 2014 (Centers for Disease Control and Prevention 2015a). Racial disparities are clearly present, given that 67% of all women diagnosed with HIV are African American. In addition, the majority of newly diagnosed HIV cases are among residents of the Southern USA (Centers for Disease Control and Prevention 2015a). Specifically, Mississippi ranks ninth in the country in rates of newly acquired infections, and Jackson, the state capital, ranks eighth among US cities in overall prevalence of HIV and fourth in the rate of new infections (Centers for Disease Control and Prevention 2015b). In the Jackson metropolitan area, African American women are 12.6 times more likely to be newly diagnosed with HIV than their Caucasian counterparts, and 97 out of the 115 women diagnosed with HIV in Mississippi in 2013 were African American (<http://aidsvu.org> (2016). These alarming figures reflect the urgent need for further research to understand and halt the perpetuation of this epidemic.

Research related to HIV acquisition among women, particularly minority women living in Southern states, has primarily focused on gaining an understanding of the individual and sociocultural factors that influence the practice of risky sexual behaviours (Mallory 2008; Mullinax et al. 2016; Nunn et al. 2012; Paranjape et al. 2006; Smith 2015; Teitelman et al. 2015; Villar-Loubet et al. 2016). Trust, the imbalance of power and an unequal gender ratio have been found to be important factors that influenced women's use of condoms when engaging in risky sexual activity, especially in the case of long-term relationships. (Bontempi, Eng, and Crouse 2008; Dauria et al. 2015; Ferguson et al. 2006; Jenkins Hall and Tanner 2016; Mallory, Harris, and Stampely 2009; Mullinax et al. 2016; Smith 2015).

Several studies have investigated the motivations for sexual activity among African American women, particularly when engaging in concurrent sexual relationships (Deardorff et al. 2013; Ludema et al. 2015). These studies found that, while participants agreed that condom use was important when engaging in risky sexual activities (for money or material things), they were not motivated to consistently use condoms when engaging in casual sexual relationships with a 'non-main' partner, or indeed, to ever use condoms. Social determinants of health, such as marital status, education, food insecurity, illicit drug use, intimate partner violence and sexual abuse contributed to concurrency.

Few studies, however, have investigated the factors that influenced women's decisions to either use or forgo the use of self-protection during sexual activities, especially in the Deep South of the USA (while there are some variations in the definition, this generally includes the states of Georgia, Alabama, South Carolina, Mississippi and Louisiana). The current study sought to explore how women living in Mississippi came to decide to protect or not protect themselves when engaging in sexual behaviours. While this study was not limited to African American women, the sample of women reflected the HIV epidemic in the state, and the vast majority of those who participated were African American.

Methods

Design

The study adopted a grounded theory approach (Glaser and Strauss 1967). This utilises an inductive process to analyse data without attempting to fit it into any one existing theory (Corbin and Strauss 2008). Grounded theory therefore strives to construct a theory that is 'grounded in the data' based upon the collected, often qualitative, data. To create the most effective HIV prevention programmes to limit transmission among women, researchers must elucidate the specific processes involved in a woman's lack of self-protection against HIV. Conducting in-depth qualitative interviews is an appropriate method for exploring women's self-protective decision-making processes.

Participants

Participants in this study were purposively selected from participants in the Women's Interagency HIV Study (WIHS) Jackson, Mississippi cohort. The WIHS is a multi-agency, longitudinal study funded by the US National Institutes of Health to examine the impact of HIV in women (Barkan et al. 1998).

The initial enrolment for the WIHS included HIV-positive and HIV-negative women from six US sites –Bronx (New York City); Brooklyn (New York City); Chicago, IL; Los Angeles, CA; San Francisco, CA; and Washington DC. Four new cohort sites joined in 2013 to examine the progression of HIV among women in the Southern region of the USA – Atlanta, GA; Chapel Hill, NC; Miami, FL; and a combined site of Birmingham, AL and Jackson, MS. Women in this cohort study participated in a study visit at their WIHS site every six months.

Eligible participants from the Jackson WIHS cohort were selected for this study from among those who were either (1) infected with HIV within the past 10 years (in order to facilitate recall) or were (2) HIV-uninfected. A theoretical sample was enrolled to achieve the inclusion of women in important sub-groups in terms of age, race, rural versus urban residence and diagnosis date. This process occurred in waves to address gaps in the sample identified in data analysis sessions, evolving as analysis occurred to suggest additional factors that might be of importance. Women who fitted the eligibility criteria with the desired characteristics were approached throughout the study period during their routine WIHS research visits and asked if they would be interested in learning about a sub-study in which they could participate. Participants had to be willing and able to be interviewed about their own sexual behaviours and use of protection and be able to speak at some depth about those experiences.

Twenty women agreed to participate from September 2014 to January 2015, and individual interviews were conducted with 14 HIV-positive and 6 HIV-negative women. Interviews were mostly conducted at the WIHS site, or at their homes. Of the sample, 75% resided in the city of Jackson, Mississippi, and 25% resided in more rural areas in surrounding counties. The sample consisted of African American ($n = 18$; 90%) and Caucasian ($n = 2$; 10%) women with a mean age of 39.1, ranging from 26 to 56 years. The median income category was US\$12,000–18,000 per year, and the median education category was having

completed some college, but not graduated. The mean length of time since HIV-diagnosis was 4.8 years, HIV-positive women who had been diagnosed less than 10 years ago were asked to think back to the time prior to their diagnosis and HIV-negative women were asked to consider their current or past decision-making practices. Both HIV-positive and HIV-negative women were enrolled to confirm that the emerging theory would describe decision-making regardless of the outcome of the decision-making regarding acquisition of HIV.

Procedure

Six female graduate psychology students from the Jackson, Mississippi, area were trained in qualitative interviewing and grounded theory by an expert in these methods (JT), followed by a series of role plays and practice interviews to refine their skills, with feedback from experienced researchers on the team (DKP and KF). A semi-structured interview guide was developed by the study team (DKP, KF, JT). Interviewers were instructed to elicit participants' thoughts related to self-protection measures that were specific to the participant's HIV status. The University of Mississippi Medical Center's Institutional Review Board reviewed and approved this study. Each participant received a \$30 gift card for the interview and additional gift cards for transportation.

Following each interview, interviewers composed a series of field notes that described observations of the participant and their impressions of the salient themes that arose during the in-depth interview. The field notes, along with documentation of data analysis and concept development, formed the project audit trail (Steubert and Carpenter 2010). Other measures for quality control included frequent team meetings among the data collection team to discuss the interviews, as well as review of transcripts and feedback from the senior research team members.

Data analysis

Audio recordings were transcribed verbatim, checked for accuracy against the recordings and de-identified by the interviewers. The first transcribed interviews, along with the corresponding field notes recorded on a standard form, were immediately sent to each member of the research team. The first step in the process was a line-by-line analysis of all of the transcribed interviews, identifying or coding key concepts and segments. Broad codes were initially assigned to blocks of text concerning specific issues related to self-protection from HIV transmission (Sbaraini et al. 2011). These initial codes were then collapsed into core categories and supporting subcategories. The simultaneous process of data collection, coding and analysis, utilising a system of constant comparison, ensured that the interviewers were gathering rich data to describe the process women applied in their decisions to either use or to not use self-protective measures when engaging in sexual behaviours. This process also allowed the researchers to determine data saturation when it became apparent that no new information was being shared. The research team, which consisted of the interviewers, the principal investigator and two qualitative researchers, met monthly to identify substantive codes, identify processes within the data, assign or categorise data using the constant comparative methodology, describe the essential categories that emerged from the data, and make sampling decisions to clarify and further elucidate the emerging theory (Steubert and Carpenter 2010). Major categories emerged and, through the iterative process

of diagramming, re-reading the text and returning to the literature, subcategories that supported the major categories were identified. To ensure inter-rater reliability, the first two authors reviewed all of the data for consistency, reviewed discrepancies and identified selections of the text that exemplified themes that emerged from the data.

Findings

Analysis of the data revealed the existence of an overarching framework, Sexual Silence, which described how the pervasive silence and lack of communication about sex and sex education impacts on women (and men) at both a societal and individual level. Within that framework, two categories and six sub-categories emerged: (1) Importance of Relationships with Male Partners described how the centrality of a relationship with a male partner took precedence in decision-making, and (2) Perceptions of Risk described assumptions and misconceptions about HIV transmission and HIV prevention, which put women at risk when engaging in high-risk sexual relationships. The first category consisted of three sub-categories: Filling the Void; Don't Rock the Boat; and Concept of Love and Trust. The second category also had three sub-categories: It Never Crossed My Mind; It Couldn't Happen to Me; and Assumptions about HIV. The theoretical model we developed, describing the process used by women to determine their use of self-protection (Figure 1), illustrates how the Importance of Relationships far outweighs the Perception of Risk, surrounded by an environment of Sexual Silence.

Sexual silence

As the two categories, Importance of Relationships and Perception of Risk emerged, it became apparent that they were embedded in the overarching background of Sexual Silence at the intimate partner level, as well as at the societal level. At the partner level, Sexual Silence discouraged frank discussion about risk within couples; at a societal level, it also discouraged education about sex within families and communities, as well as in schools. The category Sexual Silence is best illustrated in a story told by Lakisha (pseudonym), recounted after reflecting on her own transmission, which was probably in her late-20s, when involved in drugs and not thinking about HIV when having unprotected sex:

I didn't take time to sit down and think about that I was risking my life out here using drugs, having sex with men without protecting myself or them protecting themselves. ... Because Black people, we were always raised whatever is going on in this house, it stay in this house, you know. So it, it's, it's so many families that have loved ones that's been affected by the disease, but they weren't allowed to speak about it. And so that's why I think that so many Black, young women would, you know, put their lives at risk because it wasn't talked about a whole lot in the homes. It was hid in the homes with families that were diagnosed, you know?

(Lakisha, age 45, African American, HIV-positive,
diagnosed 5 years ago)

Conversely, an HIV-negative participant shared that she did talk with her partners about STDs and using condoms prior to having sex, although it was uncomfortable:

I try not to bring it up a lot, but I have, you know, brought it up to the partners that I've been with It's an uncomfortable subject, but it's better, you know, to talk about it than not to talk about it It's an important thing when you've been, become intimate with somebody, because I don't ... neither one of us need any kind of diseases, you know? So I feel like you should be open and honest with somebody, and that's something you should discuss and talk about, you know, before anything get too far, you know, the intimacy part.

(Keona, age 33, African American, HIV-negative)

Importance of Relationships with Male Partners

Interviews with the 14 HIV-positive women revealed that all but one, who traded sex for money to support her drug dependency, were infected by a partner who they believed was in a committed monogamous relationship with them. Woven throughout the shared stories of these 14 women was the centrality of their need to be in a relationship with a man. From their stories, the Importance of Relationships with Male Partners emerged as the main category, supported by the three sub-categories: (1) Filling the Void, (2) Don't Rock the Boat, and (3) the Concept of Love and Trust.

Filling the Void—Women expressed a strong need to have a relationship with a man to fill a perceived void in their lives. They described this void as being caused by loneliness, poor self-esteem or from the need for comfort, companionship and love. Women described seeking the presence of a man to bolster self-esteem, and in some cases by the social desirability of being in relationship with a man. The need to fill a void appeared to have crowded out the sense these women might have had regarding the need to protect themselves from STIs:

I guess I just had that comfort of somebody, and you thinking that they're the right person for you but they not. And, you know, I guess ... all I was just thinking about just having that, that little comfort ... from that person If I was dealing with ... myself more ... and loving myself more, I don't ... really think this would all would've happened

(Alyssa, age 40, African American, HIV-positive,
diagnosed 2 years ago)

A contrary case illuminated how drug use could supersede the need for a relationship with a man. In this case, another way to fill the void was her drug use, which was funded by prostitution:

I very seldom used condoms. When you out in the streets and you asking people to use condoms, they either look at you funny or they don't wanna do it. The only reason for bringing up a condom is that they would pay me extra money if they don't have to use the condom At that time, it was all about me and my drug of choice.

(Gloria, age 44, African American, HIV-positive,
diagnosed 7 years ago)

While drug addiction and prostitution were uncommon stories from this population of women, in this one story, the need for drugs overcame the informant's clear understanding that she was at risk for acquiring and for transmitting STIs. Her perception of risk was great, but the weight she placed on the importance of her relationship with drugs was much greater.

Don't Rock the Boat—Women had a strong desire to preserve their relationships by not pressing men too much to use condoms or by asking them to get tested for HIV. Although the risk of getting HIV was not an ever-present fear in these women, they were strongly aware of the risk of getting other STIs. Yet, it was frequently heard from women that they used condoms 'when he wanted to' or 'when he had some with him'. Women described not asking partners to use condoms because they feared he would think she was carrying an STI. This was especially true in a long-standing relationship:

We were together about six years He probably wouldn't've have been comfortable with it [condoms]. He probably would've thought I was doing something.

(Kimberly, age 31, African American, HIV-positive,
diagnosed 6 years ago)

In stories about preserving the relationship, women were definitely aware of the risk of STIs and/or HIV, but in relationships the women described as 'significant' or 'long-term', condoms were often not used. In these situations, either her perception of risk was lowered since she felt that he could be trusted not to bring STIs home to her, or she was concerned about his reaction if she insisted:

There was sometimes I was so-called with my significant other and I didn't use protection ... I might've let them talk me into having unprotected sex ... I just left it alone and went on with it.

(Mary, age 31, African American, HIV-positive,
diagnosed 7 years ago)

Concept of Love and Trust—Several women in this study described how due to an unspoken commitment, they trusted their partners to not bring home STIs. In almost every case, HIV-positive women in this sample reported they had been infected by their main partner, who either knew that he had HIV and did not tell her, or who became HIV-positive during their relationship as the result of unprotected sex in concurrent relationships. Because of this, there was a strong sense of betrayal associated with their HIV diagnosis:

I mean I loved him. I was saying, 'You say you loved me. You say you this. You say that, and you'll never do nothing to hurt me, how could you do this?'

(Katina, age 44, African American, HIV-positive,
diagnosed 3 years ago)

Because I wanted to believe that, you know, he was the only one, you know, I was the only one that he was being with despite, you know, what people would tell me Yeah, I wanted to just really believe that. And I trusted him, and I shouldn't have.

(Kimberly, age 31, African American, HIV-positive,
diagnosed 6 years ago)

Over time, women described becoming more comfortable in the relationship and beginning to trust, which informed decisions to forgo the use of condoms. Although that initial length of time when condoms may have been used more consistently varied, once she ‘felt comfortable’ she didn’t continue to request condom usage. In some cases, the decision to forgo condom use was a sign of trust. In other accounts, it is unclear if forgoing condom use was related to a decreased perception of risk because (1) she thought the relationship was monogamous, (2) she thought he would use condoms if he was having sex with other men/women or (3) she simply became complacent and did not want to think about risk anymore:

And I think I let my guard down to, um, maybe prove a point to him that I did trust him, and [laughs] wow. Yeah, that was like, I’m putting my complete trust in you ... something you thought you would never get from me ... I thought that might strengthen our relationship/make us closer.

(Jean, age 41, African American, HIV-positive,
diagnosed 1 year ago)

Maybe just starting, you know, going out with the person and everything ... that might make you want to start using a condom, ‘cause you don’t know anything about I always ask people do they have HIV, and they say no then, you know ... you get kind – you get comfortable. I guess once you grow, have feelings for someone ... and you trust them ...

(Alexis, age 38, African American, HIV-negative)

The need to use condoms for protection was known to these women, but they perceived that once they were in a long-term relationship, there was a reduction of risk and a woman shouldn’t have to worry about ‘her man’ because she trusted him.

Perceptions of Risk

In describing their perceptions of HIV/STI risk, or lack thereof, it became apparent that for many women, their decisions were influenced by their lack of education about STIs, by stereotypes of the characteristics of both men and women that they associated with HIV risk factors, and by misinformation about HIV testing. Data analysis revealed overlapping patterns, which were encapsulated in three different sub-categories: (1) It Never Crossed my Mind; (2) It Couldn’t Happen to Me; and (3) Assumptions about HIV.

It Never Crossed My Mind—As the women in this study discussed their perceptions of risk, their stories revealed that they were aware of the importance of condom use to prevent pregnancy/STIs when engaging in casual sexual encounters. For these women, if pregnancy was not a concern due to their age or if they were in a long-term relationship, they did not perceive their sexual relationship as risky and therefore it never crossed their mind to use a condom:

... mama and daddy never really taught us ... they just told us to be very careful. If you do anything make sure you use protection ... from being pregnant.

(Margaret, age 55, Caucasian, HIV-positive, diagnosed 2 years ago)

Stories woven onto the background of silence surrounding sex appear to be generational. Not only did women talk about the lack of knowledge they received growing up, many women described their own difficulties talking about sex with their children. Most stories from these women about sexual knowledge centred on pregnancy prevention, and when their parents discussed getting an STI, the consequences were trivialised. This was best illustrated in the story of one participant who described being told that if you have sex, you could get a 'little viral thing that can be treated' (Margaret).

There were other accounts where women described not thinking about condom use because they were in a long-term relationship. In these stories, the women described being comfortable in their relationship and never considered that they were at risk:

I was always protected [when I had affairs]. [I didn't use condoms with my main guy] because that was ... that was my man ... I felt like, you know, I'm just having sex with [the people I was having affairs with], I felt like I was more obligated to have protected sex with them because 'I don't know where ya'll be at'. It look like [the men I had affairs with] were more better than [he was]. ... I would've took a better chance with them than with him.

(Katherine, age 26, African American, HIV-positive, diagnosed 5 years ago)

For those women who acknowledged that they had been taught to use condoms to prevent STIs, it is not clear whether they considered HIV an STI. Several participants acknowledged that they were uneducated about HIV and didn't realise the seriousness of the disease since other infections were so easily treated:

Um, well, in ... I was uneducated about AIDS, and I didn't know how serious it was, you know, I had an accident with a STD, so the STD was trichomoniasis, and I learned a lot about that ...

(Sarah, age 27, African American, HIV-negative)

In each of the stories of the HIV-positive participants, they describe that at some point they were tested for a STI, either because something just did not feel well or as part of a routine examination. Because these women did not perceive themselves at risk for STIs, condom use never crossed their minds, and when they received the diagnosis of HIV, they described their shock and devastation:

I have always been a person that went to the clinic to check myself out ... he was like, um, 'We tested your blood for syphilis and HIV.' And I'm like, 'This blank-blank done gave me syphilis', you know, I ain't thinking that it was gonna be as bad as what he was about to say, but he was like, 'You have HIV', and all – you know, after then it was like peanuts, from like Charlie Brown. It was like, 'Wonk, wonk, wonk, wonk, wonk', I didn't even wanna hear nothing else.

(Katherine, age 44, African American, HIV-positive, diagnosed 5 years ago)

It Couldn't Happen to Me—A significant number of participants told stories of personal experiences with family members infected with HIV, having repeated infections of Chlamydia/gonorrhoea, partner infidelity or unintended pregnancies, yet maintained that they did not use condoms because they thought becoming infected with HIV could not happen to them. This form of denial seemed to be a persistent factor in the decision-making process for women in this study:

My mom she died from AIDS ... I just didn't ... probably really just didn't think it could happen to me.

(Kimberly, age 31, African American, HIV-positive,
diagnosed 6 years ago)

Unlike the stories told by women where condom use never crossed their mind, another participant told this story:

... it was just carelessness. It did [cross my mind to use protection], but I was just careless at the time And it just was something ... spare [*sic*] of the moment. Spare [*sic*] of the moment things that turned into a lifetime of trouble Yes [I was aware of HIV at that time]. I just thought that, 'No, it could never happen to me'.

(Tonya, age 43, African American, HIV-positive,
diagnosed this year)

The following story from a participant who was HIV-negative and a nurse, further illustrates how this form of denial puts women at-risk for infection. While she and her husband, who is HIV-positive, are now vigilant in condom use, her story describes her past history of risky behaviours:

I almost never [used condoms], to be completely honest, almost never You don't even really think about it. 'This can't happen to me. This is something that happens to other people. I'm not worried about it'.

(Rosemary, age 39, Caucasian, HIV-negative)

On the other hand were stories, primarily from HIV-negative women, who were very aware that it could happen to them, either from a past history of an unexpected STI or a family member or friend who was diagnosed with HIV. These women tended to be vigilant about condom use due to their memory of that situation:

Before my friend found out, when I was younger, young and dumb, and I didn't know. And then once my friend told me, then I really, really learned about it and I was like, 'uhn-uhn. No. Uhn-uhn' ... I never thought that it would happen to anyone. I'm quite sure that there's more people that I know that are HIV-positive, but that kind of hit home, and I was like, 'well if it happened to her ...'. We were like inseparable, so I knew if it happened to her, it could happen to ... me ... [If it hadn't happened to my friend] I think it would've been real different. I think I probably would've had like a nonchalant attitude about it, like I wouldn't feel as strong as I do.

(Tracy, age 36, African American, HIV-negative)

Assumptions about HIV—A recurring theme embedded in the narratives of the women in this study, was about assumptions about HIV. As their stories unfolded, it became clear that perceptions of risk factors for HIV transmission were often tied to stereotypes and that having a negative blood test frequently served as a proxy for her partner's negative HIV status. Although several women admitted to engaging in sex with multiple partners, most of the women described their relationships as long term, though not always mutually monogamous.

This issue of assumptions was illustrated in the stories of women that were shocked to find out they were HIV-positive since 'HIV is for promiscuous women!' (Annie, age 30, African American, HIV-positive, diagnosed 2 years ago). Though they did not view themselves as promiscuous, many of them admitted to having suspicions that their partner was promiscuous, yet this assumption, based on a stereotype of female promiscuity, may have led to poor decisions regarding self-protection.

Other stereotypes these women described related to men who they felt were more likely to be HIV-infected. Men who were tall and thin, or who had lost weight, were suspected of being HIV-positive, along with men who had been incarcerated and men on the down low (heterosexual men who also have sex with men). While several women described walking away from a relationship with men who fell into these stereotypes, for those whose partner was on the down low, these women often had no idea until their HIV test was positive. For others, engaging in unprotected sex with men who did not fit these stereotypes proved to be unsafe:

I was concerned when I first met him, since he's like 6'8", 6'9", and he's real thin. And I did question the fact that, you know, I'm so used to us being thick from the soul food (laughs) ... and I did question that, but, um, to be honest I think I trusted in him ... ah, that he was honest enough to tell me, 'Yeah, I'm okay'. You know, I did put trust in him instead of going by my, like my doubts and say, 'Hey, go get tested first'.

(Jean, age 41, African American, HIV positive,
diagnosed 1 year ago)

Women also described their reliance on their own blood testing as a proxy for their partner's HIV status. Although some of the women insisted on partner testing and initially insisted on condom use, their desire for a relationship built on trust diminished their agency to negotiate for consistent self-protection. Many reasoned that if their blood tests were negative for STIs, and their partner told them that they were 'ok', then they could trust that they were not at risk for infection. This phenomenon was best described by a participant who entered into relationship and, although she had been tested, she could not get her partner to test. He repeatedly assured her that he was 'clean' and over time their condom use became inconsistent. About one month after she broke of the relationship, he called informing her that she needed to be tested:

And I put all my paperwork in there and showed it to him. So, he was like, 'I'm alright. I'm fine, there's nothing wrong with me' ... we'll use condoms, and sometimes we wouldn't But, I would tell him, 'We need to go to the doctor to

make sure you're all right', and he was like, 'Oh, I'm fine. I'm fine. I'm fine. I'm fine'. And then, you know, come to find out, humph, he wasn't.

(Markisha, age 43, African American, HIV-positive,
diagnosed 3 years ago)

Like other stories, Markisha regretted not being more insistent on testing and acknowledges that she could have insisted on condom use. Although she accepts blame for her diagnosis, she also feels a sense of dismay, stating:

I do get mad with myself because I feel like, you know, I let myself down never in a million years ... I'm not a street woman, not a woman that's ... that do drugs, none of that And I get in those moments, you know like, "Lord, why me? Why me, Lord? I don't do nothing to hurt nobody".

(Markisha)

As Markisha's story concluded, she shared that she is fearful of being alone now that she is HIV-positive.

Discussion

The goal of this study was to explore the decision-making processes that women use to determine their use of self-protection (i.e. condom use) during risky sexual activities and to develop a theory to explain these processes. We used in-depth interviews that focused on gleaning the details of women's perceptions of their own experiences and factors that influenced their decision-making when they were engaging in unprotected sex. Results revealed that the importance of relationships with male partners appeared to outweigh women's perceptions of risk, with both categories situated in a setting where they were not encouraged to discuss sex (Sexual Silence).

It was anticipated that an important aspect of these women's experiences that would influence their self-protection decisions would be their financial situation and lack of economic support (Nunn et al. 2012), yet, this was not discussed by any of the participants in this study. Instead, the emotional aspects of the relationship appeared to be more important to them. Many of the women who were HIV-infected described a willingness to make concessions in order to preserve their relationship with a male partner. The concept of trust, supported in prior studies (Deardorff et al. 2013; Mallory 2008; Paranjape et al. 2006; Smith 2015) emerged as an important factor in women's decisions to forgo the use of condoms when engaging in sexual behaviours. Trust was described as assuming their partner would not expose them to an STI, trusting their partner's assurance that he was not infected and forgoing condom use as a declaration of her trust within their relationship. Other emotions and emotional responses affecting the decision-making process included the protection intimacy offered from loneliness, the desire for companionship, bolstered self-esteem, a desire to nurture both her partner and children that may result from the relationship and longing to be loved.

The concept of concurrency emerged within the categories of the importance of relationship and assumptions about HIV. In their stories, women described being in a long-term

relationship with their ‘main man’, but went on to describe situations where their main man was involved with one or more other partners (male and/or female) or situations where she entered into sexual relationships with other men. Consistent with the literature (Mallory, Harris, and Stampley 2009; Nunn et al. 2012), women described the value placed on having a long-term monogamous relationship, but most felt they lacked power to negotiate monogamy with their ‘main man’. Within these stories women related their devastation at not only learning they were infected, but also they had trusted that even though he had other sex partners, he would care enough for her that he would take precautions to protect her from infections. There were stories where women described having partners outside of the relationship, ‘we was together for 19 years ... he had his friend ladies and I had my friend guys’ (Participant 0021) but these casual sexual encounters did not interfere with their commitment to their main relationship. The stories women told supported findings by Nunn et al. (2012) that concurrency is associated with having a male partner who is incarcerated, being single and living in poverty, yet we have little understanding of how these complex social, structural and behavioural factors intersect in concurrent partnerships. Additionally, current interventions aimed at reducing HIV transmission fail to address the complex intersection of how social determinants of health underscore women’s attitudes and practices when engaging in high-risk sexual behaviours.

As women told their stories, Sexual Silence emerged as an overarching theme in women’s self-protection decision-making process but was best illuminated within the category of Perception of Risk. In their stories, women described how their community’s reluctance to discuss sexual behaviour and to educate both men and women about self-protective measures left them defenceless in navigating and negotiating self-protective decisions. Although there were few differences between women’s decision-making based on age, in the stories of older women, condom use was only associated with pregnancy prevention, not with HIV or STI prevention. As these women described, they did not consider condom use because, at their age, pregnancy was no longer a concern. Additionally, their lack of education regarding STI transmission and sexual behaviour had a negative impact on decision-making. Studies on self-reported sexual behaviours by older African American men and women support differences in self-protection behaviours between both gender and generations (Foster, Clark, and Holstad 2012; Ward et al. 2011).

Limitations

Study limitations included the small sample of 20 women living only in the urban and rural areas around Jackson, Mississippi, although the in-depth nature of the data collection and analysis justifies a small number of participants. In addition, all of these women were part of the WIHS cohort, and thus the information cannot be generalised to all women living with or at risk of HIV. Women in the WIHS study were those willing to engage in a long-term cohort study, so those with very transient lives or those without housing or transportation assistance are under-represented.

It is also important to acknowledge that women who were diagnosed up to 10 years prior to these interviews may have not remembered their decision-making processes accurately and completely, and we discovered that pre-diagnosis and post-diagnosis memories became

entangled and needed to be teased apart, possibly with unreliable results. Thoughts about using protection in the present were verbalised perhaps more readily in the women with longer post-diagnosis periods, but there were few differences between women's pre-diagnosis memories based on their date of diagnosis.

Interviewers did not have the opportunity to re-interview participants who had been previously interviewed in order to seek more in-depth information about what they had been told in a previous interview. This may have resulted in incomplete information or a distorted understanding, but the one-time interviews were long and in-depth enough to provide rich understanding of the issues being explored.

Conclusion

The implications of these results for HIV prevention activities with women are complex. It is too simple to suggest that women's perception of risk should be higher, or that women need to put less importance on relationships with male partners at all cost. Shifting the balance does appear to be important, however, perhaps by developing interventions that empower women to understand their own importance, and by developing programmes to change the sexual silence that is ongoing in the community and schools, as well as in families and relationships. In addition, programmes with men to impact their willingness to talk about sex with their partners, to get tested and to decrease their own risk are suggested, particularly in the high prevalence area of Jackson, Mississippi, where the rate of HIV in African American men can rival the rates of some African countries.

Other possible interventions might include social marketing to make HIV/STI testing more acceptable in the community, especially to men, by viewing regular testing as a way of being a 'true man' and caring for the women who care for him (Frye et al. 2013). Additionally, giving women control over her own risk could include widespread efforts to expand the use of pre-exposure prophylaxis (PrEP) to decrease her HIV risk without requiring that men test. A caveat to this approach is that women's perception of risk and their sense of self-worth must be high enough to support their continued adherence to PrEP.

Future research

More widespread research is needed to better understand the concept of intimate relationships and risk behaviours, to include a greater understanding of trust, and concurrency. In addition, this should include a better understanding of the denial of risk within the context of sexual relationships and an exploration of power differentials within relationships. Importantly, programmatic and intervention research is needed to develop and evaluate interventions such as those listed above, as well as those to reduce power differentials within intimate relationships.

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Figure 1.
Self-Protection Model.