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# Low-Income Women and HIV Risk Reduction: Elaborations from Qualitative Research

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# **Abstract**

Focus groups were conducted with 45 young, single, low-income women regarding the human immunodeficiency virus (HIV). Risk in this sample was substantial as 53% had multiple sexual partners, and 55% reported a recent sexually transmitted disease. Qualitative analysis of transcribed focus groups identified six themes that emerged across groups: (a) misinformation about vertical transmission and treatment of HIV-related illnesses; (b) risk perception linked to emotive factors rather than objective data; (c) uncertainty regarding the risk-reducing value of monogamy; (d) fatalism linked with ambivalence about HIV-antibody testing and treatment; (e) recognition of the importance of discussing HIV-related topics with children, but concern that such discussion with other women might be inappropriate; and (f) inconsistent communication regarding HIV-transmission and prevention with partners, partly the result of concerns about violating trust in intimate relationships. These themes warrant attention in the development of HIV risk-reduction programs.

#### **Keywords**

HIV; AIDS; women; prevention; qualitative methods

Sequelae of HIV-disease are the second-leading cause of death for women aged 25 to 44 (Center for Disease Control and Prevention [CDC], 1995a). Minority women have been disproportionately affected with 1% of African-American women in their thirties being infected with HIV (Rosenberg, 1995). HIV is now well-established in low-income inner-city areas (Holmberg, 1996) among heterosexual populations (Ehrhardt, 1992), with the percentage of women infected through heterosexual contact increasing (CDC, 1995b). The most effective strategy for HIV risk-reduction remains behavior change. Therefore, developing and improving interventions tailored to populations at risk is critical to curb the spread of HIV.

Descriptive research with low-income women has revealed that sexual risk-taking is common and behaviors to prevent HIV-transmission are inconsistent (Sikkema et al., 1996). Knowledge regarding the antecedents of risk behavior, especially in low-income minority communities, is inadequate (Amaro, 1988). As a result, the Office on AIDS at the National Institute of Mental Health (Pequegnat et al., 1993) has urged increased attention to the context of sexual risk among

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traditionally underserved populations. These research leaders concurred that qualitative inquiry is an appropriate method but that it has been underutilized in HIV-related research.

Quantitative and qualitative data are needed to develop a comprehensive understanding of the context of sexual behavior. To tailor HIV risk reduction interventions, it will be essential to adapt existing measures, use improved methods for participant recruitment and retention, and assess the key determinants of HIV-related risk. Such goals will require elicitation research. Focus groups and other such qualitative methods can provide valuable information regarding the cultural, social, and interpersonal contexts of sexual behavior.

To meet these aims and prepare for an HIV risk-reduction intervention, we conducted focus groups with women at a community-based organization (CBO). We selected a CBO because (a) the staff were trusted by women living in the community, (a) the site was accessible to public transportation and not stigmatized in any way, and (c) such organizations tend to foster empowerment, enhance racial identity and cultural heritage awareness, and provide community-based and culturally-appropriate programs (Stevenson and White, 1994). CBOs are also settings where racial and ethnic minority individuals have traditionally receive health, social, educational, and recretional services.

Guided by conventional focus group methodology (e.g., Basch, 1987; O'Brien, 1993), we developed an outline for focus group discussion. To improve upon previous qualitative study, the outline was guided by psychological theory, namely, the Information-Motivation-Behavioral Skills (IMB) model for HIV risk-reduction (Fisher and Fisher, 1992). Fisher and Fisher propose that there are three requisites for risk reduction: <a href="mailto:information">information</a> (i.e., knowledge) regarding HIV transmission and prevention, <a href="mailto:motivation">motivation</a> for disease avoidance, and <a href="mailto:behavioral skills">behavioral skills</a> to enact risk-reduction. Although a qualitative approach typically does not emphasize a priori hypotheses, this conceptualization provided a heuristic framework to guide our inquiry. The focus groups provided an opportunity for the women to discuss and explore issues relevant to HIV risk reduction, and allowed our team to develop gender- and culturally-appropriate behavior change strategies.

# **Methods**

Forty-five women were recruited through a CBO that serves the poorest census tracts in our community. Participants were primarily young ( $\underline{M}$  Age = 26 yrs), non-white (64% African-American, 18% European-Americans, 14% mixed ethnicity, 4% not reported), single (85%), unemployed (71%), and poor (51% income < \$8,000). Most (91%) women had children (median = 2). Self-report indicated substantial HIV risk; 53% had multiple sexual partners, 55% reported a STD during the previous year, and condom use was inconsistent. Thirteen dollars were provided as incentive to participate, and to defray child care and transportation costs

Procedures followed guidelines from the Ethical Principles of Psychologists (American Psychological Association, 1992). Eight focus groups were co-facilitated by two female leaders. One facilitator was a doctorally-trained nurse of European descent with extensive experience working with inner city women regarding reproductive health; the other facilitator was a master's level social worker of African descent who was experienced with HIV-related health and social problems. They followed an outline that included descriptors, clarifying syntax, definitions (e.g., what does "safer sex" mean to you?); and many stimulus questions, for example: Why do some women practice safer sex behaviors and some don't? Do women talk to their partners about safer sex? What is that like? What makes it more difficult versus easier to talk to a partner? If you knew a friend or sister was putting herself at risk for HIV, what would you tell her she should do to protect herself? Is HIV seen as a problem in this

community? Are there other problems facing women in this community that are more important than HIV?

Sessions were audiotaped with the participants' permission. Audiotapes were transcribed and independently coded by 2 raters for major content domains. Statements were organized into major themes, and representative quotes facilitated conceptual description of the participant responses. Statements were used to describe the pattern of responses only if a theme was expressed by more than one participant, and in more than one group (O'Brien, 1993).

# **Findings**

Themes were coded during two iterations of qualitative analysis. First, themes were coded according to the three IMB constructs (information, motivation, and behavioral skills) that guided our inquiry. Second, other themes that emerged (interpersonal trust, fatalism) were identified.

#### Information

Participants demonstrated adequate general knowledge regarding HIV-transmission although a pattern of knowledge deficits was evident about HIV-transmission during casual contact, mother-child interactions, and blood product-transmission. For example, nearly half of all participants thought that HIV could be transmitted by coughing or sneezing. Women were unsure of the implication of a woman's HIV-serostatus on her unborn child: "... if you are pregnant and you had it, is it certain that your kid would get it?" Another participant asked: "... if she had, isn't there a possibility that her children do not have it?" More than half of the women thought that a person could get HIV by donating blood. One woman asked and several nodded in agreement: "Do you remember that dentist who passed AIDS on to the girl ... how did that happen? I didn't understand that ... how did the dentist pass it to the girl?"

Information regarding disease protection was evident. Forty-two of 45 women did not know that HIV can be inactivated by bleach, and approximately one-half did not recognize the difference between latex and lambskin (natural membrane) condoms. A third of women thought that showering after sex was an effective risk reduction strategy. Women also had poor knowledge of treatment options for HIV-disease. Most participants were unaware of the value of AZT treatment for infants during and after pregnancy.

#### **Motivation**

When asked individually about risk of infection, women indicated that they thought it unlikely that they would become infected in their lifetime. However, they rated the risk of other women living in their community as quite high, and the risk for men in their community to be even higher than that of women.

Attitudes toward condoms were generally positive. When asked if they thought that condoms were a hassle, messy, or embarrassing, most women stated that they did not find them to be so. Regarding social norms for condom use, the majority of women (67%) expressed the view that they would like to use condoms; however, one-third believed that other women and men in their community rarely used condoms. They felt that women would often like to use them, but that men were typically opposed.

Many women professed their intention to be safe; however, circumstances and relationships were identified where women perceived that safer sexual precautions were not needed. For example, temporary relationships where romantic attachments had developed were viewed as safe and inappropriate for protected sex:

"I'm in a relationship with my fiancee but we're not having sex ... because we can't ... he's incarcerated. But I'm in another relationship with someone until he comes home. I'm not being unfaithful [to my fiancee] because I'm not living with my sexual partner ... but we're not using condoms ..."

Women were divided whether monogamy was a safer alternative. The following exchange between two participants depicts this dilemma:

A: "Have one, having one partner and both of you being faithful. That's the only way to have safe sex."

B: "Both of you being tested?"

A: "No, both of you being faithful and just having one partner -- that's how I do it."

B: "...one partner, you just got that partner, but you don't know how safe he was back then."

Overall, the consensus was that monogamy is seen as a strategy to avoid infection; however, women recognized that that risks that remain due to possibility of partner infidelity.

#### Behavioral skills

Regarding sexuality-related communication skills, a difference emerged between talking about HIV as a from of education (as with one's children) versus talking about it in the context of interpersonal relationships. For example, women felt that it was improper and even insulting to talk to each other about sexual risk, condoms, and risk from sexual partners:

"... we don't even talk ... she may be faithful and we may know that she's faithful to him but we know that he is not faithful to her. Then there comes the question, am I my brother or sisters' keeper? As a friend you would like to tell them but ... they always chose their men over you anyway ... you know how men are -- manipulative -- they will just say "oh, you want to believe her, she lies anyway ... ."

Another woman offered:

"My friends don't talk about AIDS as it relates to us -- no discussion about AIDS and what their life is like ... because to me, my life is my life and their life is their's."

The contrast to the lack of communication among peers, many women professed that it was essential to talk to their children about HIV:

"... I have two teenagers. That's one reason why I came here [to the focus group] ... I'm their mother and their father. I say 'you better use some protection, you know, the condom'. One child is 19 and the other is 20 ... so I teach them ... I'm not going to be with them when they are having sex ... so I talk to them about it ... but it's hard."

A participant in another group stated plainly that HIV-related education should occur early in life:

"I don't want there to be any chance [of infection] when it comes to my children ... I teach them the same way. I gave them a short workshop on babies and birth control, and I also gave them a short workshop on sex education. I went out and got the pamphlets. My little girl is 8 and my son is 10. I teach my children about [AIDS, birth control, and] such things because they need to know."

Women were mixed regarding communication with partners. Some women expressed high confidence in their ability, and their strategy tended to be marked by directness and outright

refusal. For example, when asked if it easy to talk with men about condoms, one woman responded:

"To me it is. If they want to use [a condom], they either put it on or we just don't have sex."

Another woman expressed her stance as:

"I feel like this, if they don't want to use it, then I don't know, you just won't be doing nothing."

Other women reported that discussion with partners might actually go well:

A: "I have one friend that has been after me for a year and a half. I admire him because he asked me about my sexual partners and he wants to know if I have condoms. I keep a lot of condoms, a hundred of them, in my house because I have teenagers. But I admire him because he wants to know, he asks questions, and he lets me know, 'I hope you don't mind using a rubber.' But, he's an exception."

B: "Yes, because men don't usually come right out and say things like that."

However, other women found it difficult to broach the topic of condom use and safer sex:

"I wonder how I would get my man to wear a condom. With my man, I would have problems talking about it. He would have a problem with using condoms. But, it was also my problem, too. What I mean is: He didn't tie me down to the bed with ropes or anything ... I tried condoms in the beginning but I didn't like them."

No participant spoke about techniques or skills to erotocize condom use. Thus, negotiating condom use with partners was viewed as an unpleasant but necessary task rather than an opportunity for enhancing the sexual and emotional exchange.

#### Interpersonal trust

A related issue that emerged was women's concerns regarding the potential consequences of sexual assertion. Women were particularly concerned about the lack of trust that such communications implied. For example,

"One of the reasons why men don't want to wear condoms is because they think that [wearing a condom] means that they have a [sexually transmitted] disease or something, or that you don't trust me ... if you haven't used one before, they think: 'Oh, what do you have? Why you want me to wear a condom all of a sudden? Have you been cheating on me?' "

Another woman commented on the potential threat to a relationship from such concern:

"... nobody, but nobody wants to think that if they've been together a long time that they still have to use a condom with that partner ... but, then, there's still going to be that voice in the back of your mind that's asking: Is he out there messing around? ... but, you know, you don't really want to think about that. You want to think that you have a trusting relationship."

#### HIV-related fatalism

Two indicators of fatalism regarding HIV-disease emerged. First, although not explicitly addressed in the focus group outline, a recurrent spontaneous discussion area for the women across all groups was uncertainty regarding the value of HIV-antibody testing. In response to the question: "Do women in this community get HIV-testing," many women in several groups simultaneously said "No." Some reasons for the failure to follow through on HIV-testing are highlighted in the following responses:

"... half of these people want to get tested, but they are scared to go get tested. They wouldn't know what to do if they found out that they were positive. What they going to be like [after learning that they were infected] ... just wandering around with their heads cut off ...."

"I have heard a lot of people say I would not want to be tested for AIDS because I don't want to know. If I have AIDS, I don't want to know. I'm afraid to know ...."

There was little appreciation of the potential benefits of early disease identification (e.g., access to health care and social services, prevention of disease transmission). As noted previously, women had poor knowledge of treatment options for HIV-disease and they held little hope regarding the benefits of treatment. A common response to the question "Do you think people are aware that there are treatments?" was "Not really." Other women stated: "You're just gone [once] you get it [AIDS]," or "[AIDS is] just like cancer." One woman said:

"I mean ... You're going to die of something [because] you have to die of something; but, if you're going to die of something because of your behavior that another thing ... and you leave your kids and who knows what will happen to them."

The theme of fatalism following HIV-infection was repeated by women in several groups, such as:

"There's some people's attitude, well, if it's time for me to go, hey, it's time for me to go."

## **Discussion**

Six themes emerged from the focus groups that have direct implications for HIV risk-reduction among at-risk women: (a) Women were not well-informed about vertical HIV-transmission or HIV-treatment options. (b) Women may report no or little risk perception, perhaps because they view exceptions as acceptable, especially partnerships that involve romantic attachments. (c) Women were ambivalent about the merits of monogamy. Some did not consider sexual contact with a main sexual partner to be risky, whereas others doubted the faithfulness of many men. (d) HIV-related fatalism was evident. Testing was a source of significant ambivalence and fear, usually associated with the perception of being HIV-positive as a quick "death sentence," and very limited awareness of HIV-treatment options. (e) Although communication with children about sexual risk-reduction was considered important, such discussion was viewed as inappropriate with peers. (f) Women were very confident about their communication with male sexual partners who were judged to be risky. However, they were concerned that such communication violated the trust necessary for an intimate relationship.

These findings can guide the improvement of behavioral interventions to reduce sexual risk (e.g., Carey et al., in press). First, <u>informational</u> components of behavioral interventions need to emphasize the benefits of HIV-testing and treatment for the mother and the child, to capitalize on the importance of family in this social context. In this regard, Kalichman et al. (1995) found that urban women exposed to a public health message that framed AIDS within a cultural context, personalizing risk and family issues, was more likely to be tested for HIV. Moreover, information relevant to communication with children should be highlighted, as this is an important value among women with children; also, recent data suggest that teaching others about HIV may reduce risk in the "teacher" (Kelly, 1995). Thus, risk reduction interventions should provide information (as well as motivational and skill training) with contextually-framed messages.

Findings regarding <u>motivation</u> raised the need to personalize HIV-risk through culturally-framed messages as well as the need to target both casual and primary sexual partners in risk

reduction messages. The need to increase risk perception, and to emphasize commitment to risk-reduction, is relevant even in committed relationships. Our findings are consistent with those obtained by Wingood et al. (1993) in research with young African-American women where similar barriers to communicating about HIV-risky behavior emerged. Carey et al. (in press) have demonstrated that a risk-reduction intervention that enhances motivation may assist behavior change, when supplemented with skills-training.

Regarding <u>behavioral skills</u>, communication about sexual risk and HIV-testing with all partners remains necessary (see also Fullilove et al., 1990). The high self-confidence expressed by many of the participants in our focus groups does not necessarily reflect adequate behavioral skills (see Forsyth et al., in press). The self-efficacy displayed was qualified by some women's concerns about their abilities to bring these skills to bear in primary, committed relationships. Women's concerns abut jeopardizing interpersonal trust in a committed relationship must also be addressed. Communication skills with peers and family members should also be targeted as this may increase social norms for safer behavior that were not evident among these women.

Dennis et al. (1994) have asserted that the combination of quantitative and qualitative approaches is essential, especially for research areas addressing complex, understudied, or novel problems. Without the information afforded by qualitative research, contextual issues that are immediately evident may undermine well-intentioned risk reduction efforts. Thus, HIV-prevention interventionists might consider again the consensus report of the NIMH Office on AIDS (Pequegnat et al., 1993), and employ qualitative methods to supplement quantitative research.

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