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Perceptions of Community HIV/ STI Risk Among U.S Women Living in Areas with High Poverty and HIV Prevalence Rates

Oni J. Blackstock, MD, MHS,

Department of Medicine, Montefiore Medical Center/Albert Einstein College of Medicine

Paula Frew, PhD, MA, MPH,

Department of Medicine, Emory School of Medicine/ Rollins School of Public Health

Dorothy Bota, MPH,

Department of Medicine, Emory School of Medicine/ Rollins School of Public Health

Linda Vo-Green, MPH,

Department of Medicine, Emory School of Medicine/ Rollins School of Public Health

Kim Parker, PhD,

Department of Health Studies, Texas Woman's University

Julie Franks, PhD,

ICAP, Columbia University, Mailman School of Public Health

Sally L. Hodder, MD,

Department of Medicine, Rutgers New Jersey Medical School

Jessica Justman, MD,

ICAP, Columbia University, Mailman School of Public Health

Carol E. Golin, MD,

Departments of Medicine and Health Behavior and Health Educations, University of North Carolina

Danielle F. Haley, MPH,

Department of Medicine, Emory School of Medicine/ Rollins School of Public Health

Irene Kuo, PhD, MPH,

Department of Epidemiology and Biostatistics, George Washington University Milken Institute School of Public Health and Health Services

Adaora A. Adimora, MD, MPH,

Department of Medicine at the University of North Carolina School of Medicine

Anne Rompalo, MD, ScM,

Department of Medicine at the Johns Hopkins School of Medicine

Lydia Soto-Torres, MD, MPH,

Oni J. Blackstock is the corresponding author and can be reached at Division of General Internal Medicine, Department of Medicine, Montefiore Medical Center/ Albert Einstein College of Medicine, 3514 Dekalb Avenue Bronx, NY 10467; by phone at (718) 944-3865; by fax at (718) 944-3841; and by at oblackst@montefiore.org.

Division of Acquired Immunodeficiency Syndrome, NAID, NIH

Jing Wang, PhD, and

Statistical Center for HIV/AIDS Research and Prevention, Fred Hutchison Cancer Research Center

Sharon B. Mannheimer, MD

ICAP, Columbia University, Mailman School of Public Health and the Department of Medicine, Harlem Hospital Center/Columbia University

Abstract

Although studies have consistently demonstrated that women at high risk for HIV and non-HIV sexually transmitted infections (STIs) tend to underestimate their individual risk, little is known about how women at risk perceive their community's HIV/STI risk. We explored perceptions of community HIV/STI risk among U.S. women living in areas with high poverty and HIV prevalence rates as part of a qualitative substudy of the Women's HIV SeroIncidence Study. Semi-structured focus groups were conducted. Data were coded and analyzed using the constant comparative method. Participants expressed the perception that their communities were at elevated HIV/STI risk, mostly due to contextual and structural factors such as lack of access to health care and education. Findings suggest that HIV prevention messages that target U.S. women at high risk for HIV may be strengthened by addressing the high perceived community HIV/STI risk driven by structural factors.

Keywords

HIV; sexually transmitted infections; risk perception; women; community

In the United States (U.S.), the burden of HIV among women is felt disproportionately by African Americans and Latinas. Together, Black women and Latinas constitute 80% of women newly diagnosed with HIV infection in the U.S., despite being only one-quarter of the female population.^{1,2} In addition, Black women and Latinas are at substantially increased risk for acquiring non-HIV sexually transmitted infections (STIs), such as genital herpes and *Chlamydia trachomatis*.^{3,4}

Despite being at elevated risk for HIV and STI (HIV/STI) acquisition, due to a host of contextual and structural factors, low-income Black women and Latinas often perceive their individual risk of acquiring HIV/STI to be relatively low.⁵⁻¹³ Although the relationship between perceived risk and actual risk is complex and findings have been mixed, perceived HIV/STI risk may influence self-protective behaviors.¹⁴⁻¹⁶ A perception of relatively low individual HIV/STI risk is thought to contribute to fewer self-protective behaviors (such as condom use) being practiced among Black women and Latinas, thereby increasing vulnerability to HIV/STIs.^{6,12,13,17}

A confluence of diverse factors is thought to influence an individual's perceived HIV/STI risk, a perception which is often gauged relative to other individuals or groups.^{13,18} The risk perception literature has also identified psychological dynamics that influence perceptions of

personal risk, notably optimistic bias, also known as unrealistic optimism.^{6,19} Optimistic bias leads an individual to believe that she is less at risk than others of a negative event happening.^{20,21} In particular, individuals appraise themselves to be at low risk of a negative event when considering factors under their control; given an optimistic bias, an individual unrealistically minimizes her own risk. Similarly, the perception among low-income Black women and Latinas of being at relatively low risk for HIV/STIs may suggest that many believe that their own individual choices and behaviors (e.g., having only one current male sexual partner) will protect them from HIV/STIs despite the presence of community-level factors that increase risk. There may be dissonance between one's appraisal of personal risk and risk attached to any other entity—individual or collective (e.g., community). It is this hypothesized tendency to see one's own behavior as safe (even in an unsafe context) that may create a strong barrier to internalizing prevention messages that focus on individual behavior.^{22,23}

Although understudied, perceived community HIV/STI risk—perceived HIV/STI risk for residents within a community—and related constructs such as perceived HIV/AIDS prevalence are thought to contribute to perceived individual HIV/STI risk and to risk behaviors.^{19,24–27} A cross-sectional study found that perceived HIV/AIDS prevalence in one's local community was inversely associated with an individual's number of sex partners, risky sexual practices, and STIs, with those who perceived a lower HIV/AIDS prevalence having more sex partners, higher rates of STIs, and risky sexual practices.¹⁹ Another recent study found that individuals who perceived greater community HIV risk were more likely to have received an HIV test.²⁵ However, these studies used quantitative methods; perceived community HIV/STI risk is likely to have nuances that escape quantitative methods of observation; a qualitative methodology would enable further exploration and understanding of the reasons underlying perceptions of community HIV/STI risk.

Characterizing perceptions of community HIV/STI risk may help to inform HIV prevention efforts. Public health messages about HIV prevention have often been limited to attempts to heighten perceived individual risk by focusing on an individual's behaviors.²⁸ However, HIV prevention messages may be more effective if community HIV/STI risk is addressed, or if the message focuses more on community than individual risk.²⁵ However, little is known about perceptions of community HIV/STI risk among those living in communities at increased risk. In this qualitative analysis, we sought to explore perceptions of community HIV/STI risk among a cohort of women living in areas with high poverty and HIV prevalence rates. We were particularly interested in understanding perceptions of community HIV/STI risk among this cohort, as a separate analysis of interviews of participants drawn from the same study population found the majority perceived themselves to be at low individual HIV/STI risk, a finding consistent with prior studies (HPTN 064 Qualitative Working Group, personal communication). Elucidating and understanding existing perceptions about community HIV/STI risk may help to frame HIV prevention messages for women living in these communities more effectively.

Methods

Participants and procedures

This analysis uses data from the qualitative substudy of the HIV Prevention Trials Network's Women's HIV SeroIncidence Study (HPTN 064), a multisite, longitudinal cohort study which examined HIV incidence and behavioral characteristics associated with HIV risk among a cohort of women residing in areas with high poverty and HIV prevalence rates.²⁴ Eligible women were enrolled between May 2009 and July 2010 from 10 urban and peri-urban communities in six geographic areas of the U.S. (Atlanta, Georgia; Baltimore, Maryland; New York, New York; Newark, New Jersey; Raleigh/ Durham, North Carolina; and Washington, D.C.). Institutional review boards at each site and collaborating institutions approved the study, and a Certificate of Confidentiality was obtained from the Office for Human Research Protections in the U.S. Department of Health and Human Services.

Those eligible to participate included self-identified women who met the following criteria: 1) 18–44 years of age; 2) living in an area with high rates of HIV and poverty; 3) not aware of being HIV-infected; 4) reported unprotected sex with a man during the previous six months; and 5) reported at least one additional personal or partner risk factor, such as binge drinking, drug use, or incarceration history. Venue-based recruitment was used to identify and recruit from specific locations in which women from the target census tracts or ZIP codes (in New York only) were expected to congregate.

Participants received rapid HIV testing and completed audio computer-assisted self-interviews (ACASI) at baseline and were followed up to 12 months. Quantitative data collection using ACASI included socio-demographic information, sexual history in the last six months, history of STIs, and substance use history. Details of HPTN 064 procedures are discussed elsewhere.²⁹ The primary outcome of HPTN 064 was HIV incidence.

The study design included a qualitative component to describe and gain insight into the social, structural, and contextual factors that influence women's health and HIV risk. Four of the study sites (Bronx, New York; Washington, D.C.; Raleigh, North Carolina; Atlanta, Georgia) conducted qualitative focus groups with a sample of women enrolled in the cohort. Participants were invited to participate in focus groups following their enrollment visit and were sampled in consecutive blocks of 10 to facilitate timely implementation of the focus groups. Women were compensated for their participation in the focus groups.

Data collection

Focus groups were conducted by trained interviewers with experience working with the study population at the sites and were digitally recorded and transcribed. Identifying information was removed from transcripts. Semi-structured focus group guides were developed in advance of study implementation with input from HPTN 064 investigators and community members. Focus group members were generally asked to report their perceptions of community-level phenomena. In keeping with study aims, topics covered in focus groups were designed to explore multilevel factors that influence women's health, including, but not limited to: 1) factors influencing partnerships and sexual behavior decision-making as well as perceptions of risk factors for HIV/STI infection, 2) community-level factors

including neighborhood resources and social support, and 3) other issues emerging spontaneously from interviews and discussions.

For this sub-analysis, we focused on participants' responses to the following question and related follow-up probes: "How might HIV/ STI risk be different for people who live in your community compared with other communities?" to explore participants' attitudes and beliefs about their own community's HIV/STI risk. This question and its related prompts were asked at the Bronx, N.Y., and Raleigh, N.C. sites. Although the term "community" was not predefined for participants, the question about community risk was preceded by discussions of resources within participants' neighborhoods as well as the positive and negative aspects of living in their neighborhoods. Participants' interpretation of community may have been guided by these references to the locales and neighborhoods in which they live.

Data analysis

Coding and analysis of transcripts took place in three steps: 1) Structural Coding, 2) Preliminary Analysis and Member Checking, and 3) the Constant Comparative Approach.^{30,31}

Comprehensive code workbooks and coding schemes were developed to capture relevant details from the transcripts. Six coders used the constant comparative technique, developed as part of the grounded theory approach, which uses systematic iterative review of transcripts to identify and categorize salient themes emerging from the data.³² This approach focused on identifying themes from larger segments of text instead of a single word, sentence, or phrase of a sentence. The six coders led by a team leader developed a lists of codes through independent review of all transcripts and refined. Subsequent axial coding was conducted to evaluate relationships among categories and facilitate the emergence of thematic linkages among codes. Six coders received training on how to apply the codes and corresponding definitions. Two members from each site applied the codebook to a randomly selected subsample of transcripts to assess the validity of the codebook and make needed refinements. For this sub-analysis, further selective coding was performed on responses to the question(s) about community HIV/ STI risk, as described below.

Results

Participant characteristics

Among the 68 focus group participants, median age was 25 years old (interquartile range [IQR]: 22–32). Nearly all participants self-identified as non-Latina Black (69%) or Latina (29%). More than one-third (37%) had less than a high school education and most were single (60%). About half (47%) were from households with a yearly income below \$10,000. With regard to risk behaviors, the median number of male partners in the last six months was two (IQR: 1–4). Unprotected intercourse was common: 76% of participants reported no condom use at last instance of vaginal intercourse. Anal intercourse in the last six months was reported by almost half of participants (43%), and, among those, most (86%) reported no condom use at last instance of anal intercourse. About one-third (34%) reported transactional sex and half (47%) reported having a sexual partner outside of their current

main relationship in last six months. Nineteen percent reported at least weekly drug use and about one-quarter (22%) at least weekly binge drinking. One-third (32%) had a current male partner with illicit drug use and more than half (59%) had a male partner who had been incarcerated within the last five years. There were no statistically significant differences in characteristics between the focus group participants in this analysis and the overall study cohort, except that focus group participants were more likely to be younger (25 v. 29 years old, $p=.01$) and to be Latina (29% vs. 11%, $p<.001$).

Themes relating to perceived community HIV/ STI risk

In general, participants perceived differences with respect to HIV/STI risk in their communities as compared with other communities. Among those who believed their communities had higher HIV/STI risk than others, we identified the following four prominent explanatory themes related to community HIV/STI risk: 1) lack of access to health care, education, and information; 2) competing priorities; 3) close proximity to others; and 4) more people with high-risk behaviors in their communities. A minority of participants expressed that there was likely no difference in risk or greater risk in other communities as compared with their own. These perceptions were attributed to 1) privilege enabling HIV status to remain hidden and 2) differential testing (i.e., overtesting in poorer communities and undertesting in more affluent neighborhoods).

Lack of access to health care, education, and information—Most participants spoke about differences in structural factors between their communities and others. Specifically, participants frequently mentioned lack of access to health care as a factor that contributed to differences in community HIV/ STI risk in that it prevented residents from obtaining necessary health information that could be used to protect themselves from acquiring HIV/ STIs. For example, one participant stated:

It's harder for us. I feel like in certain communities they have more access to doctors and information that they need.

Another participant said that both lack of access to health care and education about health issues increased risk for those in her community compared with other, more affluent communities.

Let's say people [elsewhere] are more comfortable; they get educated better. People that aren't financially as well off, they don't get educated properly. So maybe if there is a difference [between communities], it would have to do with that. Also, people aren't going to doctors because they don't have medical coverage. They're not going to the right places to get help, to get information. So, maybe they go to backyard doctors or get home remedies from people who are doing things. They're not getting educated. I think it just all boils down to education. People just not educated right, because what you don't know, you don't know.

Similarly, another participant expressed the view that those in more affluent communities had health information, literally, brought to their doorstep, whereas people in her community had to seek out health information to protect themselves.

It's a lot different especially for people who have money. They're more educated. They're more like getting pamphlets at their doorstep, but in the Black community, it's like we have to go out and get the information or people. It's like that information is not easy access for us.

Competing priorities—In addition to structural factors, participants cited contextual factors, such as being confronted with competing priorities in the face of poverty, as contributing to higher HIV/STI risk in their communities. Participants felt that because people in their communities were focused on surviving from one day to the next, it was less likely for residents to consider self-protective sexual behaviors. This led to excess risk in their own communities compared with other communities where poverty was not part of residents' day- to-day reality.

I think people in the [city name] don't think about it. People don't think about going to the doctor. People don't think about, "Oh, I could possibly catch AIDS if I have sex with this guy tonight," or "If I have sex with this girl tonight without a condom." People don't have that awareness, people don't think about it. In our neighborhoods, everybody's just worried about, "I need money, I need this, I need to survive;" nobody's thinking about, "I could catch this disease."

Living in close proximity to others—Some participants from urban communities opined that the difference in risk between communities was based on the fact that, in their communities, people lived in very close proximity to one another. This close proximity to others or, also, increased accessibility due to available transportation, was thought to increase the likelihood of sexual encounters, thereby increasing risk of acquiring HIV/STIs. Conversely, the assumption was that those who lived in affluent communities were less likely to live in close proximity to one another and had fewer opportunities for sexual encounters, and therefore, were less likely to acquire HIV/ STI.

Maybe in the suburban community, there's no transportation. So it's like, "All right, my mom's out with the car, so I would have to walk about 50 blocks to go to my girlfriend's house." So they don't go. Over here, you get on a train, a bus, a cab, and go get some.

More people with high-risk behaviors—In addition to perceiving increased community HIV/STI risk due to close proximity to others, some participants believed that their own communities had a higher concentration of high-risk partners, more specifically, people who were likely to be "promiscuous". This perceived hyper-concentration of high-risk people was thought to elevate community HIV/ STI risk compared with communities with proportionately fewer individuals at high risk for HIV/ STIs. For example, a participant commented:

Some people just don't care. They are just promiscuous in my neighborhood. You would be amazed. You can look at the sweetest person and don't realize that she's promiscuous.

Privilege enables hiding HIV—While most participants felt that contextual and structural factors contributed to their own communities having a higher HIV/STI risk than others. A few participants posited that there was no real difference in HIV/STI risk between their community and others or that, in fact, other communities had higher HIV/STI risk. They believed perceived differences were a result of certain communities being able to “hide” risk behaviors due to the resources available to them.

It depends on how much money you have. Because if you're rich you can hide your status, 'cause I'm pretty sure Michael Jackson had the [expletive].

One participant even expressed the view that more affluent neighborhoods might have higher HIV/STI risk since they had more financial resources to acquire drugs which could then increase risk of acquiring HIV/ STI.

Better neighborhoods may be worse. They have more money to spend to get high. They have better drugs probably.

Differential testing—A few participants also expressed the view that targeted testing programs promoted testing in their communities while bypassing more affluent neighborhoods. As a result, targeted communities were publicly identified as having more cases of HIV/STIs than those without large-scale testing initiatives. For instance, one participant said:

The government, the man or whatever people from whatever programs, and our communities, Hispanic and Black minorities, there's more programs that get you tested as opposed to these rich housewives that their husband is [expletive] every Tom, Dick, and Harry. They don't want to go get tested, and most of the times they don't, and they don't want to consent to it, and they could have the virus. I'm pretty sure if everybody was mandated to take a test you would see a whole bunch of numbers much higher than what they are right now.

Discussion

To our knowledge, this is the first qualitative study to examine perceived community HIV/STI risk among a cohort of U.S. women living in areas with high rates of poverty and HIV infection. Most participants perceived their communities to be at higher HIV/STI risk than other communities. Participants identified contextual factors, such as competing priorities in the face of poverty, and structural factors, such as lack of access to health care and education, as being responsible for elevating their community's HIV/STI risk. Only a few participants felt that risk in their communities was similar or lower than other communities. These participants expressed that more affluent communities were able to conceal their HIV rates due to available financial resources. Others felt that poorer communities, like their own, were targeted for HIV/STI testing which made HIV/ STI rates seem higher in their communities.

This study contributes to the limited body of literature that exists about perceived community HIV/ STI risk, a potentially important construct given its possible role in overall HIV/STI risk perception and behavior, as well as a target for HIV prevention messaging.

Perceived HIV/AIDS community risk and its related measures, perceived community prevalence and burden, may be associated with self-protective health behaviors.^{19,25–27} For example, one study found that those who perceived greater community HIV/AIDS risk were more likely to have been tested for HIV.²⁵ However, these previous studies are limited in that they utilized quantitative methods; a qualitative approach, such as in this study, permitted a more in-depth examination of participants' perceptions of community HIV/STI risk and what beliefs underlie these perceptions. While prior studies have consistently found that low-income Black women and Latinas, in general, underestimate their risk, our findings confirm that they also acknowledge higher levels of contextual and structural risk. If this is true, HIV prevention messages that highlight community risk may resonate more effectively than those that focus on individual risk.

Our findings reinforce the need for HIV prevention messaging to move beyond individual risk behaviors and risk reduction to focus on community-level risk. Prevention messages targeting women at high risk must emphasize, in part, that despite normative behaviors (e.g., having just one current male sexual partner), the relatively high HIV/STI prevalence in affected communities places women at increased risk for contracting HIV/STIs. Framing prevention messages by using community-level risk may also extend to more recent prevention measures such as pre-exposure prophylaxis (PrEP). The U.S. Public Health Service and Centers for Disease Control and Prevention recently recommended PrEP for several risk groups including heterosexual women at substantial risk for HIV acquisition, such as our study participants.³³ As perceived risk has been associated with PrEP interest and uptake, low perceived individual risk among our participants may correspondingly translate to low levels of PrEP interest and uptake.^{34–36} As such, prevention messages focused on women at risk that promote PrEP may increase their saliency by highlighting community HIV/STI risk.

However, public health messages that highlight HIV/STI risk in communities with high poverty rates and HIV/STI prevalence may be perceived as negatively targeting communities of color or low-income communities while ignoring risk in more affluent communities. As these messages may lack credibility, there may be a need also to address conspiracy beliefs about HIV and HIV testing in these communities, including those that were voiced by several our participants about their neighborhoods being targeted for HIV testing. Health-related conspiracy beliefs, particularly those regarding HIV are relatively common in Black communities, and may be associated with increased risk behaviors.^{37–39} Additionally, individuals within the same community may interpret community HIV/STI risk differently, and, consequently, prevention messages may have a different impact depending on an individual's perceptions of community HIV/STI risk.

This study's findings should be interpreted in the context of several limitations. First, we combined HIV and non-HIV STI risk. While there were some similarities and differences between how participants talked about HIV and non-HIV STIs such as genital herpes, we found that when participants spoke about the risk of acquiring HIV and STIs they seemed to either group HIV and non-HIV STIs together or to focus primarily on HIV (which seemed to be the ultimate STI on a continuum of STIs). Second, in our focus group discussions with participants, we did not explicitly distinguish between one's physical community (e.g.,

neighborhood) and social communities. However, the study questions regarding community HIV/STI risk were asked in the context of neighborhood resources and participants' responses were consistent with this interpretation. Third, study participants were recruited from venues with high poverty rates and HIV prevalence and selected on the basis of specific inclusion criteria related to risk behaviors of themselves and their male partners. Therefore, the study participants were not a representative sample of U.S. Black women and Latinas, but instead a subpopulation identified as at high risk for HIV. Moreover, there is also self-selection bias in that those willing to enroll as a study participant and engage in qualitative interviews may be different in unmeasured ways than those who decline to participate. However, the number of women declining to participate in the qualitative substudy was very low.

In general, we found that this cohort of U.S women living in areas with high poverty rates and HIV prevalence perceived their community HIV/STI risk to be elevated compared with other communities. They attributed this elevated risk to contextual and structural factors. Therefore, HIV prevention messages that target U.S. women at high risk for HIV acquisition may be strengthened by addressing the high perceived community HIV/ STI risk driven by these factors.

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