Gendered Violence, HIV Acquisition, and Clinical/Behavioral Research

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ABSTRACT

HIV incidence and prevalence rates for US women continue to increase, especially among Black and Latina women. In addition, the link between violence and HIV acquisition has been well documented. However, the interaction between violence, HIV risk, and HIV acquisition remains an under-addressed issue in current clinical and behavioral HIV research designs. Because violence against women plays an important role in HIV acquisition and transmission, it is imperative for clinical research to address violence in trial design and implementation. In this article, we discuss the prevalence of violence in women’s lives; the role violence plays in HIV acquisition; and the absence of violence in clinical research designs. We conclude with recommendations for integrating concerns about HIV and violence against women into sponsor- and investigator-driven HIV research priorities and clinical trial design.

Keywords: HIV acquisition, Violence, Women
INTRODUCTION

In recent years, HIV incidence rates for U.S. women have quietly risen, especially among women of color (CDC, 2011). Although few women were impacted in the early epidemic, rates have skyrocketed in recent years. According to the U.S. Centers for Disease Control and Prevention’s (CDC) 2011 surveillance data, adult and adolescent women make up a quarter of individuals living with HIV in the United States. Black and Latina women are hardest hit by the HIV epidemic, with dramatically disproportionate prevalence and incidence rates in these communities (CDC, 2011). Results from the HIV Prevention Trials Network (HPTN)’s 2012 “Isis Study” (HPTN 064) illustrate this racial disparity. The Isis Study found that HIV rates among Black women in the northeast and southeast U.S. are five times higher than the CDC had previously estimated. HIV rates in these communities were comparable to rates in parts of sub-Saharan Africa.¹

Violence plays a very real role in many women’s lives. The World Health Organization (WHO) reports that globally, over one-third of women have experienced some form of physical or sexual violence (WHO, 2013). In addition, at least 15 percent of adult women have experienced sexual violence. In some geographic areas prevalence rates of lifetime physical and/or sexual violence by an intimate partner are as high as 71 percent (WHO, 2004). In the U.S., one in five women (18.3%) report having been raped at some time in their lives. Of these women, more than half (51.1%) reported that the rape was committed by an intimate partner, and 40.8% reported being raped by an acquaintance (WHO, 2004). Recent social and behavioral data on HIV risk provides evidence for a strong relationship between violence and HIV acquisition.² Rape removes women’s choice to engage in consensual sex and to use a condom for protection during sex (Zierler, 1996). In addition, it greatly increases the risk for HIV transmission due to vaginal and/or rectal tearing (Slaughter, 1997). In response, the US government, non-governmental organizations, and community-based care providers formed several work groups and task forces to begin to address and remediate this issue.³

¹ Note: For press release on the ISIS study, brochures, and other study information: http://hptn.orresearch_studies/HPTN064Media.asp
² Note: (Campbell, 2012); (Cavenaugh, 2010); (Dunkle, 2004); (Garcia-Moreno, 2000); (Jewes, 2003); (Maman, 2002); (McDonnell, 2005); (Wyatt, 2002); (Zierler, 1996).
³ See: Working Group on the Intersection of HIV/AIDS, Violence Against Women and Girls, and Gender-related Health Disparities; UN Inter-Agency Task Force on Violence Against Women; UNAIDS Inter-Agency Task Team on Gender and HIV/AIDS; Global Commission on HIV and the Law; Greentree Meeting on Sexual Violence and HIV.
Disparities provides just one example of this type of working group. Efforts like these are a step in the right direction to glean a better understanding of the complex relationships between violence against women and HIV, which could hopefully lead to effective interventions that reduce HIV rates in women.

While work groups and task forces are important components of ending violence against women, the Women’s HIV Research Collaborative (WHRC) believes that clinical and behavioral research also plays a critical role in addressing this issue. Clinical and behavioral research can answer important questions about transmission, prevention, and treatment of HIV. The NIH HIV/AIDS Clinical Trials Networks are currently structured to address questions related to prevention (HIV Prevention Trials Network, or HPTN), HIV vaccines (HIV Vaccine Trials Network, or HVTN), treatment (AIDS Clinical Trials Group, or ACTG), maternal-child transmission and treatment (International Maternal Pediatric Adolescent AIDS Clinical Trials Group, or IMPAACT), and microbicide research (Microbicide Trials Network, or MTN). Clinical and behavioral research design includes an initial screening visit followed by numerous study visits for clinical testing, treatment, monitoring, and/or observational data collection. Presently, violence is not always included in screening, intake, or visit questionnaires. The WHRC feels that this is a missed opportunity for important data collection about the role of violence in women’s lives.

Although the WHRC’s primary relationship is with the NIH HIV/AIDS Clinical Trials Networks, we encourage all sponsor- and investigator-driven HIV research to consider the role violence plays in the domestic HIV epidemic. We urge the HIV research community to frame violence not only as a behavioral or social issue, but also as a policy concern. Towards this end, we have prepared this position paper to review current mechanisms for capturing data on violence and to outline the need for clinical and behavioral researchers to continue exploring violence as a confounding factor in HIV acquisition. Our hope is that this paper can provide justification for the collection of data on violence in clinical and behavioral research, as well as be a resource for researchers and advocates working in the fields of violence prevention, HIV education and prevention, and women’s health more generally. Violence against Women and Risk for HIV

Violence against individual women is primarily categorized as domestic violence (DV) and/or intimate partner violence (IPV), while structural violence represents a larger category of violence against women as a gender group (WHO, 2013). For the purposes of this white paper, we are using the United Nations’ definition of violence: “any act of gender-based violence that results in, or is likely to result in, physical, sexual or mental harm or suffering to women, including threats of such acts, coercion or arbitrary deprivation of liberty, whether occurring in public or in private life.” (United Nations, 1993). Structural violence

Note: http://www.whitehouse.gov/the-press-office/2012/03/30/presidential-memorandum-establishing-working-group-intersection-hivaids-
represents larger social forces (e.g., governments, belief systems, or cultural practices) that place certain people, or groups of people, particularly women, at increased risk or disadvantage. Examples of structural violence include blaming women for rape, placing the burden of proof on women, and glorifying rape and violence against women (Farmer, 2006). Structural violence creates a climate of risk for domestic and interpersonal violence (Farmer, 2006). As we discuss below, all types of violence contribute to the HIV epidemic, however, sexual violence may be the easiest to link directly to risk for HIV acquisition. Therefore, sexual violence is an ideal place to start when crafting behavioral research questions. Nonetheless, even though it may be more difficult to tease out direct relationship between structural violence and HIV risk, this is an important area for further research.

The profound impact structural violence has on health disparities is well documented, and extensive research has been conducted on sexual violence against women, both domestically and internationally. Lane et al identify several pathways by which structural violence contributes to HIV infection: “community rates of infection, concurrent partnerships, and increased vulnerability” (Lane et al., 2004). Raiford et al highlight the high rates of dating violence in African American teens and call for the need to train clinicians on how to screen for this type of violence (Raiford et al., 2012). Data like these reveal the importance of considering violence—including structural violence—in both research and clinical practice. It is for these reasons that we argue for the collection of data on violence in clinical and behavioral research.

RESULTS

Table 1 provides an overview of intimate partner and sexual violence in the U.S. from the CDC’s 2010 National Intimate Partner and Sexual Violence Survey (NISVS). Because violence against women is highly prevalent across racial groups, age groups, and ethnic groups, it is imperative for HIV research—and all research that includes women as participants—to incorporate screening for violence and appropriate referral mechanisms into clinical and behavioral research designs. Should these practices be incorporated into clinical and behavioral research designs, researchers will be better able to capture the realities of many women’s lives, and more fully identify mechanisms of HIV risk acquisition. In this section, we discuss intimate partner and sexual violence as they relate to HIV risk and acquisition.

At the intimate or interpersonal level, the presence or threat of violence can decrease a woman’s “ability to recognize risk [and] lower her self-esteem” (WHO, 2010, p.26). This, in turn, can decrease a woman’s decision-making power to negotiate condom use (p.17). Even without the presence or threat of violence, women may have a lower self-perception of their HIV risk, which can impact adherence for novel HIV prevention strategies, such as pre-exposure-prophylaxis (PrEP) (Van Damme, et al, 2012). Many reports have identified pathways by which violence increases women’s risk for HIV-acquisition,
including forced sex with an HIV-positive partner, having unprotected sex out of fear of violence or abuse, and engaging in risky behaviors that may be related to trauma from childhood abuse (Gielen et al., 2000 & 2005; Maman, 2002). In addition, research finds that HIV-positive women may fear intimate partner abuse or domestic violence upon disclosure of an HIV diagnosis (Rothenberg, 1995; Zierler et al., 2000 & 1996; Vlahov et al., 1998; Gielen et al., 2000a & 2000b). Although there are HIV prevention methods currently in development that women feasibly could control themselves--such as microbicides and oral PrEP—(which may mitigate HIV acquisition risk and allow women to use prevention methods discreetly, if they wish), more research (and more time) will provide further insight into the efficacy of these approaches.

Exposure to sexual violence has been identified as a risk factor for women and HIV acquisition. Women who are sexually abused are more likely to contract HIV (Zierler, 1996; Dunkle et al., 2004; Ehrhardt et al., 2002; WHO, 2010). Researchers have identified a “continuum of risk” that begins with childhood abuse and leads to a lifetime of susceptibility to greater risk-taking: such as sexual promiscuity; illicit drug use, vulnerability to rape; multiple partners; and partners who also use drugs (Lichtenstein, 2005).
Table 1. Lifetime Prevalence of Rape, Physical Violence, and/or Stalking by an Intimate Partner, by Race/Ethnicity – U.S. Women, National Intimate Partner and Sexual Violence Survey 2010

<table>
<thead>
<tr>
<th></th>
<th>Hispanic</th>
<th>Black</th>
<th>White</th>
<th>Asian or Pacific Islander</th>
<th>American Indian or Alaskan Native</th>
<th>Multi-racial</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rape</td>
<td>Weighted %</td>
<td>8.4</td>
<td>12.2</td>
<td>9.2</td>
<td>*</td>
<td>20.1</td>
</tr>
<tr>
<td>Physical Violence</td>
<td>Weighted %</td>
<td>35.2</td>
<td>40.9</td>
<td>31.7</td>
<td>*</td>
<td>45.9</td>
</tr>
<tr>
<td>Stalking</td>
<td>Weighted %</td>
<td>10.6</td>
<td>14.6</td>
<td>10.4</td>
<td>*</td>
<td>18.9</td>
</tr>
<tr>
<td>Rape, physical violence, and/or stalking</td>
<td>Weighted %</td>
<td>37.1</td>
<td>43.7</td>
<td>34.6</td>
<td>19.6</td>
<td>46.0</td>
</tr>
<tr>
<td>HIV Prevalence Rate</td>
<td>All women: 25%; % of all women</td>
<td>17</td>
<td>64</td>
<td>15</td>
<td>1</td>
<td>.7</td>
</tr>
</tbody>
</table>

Race/ethnicity was self-identified. The American Indian or Alaskan native designation does not indicate being enrolled or affiliated with a tribe.

* Estimate is not reported.


These risk factors are even more prominent among young women and women of lower socio-economic status, who are more likely to depend on their male partners for financial security and engage in high-risk behaviors such as trading sex for money, drugs or shelter (CDC 2013, El-Bassel et al 2005).

Research has also found that physical violence/beatings, verbal abuse, rape, or sexual coercion correlate with HIV risk (El-Bassel et al, 2005). Both overt and covert threats of violence pressure women to engage in unsafe practices they might otherwise not engage in were violence not a factor in their lives, directly impacting risk of HIV acquisition. For example, women with abusive partners may be afraid to ask them to use condoms out of fear their partners will see such a request as a question about their fidelity or trustworthiness (See Kalichman, 2005; Wingood, 1997; Lichtenstein, 2005; Zierler, 1996). Condom use is a crucial HIV prevention tool, particularly when it is estimated that 80% of women contract HIV from high-risk heterosexual contact (CDC, 2011).
The public health and social-behavioral research discussed above explores violence as a risk factor in HIV acquisition. However, many current HIV research protocols do not fully address violence. Screening and intake forms often do not include questions about violence, even though this discussion often occurs between clinicians and patients. For example, in the HIV Vaccine Trials Network (HVTN), only two protocols—both of which were observational—including questions about sexual victimization (personal communication with network representatives). “Risk”, in the context of clinical trials, is often assessed by obtaining information about sexual practices, partner sexual practices, alcohol and drug use, and condom use. Existing assessments do not include questions that would provide data about the complicated and complex social relationships that women must navigate, and the role of violence in those relationships. Including questions on case report forms that solicit information about both current and prior experiences with sexual and physical violence may capture critical insights between violence and drug use, sexual decision-making, risk perception and other risk behaviors. There is overwhelming evidence that past histories of sexual and physical trauma may have considerable influence on present day decision-making around sexual behavior, which is integral to understanding the critical links between violence and HIV acquisition for women who experience violence (See: Norman et al., 2012; Cavanaugh & Classen, 2009; Machtinier et al, 2012).

Currently the majority of behavioral and clinical HIV research utilizes standardized risk assessment questionnaires that ask individuals to report specific HIV risk-related activities—including intravenous drug use, unprotected sex, and transactional sex. Questions generally ask women to report total number of male sexual partners and the types of sexual activities engaged in with these partners. The WHRC takes the position that this line of questioning creates a situation whereby women are overtly or subtly blamed for their HIV infection. Because of unequal power dynamics in individual, familial, communal and societal relationships, it is important that risky behaviors are not seen as choices made by an individual. For example, women of lower socio-economic status may participate in types of transactional unprotected sex due to a perceived lack of other options. Female victims of intimate partner violence may participate in risky sex with their partner if they depend on that partner for food, shelter and support (Lichtenstein, 2005). This reflects only a fraction of the context in which women may not have the ability to make protective choices that prevent HIV infection.

DISCUSSION

In this position paper, we have argued that the need for better assessment procedures that can capture violence in the lives of women. The well-documented relationship between violence against women and HIV acquisition among women in the U.S. highlights the need for clinical research that considers the role violence plays in HIV acquisition and transmission. To this end, the WHRC urges the HIV research community to examine the following recommendations for...
integrating concerns about HIV and violence against women into sponsor- and investigator-driven HIV research priorities and clinical trial design. We suggest that the HIV research community:

**Allocate resources according to identified national policy priorities.** According to the National HIV/AIDS Strategy (National HIV/AIDS Strategy, 2010), additional research is needed into the unique factors that place women at risk for HIV infection. In order to address this need, researchers need adequate financial and personnel resources to gain greater insight into the unique factors that drive the epidemic in the U.S., particularly among women of color. As we have discussed, violence is a unique factor that places women at risk for HIV infection. Therefore, resources should be allocated for research into violence and HIV. Resources should also be allocated such that violence data can be collected in clinical and behavioral research.

**Increase solicitations for sponsor- and investigator-driven clinical research addressing violence, women, and HIV in the United States.** Early HIV-prevention interventions tailored for women were based on theoretical models of HIV-risk behavioral change that have limited empirical support (Fisher & Fisher, 2000). Most of these models [e.g., Health Belief Model (Rosenstock, Strecher, & Becker, 1988); AIDS risk reduction model (Catania, Kegeles, & Coates, 1990); Stages of Change (Prochaska, DiClemente, & Norcross, 1992); Theory of Reasoned Action (Fishbein, Middlestadt, & Hitchcock, 1994)] of behavioral risk reduction applied to understand risk behaviors did not adequately consider the range of important contextual, emotional, and social or real-world factors that influence women’s sexual behavior. Recent HIV prevention strategies have drawn from more gender sensitive theories such as the Theory of Gender and Power (Connell, 1987), the Ecological Model (Bronfenbrenner, 1979), Social Cognitive Theory (Bandura, 1994) and a Modified AIDS Risk Reduction Model (M-ARRM) (Miller, Exner & Williams, et al., 2000). These allow structural factors specific to women’s experience to be addressed. An increase in gender sensitive research can better account for the role of violence in women’s lives, in the risk of HIV acquisition, and in disease progression. If violence is made a research priority, we will be better able to identify strategies to ameliorate this problem.

**Craft research questions that acknowledge complex social relationships and power dynamics.** It is important that researchers consider the social and cultural context in which they conduct research. Our real-world experience leads us to conclude that female study participants navigate unique community, family, and interpersonal relationships with deeply embedded power dynamics that affect their risk for HIV acquisition and transmission. Therefore, researchers should consider and integrate each level of these relationships into study design. A better understanding of women’s social relationships and the power dynamics attendant in these relationships will allow research to reach more accurate conclusions about risk, acquisition, and transmission.
Revise risk assessments to collect data on gender-based violence and sexual power dynamics with partners. Including questions on women’s experiences with violence may reveal correlations between violence and drug use, sexual decision-making, risk perception and other risk behaviors. While transactional sex may be an active form of currency for a woman’s financial and familial stability, our experience with the NIH clinical trials networks shows us that the vast majority of protocols do not screen for this and other indicators associated with increased risk for HIV acquisition of transmission (survival sex and past histories of sexual and physical trauma) that may have considerable influence on present-day decision making around sexual behavior. Therefore, we recommend that risk assessments be revised to collect data on violence and sexual power dynamics with partners. This data will be important when crafting interventions aimed at reducing risk of HIV acquisition as well as risk of violence.

CONCLUSION

The clear and well-documented relationship between violence, HIV acquisition, and the increasing prevalence of HIV in U.S. women raises the question of how HIV research can more fully address the relationship to gender-based violence. Research should ensure that collection and analyses of gender and violence are considered and included in research study design wherever possible. When violence against women is prioritized in clinical and behavioral HIV research, valuable data will continue to emerge. Researchers, health care workers, and other stakeholders can then use this data to develop effective, gender-specific interventions and address important drivers of the HIV epidemic.

ACKNOWLEDGEMENTS

The WHRC is a working group of the Office of HIV/AIDS Network Coordination (HANC)’s Legacy Project. HANC is funded in whole or in part with Federal funds from the Division of AIDS, National Institute of Allergy and Infectious Diseases, National Institutes of Health, Department of Health and Human Services, grant number 5 U01 AI068614, entitled Leadership Group for a Global HIV Vaccine Clinical Trials (Office of HIV/AIDS Network Coordination) with additional support from the National Institute of Mental Health.

REFERENCES


87 Gendered Violence, HIV Acquisition, and Clinical/Behavior Research
Barr et al.

(Eds.), Primary prevention in psychopathology (pp. 93-110). Newbury Park, CA: Sage.


