A COLLISION OF EPIDEMICS
VIOLENCE, DISCRIMINATION AGAINST WOMEN, AND LIVING WITH HIV

A case study from focus group discussions with HIV positive women in Jamaica

Jamaica Red Cross and Canadian Red Cross
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INTRODUCTION

The Jamaica Red Cross (JRC) has worked to address the problem of HIV since 1988. Since 2010 they have also included components to prevent interpersonal violence (sexual, physical and psychological) as part of their HIV programming with vulnerable populations.

In developing and implementing a violence prevention component in their HIV programming, the JRC found that the there was limited information indigenous to Jamaica, showing the specific links between HIV, violence and gender. Meanwhile, these issues were clearly being highlighted by volunteers, partner agencies, and community members. Additionally, the voices and specific experiences of people living with HIV often were missing from formal documents and reports.

To help remedy this gap, and to enhance their own operational work with vulnerable populations, the JRC partnered with the Canadian Red Cross to develop the following case study on the intersections between being a woman, living with HIV and experiencing interpersonal violence.

BACKGROUND

Violence is often a neglected, but important aspect, related to HIV transmission and the safety and health of people living with HIV. This is particularly true for women, as violence against women is seen as both a cause and consequence of HIV/AIDS.[i]

The World Health Organization summarizes the linkages between violence, women and HIV:

> *"Over a decade of research from countries in different regions of the world documents an undeniable link between Violence against Women (VAW) and HIV infection. The relationship between VAW and HIV risk is complex, and involves multiple pathways, in which violence serves both as a driver of the epidemic, and at times a consequence of being HIV positive.*
>
> *"Rape is one potential cause of direct infection with HIV through violence for some women. However, the primary burden of HIV risk from VAW and gender inequality arises through longer-acting indirect risk pathways. These involve both chronically abusive relationships where women are repeatedly exposed to the same perpetrator,*
> *as well as the long-term consequences of violence for women who have experienced prior, but not necessarily on-going, exposure to violence (in childhood or as adults). Addressing both VAW and gender inequality jointly in programmes will contribute to effective HIV prevention. Such synergistic linking forms an important element of effective combination prevention for HIV."*[ii]

METHODOLOGY

This case study is based on a half-day focus group discussion with six women aged between thirty years old and into their early forties. The dialogue took place in Central Village, Spanish Town, in the province of St. Catherine. All of the women had some level of formal education, though the level varied from common entrance to basic literacy. Most of the participants had at least seven years of formal school.

Before the discussion, the women were informed of the purpose of the meeting: to attempt to identify a relationship between violence and HIV based on participants' life experiences. Participants were chosen from the Jamaica Aids Support for Life network, and were adept at actively discussing issues related to infection and testing. The focus group dialogue was open and frank, given that participants had and attended many trainings on HIV related issues. However, they were very careful about disclosing status, and only did so during the focus group due to trust in the consultant and the group's high level of mutual trust. Participants were guaranteed anonymity (such as the use of pseudonyms in this report). Each participant consented to the dialogue.

Participants shared that they were only able to establish their HIV status from the time they were tested. Some could assume that they had been HIV positive for a longer period of time before being tested, and some were only made aware of their HIV status after being tested when pregnant at a prenatal clinic. Some of the participants sought testing because they became ill, or their partner became ill. In some instances, their male partners were positive, but did not know of their status, or denied it.

DIALOGUE SUMMARIES

After initial conversations about participants' backgrounds, the dialogue was framed around four strategic questions:

1. What is violence; what does violence mean to you?
2. Did you experience violence as a child?
3. Did you experience violence because of your HIV status?
4. Was partner violence an important part of your becoming HIV positive?

[Note on the language used in the dialogue summaries: The language used to represent the participants in the case study uses the colloquial spelling as documented by the author, Dr. Haniff, in her transcripts of the dialogues.]

STRATEGIC QUESTION 1:
WHAT IS VIOLENCE; WHAT DOES VIOLENCE MEAN TO YOU?

Question(s) posed
When we say violence, what do you mean by violence; is slapping somebody, is hitting in the face violent; is using a belt violence? What do you consider violence? What is violence?

Participant responses
Participants discussed physical violence, but commented that the physical acts are "also violence but the words, the words they use to abuse you." When asked for clarity about this, one participant explained that it wasn't necessary to be physically hurt for it to be violence, but the words used against persons with HIV, and being shunned, are sometimes worse than physical violence. A discussion ensued about if this was related to stigma for being HIV positive, and one participant stated: "It's stigma but it's also part of violence, they curse you and some community they run you and beat you."

Conclusions
The dialogue found that physical violence was a common reality. However, part of the reality of living with HIV for the participants, was not just physical violence, but also psychological violence. Physiological violence manifested itself in everyday experiences of fear caused by the silent collusion of their rejection and the callous words and behavior that they confront.

"Dem don't have to lick you, because the words they say to us HIV persons that hurt you more than the licks…."
FOCUS GROUP PARTICIPANT

STRATEGIC QUESTION 2:
DID YOU EXPERIENCE VIOLENCE AS A CHILD?

Question(s) posed
When you were growing up, were you beaten? How old were you? When you were beaten, did you leave? Did you live with both parents? Who was there person who beat you or molested you when you were a child?

Participant responses
Participants' experiences with physical violence were varied; however the majority expressed childhoods that included some form of physical violence. This included being hit with various objects (a belt, an electric wire, a two-by-four board, a stone), being burned, and cut. Perpetrators of the violence were varied: mother, father, step-father or mother's boyfriend.

Participants shared experiences of being victims of sexual violence as young as five years old, and this violence was brought upon them from uncles, step-fathers and strangers. One participant noted that the physical violence was accompanied by emotional abuse.

Many participants shared that these experiences of violence led to them leaving their homes, some as young as fourteen years old. They also shared that their siblings suffered equally, and many ran away from home also: "My mother came and take the younger ones and leave two of them…. Dem run away and get pregnant and come back and I do the same thing go out on the road and get bad." If the violence did not result in leaving home, many participants expressed that it did cause them to enter into relationships for physical or financial protection: "…I got a boyfriend and he help me and I leave school after that at 16." For one participant, it was through this relationship that she contracted HIV. After being hit in the head by her mother's boyfriend, she was thrown out of the house at fourteen years old, and then moved around until she was eighteen and met the man from whom she contracted HIV.

Participants attributed the "causes" for the physical abuse to various reasons. One participant was burned by her mother because of sucking her thumb. One participant stated, "Well me get beatin from all body, sometimes I cause it, because I was bad and feisty." One participant was beaten by her mother for having been raped by a stranger, and not disclosing the rape to her parents.

Most participants did not live with both of their parents. Some had significant relationships with both mother and father, some not. While the majority of the times that participants disclosed the abuse, there was little recourse, one participant shared that after disclosing being raped by her mother's boyfriend when she was thirteen, the boyfriend was kicked out of the house. The majority of the women did not disclose the sexual abuse to their mothers or to anyone for extended periods of time.

"[My mother] was right there and when me tell her what de man do she take my clothes and throw dem out and I went to live with my grandmother in the country. I was fourteen. From then I move from place to place, friend to friend I don't have a regular place. On my eighteenth birthday I met this man and that is how I got HIV."

FOCUS GROUP PARTICIPANT

Conclusions

The women in this focus group who experienced violence at home felt that there was a double standard for their brothers and themselves. The boys were beaten for "large offenses," whereas the girls were beaten for many "small offenses." The attitude from the discussion was that in most instances, the violence they experienced was normal. On the whole, the participants came from impoverished families, and attributed the "routine" nature of violence to the communities in which they lived. The cycle of poverty was repeated; these women could not complete school, and were in many cases driven into homelessness because of they had to leave violent homes.

STRATEGIC QUESTION 3: DID YOU EXPERIENCE VIOLENCE BECAUSE OF YOUR HIV STATUS?

Question(s) posed
Did you experience stigma because of your status? Are there messages (for example on TV) they speak out against discrimination and stigma? Have you seen changes in the way persons with HIV are treated?

Participant responses
The bulk of participant responses were not about individual acts of violence, but a continual emotional violence from their communities. They shared the sentiment that the discrimination and stigma "hurt more than the licks" they had received physically as children. They also shared that the fear of people knowing of their HIV status, and the possible discrimination that could come from that, was a form of emotional violence in itself.

Reactions from participants' families, workplaces, and communities were very diverse. One participant shared that after the initial gossip in her workplace, she disclosed her status to her co-workers, and they were saddened by the news, and supportive of her remaining on the team, even though she had frequent visits to the hospital… "and the people dem say we want her because she can do the work."

"Every time you turn you back, dey talk about you…."
FOCUS GROUP PARTICIPANT

However, many others experienced negative reactions that included discrimination against them when shopping or in public places, and constant gossip. One participant shared that she disclosed to a cousin, who then informed others of her status. This led to rejection of her child at school. Others faced rejection from their families and friends: "Because of my HIV virus people discriminate me, my family reject me."

Their perceptions of changes in the public were poor. Participants shared that though there are campaigns and commercials, they have not felt discrimination lessen. One participant stated: "The ads don't matter to them. When people find out they just go on the same way…." Another participant, who has known of her HIV positive status for eleven years, simply stated, "11 years, no, nothing has changed."

Conclusions
Whether or not they disclosed to their families and communities, all participants seemed affected by the emotional weight of their HIV status. Some dealt with their status in private, living in fear that others would find out. Some dealt with their status in public, however also living in fear of family and community reactions. As women, they felt double afraid that whatever reactions would fall on their children, and affect their abilities to be good mothers.

Though there has been a significant amount of public awareness campaigning, given the conversation, there seems to be a great disjuncture between intended and achieved results of public policies. The lack of change in public perception results in persons living with HIV operating in constant states of emotional violence, given that their very existence is threatened by a possibly impending violence.

STRATEGIC QUESTION 4: WAS PARTNER VIOLENCE AN IMPORTANT PART OF YOUR BECOMING HIV POSITIVE?

Question(s) posed
Did you ever suspect that your partner was HIV positive? Did you experience physical violence from your partner? What is your relationship with your partner; are you married?

"The new person I was with he was aware of my status. He said me a tell lie and want to have bareback sex. Me say no me not doing it."
FOCUS GROUP PARTICIPANT

Participant responses
Participants shared that the majority of the violence and discrimination they suffered from their partners began after becoming HIV positive. After one participant disclosed to her husband, he accepted her initially. He then began to follow ("stalk") her and tell everyone she knew about her HIV status. Her husband was also HIV positive. This stalking occurred for about six to seven months.

Another participant shared that her husband had taken the family to the countryside, and left them there while he returned to work in the city. She began to fall ill, and after a long while her husband took her to the city and "leave me on the bench outside the gate." She was hospitalized for months, and at that time found out about her HIV status and that she was pregnant. Her husband left her, and took the children. Much later, she found out from an uncle, that her husband had been positive for eight years before her.

Most participants shared this experience of having been infected by partners who knew of their status, but had not disclosed. One participant found out about her status after having to take her husband to the hospital. In the hospital he disclosed to her that he was positive status. Another participant did not know that her husband was on treatment, but knew that he had a drinking problem, "He told me on a Saturday and he died the next Wednesday. It was after I took a test and found out I was positive."

After being HIV positive, when finding new partners, the participants faced difficulties. One woman shared that since she is unable to have a child, her husband seeks out other women via the internet to have unprotected sex with them. He is aware of her HIV status, and also has a sexually transmitted disease. Another participant shared that after disclosing to her new partner, he accused her of lying, and wanted to have sex without using a condom. She refused.

Conclusions
The conversations about intimate partner violence demonstrated that the violence received by HIV positive women is much greater post-disclosure. On a deeper level, the dialogue exhibited their male partners' unwillingness to disclose if they were HIV positive, and/or unwillingness to accept their HIV positive status. The violence (physical, emotional and neglect) against the women stemmed from their partners' inability to accept their own HIV positive status.

RESILIENCE

There is no question that the lives of these women have been shaped by the inequality of the status of women. As a result of poverty, entering into early transactional sexual relationships for survival and for school, histories of abuse from in their families, being responsible as the main parent for children, all combined with their HIV status, tell the story of the daily lives of these women who must struggle against immense obstacles to just feed and clothe themselves and their children.

However, it is clear from the dialogues that while these women have been victims in many instances, they have developed strength through resiliency, and have left abusive situations from their families or partners, and defended themselves many times in their workplaces and communities.

Their coping mechanisms or responses have not always been positive, and they themselves have resorted to violence. This instinct towards violence as a defense mechanism calls for reflection on the cycle of violence, and comfort with violence as a normalized activity, given that some of the participants, though having been victims of violence in childhood, used non-violent means in adulthood. Many of the women left their partners, without violence involved.

"She said her husband told her harsh things and did not love her kids, and when asked if she was physically abused, she said that she would 'chop him' if he abused her."
FOCUS GROUP LEADER

CONCLUSION

Although this was a small focus group discussion which was conducted in December 2012, the information generated by these women gave great insight into the relationships between being a woman, being HIV positive, and violence.

The participants revealed significant levels of violence experienced in their childhoods, and the oppression they faced from poverty, discrimination, sexism and class segregation. In many instances, escaping from childhood violence is what led to their relationships with HIV positive partners.

However, this HIV status many times led to further physical and/or emotional violence, which also led to the women themselves being violent. It is evident that violence is a circle within all of the women's lives, which makes their resilience impressive.

This dialogue calls for further investigation about the relationships between violence from family members in childhood, combined with violence from communities related to HIV status, and violence from intimate partners, many times also related to HIV positive status.

[i] http://www.unfpa.org/hiv/women/report/chapter6.html
[ii] WHO. (2010). *Addressing violence against women and HIV/AIDS: What works?* Geneva, Switzerland.