

If I knew what would happen I would have kept it to myself...

FACT SHEET

GENDER VIOLENCE & HIV

PERCEPTIONS AND EXPERIENCES OF VIOLENCE AGAINST WOMEN LIVING WITH HIV IN ILLOVO, KWAZULU NATAL

Gender violence as both a cause and effect of HIV has long been recognised. Evidence shows that violence in its various forms greatly impact on the extent to which women are in the position to claim and exercise their rights, and to access and benefit from available HIV prevention, testing, treatment, care and support services. Violence, including the fear of violence, also has an effect on women's decisions as to whether or not and when to access services, as well as whether or not and to whom to disclose an HIV positive diagnosis.

THE STUDY

The AIDS Legal Network (ALN), in collaboration with Her Rights Initiative (HRI), South Africa Positive Women Ambassadors (SAPWA), South Africa Partners, and the Mitchell's Plain Network Opposing Abuse, engaged in a study to assess perceptions and experiences of violence and other rights abuses against women living with HIV. The data presented here forms part of the broader study, which took place in four areas, namely in New Brighton (Eastern Cape), Illovo

(KwaZulu Natal) and Beacon Valley and Tafelsig (Western Cape) between April and September 2012.¹

The project intended to a) document women's realities and experiences of violence based on and in the context of HIV; and b) build an evidence and knowledge base on HIV-related violence – so as to enhance women's access to, and benefit from available HIV-related services without fear of discrimination, abuse and other rights violations.

In Illovo, 727 community questionnaires were administered; two focus group discussions with women living with HIV were facilitated; 28 women were interviewed; and 10 incident forms were collated.

MAIN FINDINGS: ILLOVO, KWAZULU NATAL

...I must not be seen as a woman who is HIV positive, but as a woman who is a human being...²

Communities' perceptions of women's HIV disclosure consequences

Contrary to women's experiences of HIV disclosure in Illovo, more than a third of community members participating in the study (39%) believed that women living with HIV would get '*support*' and '*love*' from family and household members, and more than two thirds (68%) also thought that women living with HIV would be '*treated well*' and '*with respect*', as it is healthcare providers' *job to treat and support women*.

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Beliefs that women would be 'rejected', 'treated badly', and 'discriminated against' as and when their HIV positive status becomes known varied. While only 12% of participants believed that women would be at risk of ill-treatment and abuse based on their HIV positive status within healthcare provision, 59% highlighted the risk of rejection, abuse, and discrimination upon women's HIV disclosure at a community level, and 25% thought that women would be 'treated badly' by their families.

...the community will destroy you by discriminating you and violating your rights... [Woman, 20s]

Despite these levels of awareness of the risks associated with women's HIV disclosure, the majority of community members (81%) felt strongly that women need to disclose their HIV positive status. The data further shows that women in Illovo were far more likely to believe in disclosing to families (25%), than to partners (15%). Contrary, almost four times as many men expressed the need for women to disclose to their partners (42%), as compared to disclosing to their families (11%).

...if the family is educated they do take care of her... [Woman, 40s]

Women's experiences of HIV disclosure

The majority of women recalled experiences of various forms of abuse and violations, ranging from blame and rejection to insults and physical abuse, by partners and family members. Some women also spoke about being forced by their partners to engage in sex without a condom, and the abuse endured as a result of insisting on condom use.

...he blamed me and forced me to have unprotected sex for many years...

Women in Illovo shared experiences of being chased away and asked to leave the family home after their HIV positive status became known.

...the in-laws blamed me and they chased me out of my husband's house, while I was sick...

Women also shared numerous accounts of abuse and violence, due to the unlawful disclosure of their HIV positive status by people close to them and people they trusted. Most women expressed not only feelings of betrayal, disappointment, and humiliation, but also a certain degree of unpreparedness, as women were not the ones deciding on the time of, or the manner in which, their HIV status became known to families, friends and community members.

...I was so embarrassed, I couldn't even go out of the house...

I decided to stay indoors with my kids to prevent being hurt by our neighbours...

Women's experiences of access to healthcare

Many women shared experiences of healthcare staff being rude and shouting at them for missing their appointments without ascertaining the reasons as to why women did not honour their appointments. Women also frequently spoke about the lack of assured confidentiality within healthcare provision, and the risks of involuntary disclosure of their HIV positive status, based on the infrastructural set-up of the clinics, as well as the separation of services.

...when the nurses called for all who came for CD4 test results I didn't stand up because I was scared that my neighbours who were there will know about my HIV status...

Recognising the risks of potential HIV status disclosure, as well as other rights abuses, in clinics and hospitals, women made multiple references to how these challenges impact on their and other women's access to healthcare, particularly access to ARV treatment.

...you might be scared to go back to the clinic because you are scared of what will happen to you...sometimes you end-up defaulting...

Communities' awareness of redress mechanisms

The data indicates that Illovo community members are fairly aware of women's right not to have their HIV status disclosed without their consent, as well as women's right not to be discriminated against based on their HIV positive status.

Almost a third of community members participating in Illovo believed that women should take *'legal actions'* against the person (or persons) who discloses their HIV status without their consent (32%), and against people who discriminate against women living with HIV (30%).

...it's against the law; she would have to go to the police...

[Woman, 40s]

However, a significant number of Illovo community members also thought that there is *'nothing women can do'* in cases of unlawful HIV status disclosure (21%) and HIV-related discrimination (25%), as women *'should just ignore and go on with their lives'*. In addition, several references were made that women should *'move away'* as response to their rights being violated.

...pretend as if nothing happened...move on with your life, because people will only destroy you... [Woman, 40s]

Women's experiences of seeking redress

The data suggests that women, although aware of their right to take legal actions, are more likely to decide not to lay charges, and instead seek support and advice from family, friends, social workers and counsellors.

Fear of further abuse and humiliation, as well as feelings of shame, embarrassment, and *'not wanting to deal with it'*, were some of the reasons why women decided not to lay charges. Some women also mentioned the difficulties of taking legal actions against family members.

...I was scared that he will beat me again...I was also scared that people will know about my HIV status...

Communities' knowledge of rights protection for women living with HIV

The data clearly shows persistent levels of stigma, prejudice and discrimination against women living with HIV, leading to, among others, the limitation of women's sexual and reproductive rights and choices.

Community members' general lack of knowledge of women's rights is most evident with regard to perceptions about women's right to have children upon an HIV positive diagnosis. More than a quarter of Illovo participants (28%) believed that women living with HIV should not have children – for reasons of *'risk of transmission'* (48%) and because women living with HIV are *'not supposed to'* engage in sex and *'shouldn't get pregnant, because of their health'* (38%).

...you're sick, why get pregnant... [Woman, 20s]

Communities' perceptions of women's risks of HIV-related violence

The study reveals community members' awareness of both women's greater risks of violence and abuse based on their HIV positive status and the needs to address violence against women living with HIV.

More than half of Illovo participants (52%) agreed that women living with HIV are at greater risk of violence and abuse, with a far higher percentage of women (58%), as compared to men (43%) believing that women are at risk of violence based on and in the context of HIV. Women's greater levels of awareness arguably underscore as much women's knowledge of the links between violence and HIV, as they point to women's experiences of HIV-related violence.

...if you have HIV, you must not tell people, because if you do, they will treat you like dirt... [Woman, 30s]

Further explaining their responses, 43% of Illovo community members made reference to women being *'treated badly'* and *'discriminated against'* because of their HIV positive status, while an additional 40% also mentioned that women living with HIV are *'abused', 'beaten by their partners', 'called names',* and *'forced to have sex without a condom'*.

Recognising the high levels of violence and abuse, community members' recommendations for change mostly stressed the need for *'awareness and education'* (52%).

...we need educational programmes which will enlighten people's minds and change their attitudes towards women in general... [Woman, 30s]

RECOMMENDATIONS

What do women in Illovo recommend?

- Equal treatment and respect
- Education and information on HIV and women's rights
- Safe places for women living with HIV
- Access to healthcare and quality services

What do Illovo community members recommend?

- Education and awareness raising
- Women to speak up and claim their rights

Advocacy responses

To ensure a) the protection and advancement of the rights of women living with HIV; b) the adequacy and effectiveness of programmes and interventions addressing violence against women living with HIV; and c) enhanced access to healthcare provision, and other services, without fear of violence and abuse, it is essential to advocate for and create sustained change in the following areas:

Societal and community levels

- Enhance levels of awareness and understanding of the multiple causes, forms and effects, and the continuum of violence against women based on and in the context of HIV
- Address and transform gender and power imbalances so as to ensure that women are in the position to claim and exercise their rights, and to freely access and

benefit from available services, without fear of stigma, discrimination, abuse and other violations of rights

Policy and programme design and implementation

- Ensure that policy design and implementation is truly based on and informed by women's experiences of HIV-related violence and abuse
- Re-evaluate the understanding of violence to incorporate all forms of violence, including institutional, structural, cultural and systemic violence, and ensure that policies and programmes are premised on a broad and inclusive understanding of violence against women

Service provision and human resourcing

- Build capacity on the various forms and effects of violence on women, as well as the rights and needs of women living with HIV, among service providers and service users so as to ensure access to services free of violence and abuse
- Establish and sustain effective accountability mechanisms for service providers who violated women's rights based on and in the context of HIV and service provision

FOOTNOTES:

1. Kehler, J. et al. 2012. *Gender Violence and HIV: Perceptions and experiences of violence and other rights abuses against women living with HIV in the Eastern Cape, KwaZulu Natal and Western Cape, South Africa*. AIDS Legal Network.
2. All quotes in this document, unless otherwise indicated, illustrate women's experiences of HIV-related violence, as collated through narratives and focus group discussions of women living with HIV in Illovo, KwaZulu Natal.

